

**ASSISTED LIVING:
EXAMINING THE ASSISTED LIVING WORKGROUP
FINAL REPORT**

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED EIGHTH CONGRESS

FIRST SESSION

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WASHINGTON, DC

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APRIL 29, 2003

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ASSISTED LIVING: EXAMINING THE ASSISTED LIVING WORKGROUP FINAL REPORT

TUESDAY, APRIL 29, 2003

**U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
*Washington, DC.***

The committee convened, pursuant to notice, at 10:02 a.m., in room SD-628, Dirksen Senate Office Building, Hon. Larry Craig (chairman of the committee) presiding.

Present: Senators Craig, Breaux, and Wyden.

OPENING STATEMENT OF SENATOR LARRY CRAIG, CHAIRMAN

The CHAIRMAN. Good morning, everyone. Let me convene the Senate Special Committee on Aging. Thank you for attending this hearing this morning.

Two years ago, this committee held a hearing to gain a better understanding of the emerging industry of assisted living. We learned that there are over 30,000 assisted living facilities nationwide, housing nearly one million people, and that such facilities are not regulated at the Federal level. Instead, individual States are responsible for oversight and are free to govern without Federal mandates.

However, we have seen a great disparity of care given by assisted living facilities around the country. These facilities in some States are exemplary in providing appropriate quality care for their residents, while in other States, such facilities are clearly handling more than they are probably capable of doing.

Because of the need for uniform guidance in rendering appropriate and competent care, the Special Committee on Aging charged consumers and industry groups within the assisted living community to come together and develop recommendations designed to provide uniform models of best practices to ensure more consistent quality in assisted living facilities nationwide and to provide consumers with sufficient and useful information.

In the fall of 2001, the Assisted Living Workgroup, known as ALW, was formed with nearly 50 member organizations representing providers, consumers, long-term care professionals, regulators, and accrediting bodies. Our primary directive for this group was to be inclusive and our expectation was that model rules for assisted living care would be achieved. We have discovered difficulty.

The committee recognizes that a great deal of time and monumental effort went into the final product. We appreciate that each recommendation was clearly put through a thoughtful, thorough

process with the welcoming of divergent views. We commend the ALW on its effort to provide a comprehensive list of recommendations for assisted living facilities. We also appreciate the effort to bring about consensus and hope this product will be helpful to consumers and the industry alike.

Having said that, I feel much more needs to be done. This report does not present a uniform set of model rules and regulations for the rendering of health care services in the assisted living context. However, it demonstrates the diversity of opinion and what needs to be done. Accordingly, it is a most important and valuable step in the further study of this important quest for uniform guidance.

Today, we plan to examine the Assisted Living Workgroup final report and focus on the process in which the report was developed, the benefits and the shortfalls of the report, and how the report can best be used in the future. We will be hearing from industry and consumer groups that were involved within the ALW.

Our first witness is Stephen McConnell, a Vice President of Advocacy and Public Policy with the Alzheimer's Association.

Our next witness is Dan Madsen, President and CEO of Leisure Care, Inc., a member of the American Seniors Housing Association. Both of these witnesses are members of ALW and were involved in developing the report.

We will also hear from an outside expert observer who was not involved in the ALW. We hope he can provide us with an objective opinion of the report. Bob Mollica is a Senior Program Director for the National Academy for State Health Policy.

Before I turn to our witnesses, let me turn to my colleague, the ranking member here on the committee, Senator John Breaux of Louisiana. John.

OPENING STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Thank you very much, Mr. Chairman. Welcome back. We have a great deal to do and we are delighted to have this hearing today.

It was back in August 1999, as you stated, that the Aging Committee asked the assisted living community to do something that had never been asked for before in the area of health care, and that is to come up with recommendations themselves as to how quality health care can be guaranteed in the assisted living area.

What they have come up with, indeed, is a lot more than many of us actually expected. It is over 380 pages of really substantive recommendations and discussions about how the entire area of health care and our assisted living facilities are going to be managed and handled. Indeed, I think that the given length and the substance and the time that went into this report all of the people who have been involved in this process are to be commended. They did a terrific job.

We were not necessarily, when we made the request, seeking some type of a unanimous recommendation, knowing that that was not going to be possible the way it was structured, but to try and come up with something that could pass at least a two-thirds recommendation, and that is what we have today. There is a lot of substance in this report. Each one of the votes that were taken

really were taken with a sense of trying to find out the best recommendation that could possibly be put together.

I said this was a unique and a new way of doing business. Most times, the Federal Government just says, all right, here are the regulations, go follow them, and we dictate from Washington. As a result, in some programs like Medicare, we have 133,000 pages of rules and recommendations, three times more than the Internal Revenue Code.

This was unique in the sense that we said, "All right, we want the people who are involved in running the facilities to sit down with those people who utilize the facilities," and we involved different organizations and groups that represent the various interests of assisted living facilities. So for the first time, we actually have those who own and run the facilities talking with those who utilize the facilities. I think this process was very, very unique. It was different from what we had done in the past, and hopefully this could be sort of an imprimatur type of process for how we ought to consider doing things in the future when we bring various groups together to create health care policy.

As the chairman has pointed out, the regulations dealing with assisted living facilities are almost entirely State regulations. There are huge differences in the type of rules and regulations. It is hard to know what the rules are until you get out a geography map and figure out what they are. That is obviously not the right way to set up rules and standards, by a geography book, but rather by what is best for the people who utilize the services.

In my own State of Louisiana, I think the type of recommendations developed by the ALW could be helpful and important towards developing some type of basic rules and regulations on a State level.

There are a few organizations, I think, that need to be mentioned. There were some 13 organizations who acted as the steering committee and they are to be thanked for their time and their effort and their commitment. This was not an easy task. If it had been easy, we would not have had to do it.

The Consumer Consortium on Assisted Living and the American Association of Homes and Services, deserve a nod for their work as co-chairs of the working group and the latter group for hosting the meetings and coordinating the workgroup website which is now in place.

Additionally, the National Center for Assisted Living provided the resources, which we thank them for, for the creation of this written product. Indeed, a thank you to everyone who served on the panels.

This is not the end of the process. I think it is rather the beginning of the process. But now we have some documents that have substance behind them. They have clarity and they have support from both the users and the providers, which I think is what is so unique. This is not a dictate from Washington but rather a recommendation from the people who are truly to be affected by what happens. So we thank them very much for their performance. It was a job very well done. Thank you.

The CHAIRMAN. John, thank you for that comprehensive statement. As both Senator Breaux and I know, the difference between

a rural community in Louisiana and Idaho, where there may be a facility that houses four, or five, or six, versus a large urban setting are a world apart often. While we believe that consistent and high-quality care needs to be delivered in both settings, at the same time, we recognize clearly the difference.

With the witnesses we have today and the work that our staff will do in reviewing this, I have already contemplated with my staff the possibility, Senator, of doing a white paper to put on top of this for the public and for the professional provider community as a whole to consume in an effort at the State levels, I would hope, to continue to work to build this kind of consistency, and I thank you for recognizing those who were largely responsible for keeping the group together and causing it to function.

So now if we would ask our witnesses to come forward, I want to thank them again for their time this morning. Stephen McConnell, Vice President for Advocacy and Public Policy, Alzheimer's Association of Washington, DC. Stephen, we will let you start. Thank you, Stephen.

**STATEMENT OF STEPHEN McCONNELL, VICE PRESIDENT FOR
ADVOCACY AND PUBLIC POLICY, ALZHEIMER'S ASSOCIATION,
WASHINGTON, DC**

Mr. McCONNELL. Mr. Chairman, Senator Breaux, thank you for inviting the Alzheimer's Association to testify this morning. Thank you especially for shining a light on this very important issue.

I am humbled by the invitation and hope I don't humiliate myself here today. There are many knowledgeable people, as both of you have pointed out, that have been involved in this process. Many of them are in the room behind me, and it is important that we acknowledge them, as you have.

Perhaps we are testifying because the majority of people within assisted living facilities have some form of dementia. Perhaps we are testifying because we were among the more moderate views in the group. Perhaps we are testifying because our organization's name begins with the first letter of the alphabet. [Laughter.]

But nonetheless, we are very pleased to be here.

We are not any more right on this issue than any of the other stakeholders that were involved in the process and that is perhaps the essence of the success and the failures of this undertaking.

I would like to make four points. First, to ask a question, did the process succeed? More specifically, did it create a single definition? No. Did it achieve consensus on all the recommendations? No. Did it develop an exact blueprint for the States and the Federal Government? No. Did it answer all the right questions? No. But was it an honest process? Was it a good faith effort by all the organizations involved? That is an unqualified yes. Does it produce useful recommendations that address many of the key issues? It does. Is it a good resource document to guide States and the Federal Government as they move forward? Yes. Will it inch us forward toward better care? We believe it will.

In some ways, this document is a bit like Los Angeles. If you try to relate to it as a whole, it is impossible, full of contradictions. But if you connect to the individual communities, the individual recommendations, there is a lot there and it makes much more sense.

Perhaps this document is the best that could be achieved given that there wasn't a specific legislative outcome tied to it. All the groups needed to put forward their best thinking, as they did. Many of the groups helped to improve recommendations to the very end, even though in the end, they might have voted against one or more of these recommendations. But in the end, legislators must make the tough decisions, make the call. Making the final call was very difficult for a group process like this.

The second major point is that there are differences among the groups as a result of different experiences and data, not unlike what you just pointed out, Mr. Chairman, about the differences between facilities in Idaho and California. There are differences in philosophies about how to approach care and there are different views about solutions.

Our philosophy in this process followed six basic principles: (1) that care is a partnership between the resident and the provider; (2) that assisted living residents are diverse and a single set of prescribed services won't work; (3) preferences of individuals are important and flexibility is essential; (4) dignity, independence, and choice are important and assisted living should ensure these; (5) essentials must be provided and States should mandate these, for example, basic safety. Finally, even small steps forward are better than holding out for the perfect.

The third major point I would like to make is that the process and the final product would improve care for people with dementia, which by some estimates could be as many as 40 to 60 percent of the people in assisted living.

I would draw your attention to just a couple of the things that are included in this report related to dementia. First, is that all staff have to be trained to recognize the signs and symptoms of dementia. This is pretty basic, but that awareness is not the case in many assisted living facilities, many hospitals, or many other settings where people with dementia reside. Second, the care plans must be adapted for residents with dementia to account for their cognitive impairments. Third, the direct care staff should receive training about dementia. Fourth, individualized activities should match the residents' abilities and interests. Finally, the residents should be protected from danger, especially unsafe wandering.

Did we get all we wanted? No. We wanted specific numbers of hours for training and a variety of other things. But the key is that the dementia provisions would apply to all facilities, not just those that say they provide special care for people with dementia. This is a very important step forward. According to a University of North Carolina study in 1997 and 1998, 68 to 89 percent of people with dementia in assisted living are not in special care units. So it is important that we ensure good care for people with dementia even though the facility doesn't hold itself out as providing special care. That is perhaps one of the most important recommendations in this report.

The fourth and final point is that the key focus of the debate is really at the State level. Most States are examining or reexamining this issue. The key stakeholders, including the Alzheimer's Association and all the groups involved, need to get involved in the State legislative and regulatory process. The Alzheimer's Association will

distribute this report to our advocates at the State level and work with them to ensure that as many of these recommendations as possible are implemented.

Finally, I would encourage the Federal Government to play an ongoing oversight role, to continue to fund research so we understand outcomes better and we don't have to have as many regulations that are based on process, but more on the outcomes we are seeking. Finally, to help ensure access to assisted living for people who can't now afford it.

I don't want to trivialize this process, Mr. Chairman, but I think of it as a bit like Goldilocks and the Three Bears. The porridge was too hot or too cold, and even when it was just right, after all, it was only porridge, and in the end, Goldilocks was damn lucky to get out of there alive, but—[Laughter.]

I think that is the way I will hope for it today. [Laughter.]

Thank you again for shining a light on this very important issue. We look forward to working with you in the future.

The CHAIRMAN. Stephen, I find it ironic that there are three people sitting up here at the dais at this moment. I don't know whether we are black bears, brown bears, or grizzlies. [Laughter.]

We are not Goldilocks, probably. [Laughter.]

[The prepared statement of Mr. McConnell follows:]



TESTIMONY OF

STEPHEN McCONNELL

Vice President for Advocacy and Public Policy, Alzheimer's Association

Presented to
U.S. SENATE SPECIAL COMMITTEE ON AGING

April 29, 2003

ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION, INC.

Washington Office: 1319 F St., NW, Suite 710 • Washington, DC 20004 • Phone: (202) 393-7737 • Fax: (202) 393-2109

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). Lyketos 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.

The CHAIRMAN. Dan, before I turn to you, let me turn to my colleague from Oregon who has joined us, Senator Ron Wyden, who has spent both his private and his public career working on behalf of our elderly and who comes from a State with probably a very clear set of regulations as it relates to assisted living.

OPENING STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. Thank you, Mr. Chairman. I will be brief, and I am pro-Goldilocks. [Laughter.]

The CHAIRMAN. Well, I am not anti-Goldilocks. She was a bit naive, that is all.

Senator WYDEN. We'll build a bipartisan consensus from there.

I think that it is important to remember the origins of this whole exercise. Then-Chairman Grassley and Senator Breaux and I began this effort and commissioned the government auditors to look at these issues. A host of discussions began from that report. As we said, given the demographic tsunami that is coming, with millions of baby boomers retiring in 2010 and 2011, we want to do this job right. The real challenge is to learn from the nursing home experience.

I was Co-Director of the Gray Panthers for about 7 years before I was elected to the House and specialized in these issues then. When this committee began examining assisted living I think our sense was that there were a lot of things you would have done differently for nursing home patients if you could go back and look at the nursing home experience. So we wanted to hear from that experience we thought then that the challenge for assisted living issues was to see if we can find common ground between consumer groups and industry groups, and clearly, we have made progress in a number of areas. Clearly, we still have a fair amount of work to do, as well.

I think the principal concern that I have today is we have got a number of States that are doing a good job and we want to ensure that that progress goes forward. Second, we have got to have a safety net to ensure that every vulnerable older person in this country in every assisted living facility has certain basic protections, because they continue to be some of the most vulnerable people in our society.

Beyond that, I think the challenge is going to be to get consumer groups to say that they are willing to meet the industry halfway on some things that are important to them the industry, then has to reach out to consumer groups on some of the issues that are still in contention, too.

But we are on our way to putting in place a Federal-State, public and private long-term care partnership in this country with assisted living playing a key role. So if you all and the others who are involved in this exercise continue to work with this committee under Chairman Craig and Senator Breaux, and I am sort of a junior partner on these initiatives, but if you continue to work with us as you have in the past, I think we can set in place that kind of framework that allows older people in this extraordinarily fast-growing sector of senior health care to get the protections and the services they need while at the same time ensuring that we have

the kinds of facilities and the number of facilities that we are going to need giving this demographic explosion which awaits us.

I thank you, Mr. Chairman, and appreciate the good work of both you and Senator Breaux in this.

The CHAIRMAN. Ron, thank you very much.

Now, let us turn to Dan Madsen, President and CEO of Leisure Care, Inc., from Bellevue, WA, who in another life spent time in Idaho.

Mr. MADSEN. Yes, a lot of my life.

The CHAIRMAN. For those of you who are here who are wondering why you are here, as Stephen had mentioned, my staff said that the spectrum of, and I think Senator Breaux mentioned that and certainly Ron Wyden understand that, if you were to graph you all, it would be a bit of a bell-shaped curve. You fall somewhere in the center of the bell, and I mean that reflective of probably the collective interests, but maybe not the extremes of the curve, but we think the report because of its process is reflective of that broader spectrum.

Dan, please proceed.

STATEMENT OF DAN B. MADSEN, PRESIDENT AND CHIEF EXECUTIVE OFFICER, LEISURE CARE, INC., BELLEVUE, WASHINGTON, ON BEHALF OF THE AMERICAN SENIORS HOUSING ASSOCIATION

Mr. MADSEN. Good morning, Chairman Craig, Senator Breaux, and Senator Wyden. As mentioned, my name is Dan Madsen. I am the President and Chief Executive Officer of Leisure Care. We are located in Bellevue, WA, near Seattle. We operate 33 retirement communities in nine Western States. We serve approximately 5,000 residents and their families.

I am here today on behalf of the American Seniors Housing Association and representing over 250 companies involving management, ownership, financing, and development of senior services in housing. ASHA's members currently serve over 500,000 seniors nationwide.

We are proud to have been asked by the committee to participate in the Assisted Living Workgroup, the topic we are here to discuss today. I am proud to have been selected by ASHA to represent them and am very honored to be here today.

The most positive aspect of ALW has been the opportunity and the interaction, as mentioned by everyone, between the organizations, people from all ends of the spectrum. The spirit of consensus and coalition building that produced this report will help policy-makers at the State level understand what issues are important when they examine their current regulatory systems in assisted living.

ASHA and its members are very committed to improving quality in assisted living residences nationwide and believe that ALW's report will be helpful to consumers, operators, and State policy-makers in promoting quality of assisted living. In the end, ASHA supports more than 100 of the 127 recommendations included in the report. As mentioned previously, did we agree with all the recommendations? Of course not. On rare occasions, ASHA felt that certain recommendations would not have had an impact on quality

or would dramatically have altered the way assisted living services are provided.

We also carefully took into account the effect that some recommendations would have on accessibility of assisted living to low- and moderate-income individuals. We also voted against some recommendations because we simply didn't feel that they were consistent with ASHA's members' belief in the vital issues related to quality.

For example, ASHA opposed language requiring assisted living operators to offer only private single-occupancy apartments. Many of ASHA's members offer shared room environments for residents, and requiring operators to offer only private apartments would significantly limit the accessibility for assisted living in moderate- and lower-income individuals. It would undermine consumer choice, as well, and affordability, and it has very little impact on quality.

The Assisted Living Workgroup didn't operate in a vacuum. Since 2001, as Senator Breaux mentioned, 47 of the 50 States and the District of Columbia have made significant changes, as our exhibit shows, in the regulation of assisted living. These updates allowed assisted living operators to adapt and innovate while providing meaningful oversight of an industry caring for a population whose average resident is over the age of 80.

The presence of State regulators at the ALW was a significant benefit. We hope that as States continue to monitor laws and the regulations, they will continue to implement a process that involves a wide variety of stakeholders to offer input, like the committee has done with the ALW.

Assisted living residents and their family members are best served by State and local-based regulations that can truly meet the unique needs of the residents and the culture of the State, and this is vitally important because the culture of each State is different.

Leisure Care operates in nine States, and while the core of what is required is very similar in those States, it is the variation of assisted living between States that allows the assisted living to be able to best meet the needs of those residents. An example of such variation would be the staffing patterns in those States.

We recently, through our resident opinion surveys, made some significant changes in the way we operate on weekends. That was well accepted in our area in Los Angeles, scheduling more activities on Saturdays and Sundays and beefing up, so to speak, how we operated on those days. At our communities in Idaho Falls, ID, the residents came out against some of those initiatives and said we would like to see less staff on Sundays and have them home with their families where they should be and we would like that day in peace, as well. There is a perfect example of how regional preferences may dictate how we operate.

We urge this committee to examine one item that is not covered in the Assisted Living Workgroup report and that was the cost of financing needed in long-term care services. Most Americans are woefully unprepared financially when they require assistance with activities of everyday life. We encourage this committee to continue to efforts to educate the American people on this pressing need.

We are also pleased that President Bush supports similar proposals. In fact, Leisure Care, as a company, offers long-term care

insurance free of charge to all 2,000-plus of its employees. We make that accessible to their families, their immediate families, and their in-laws, as well.

ASHA does not view today as an end to the ALW process. We will make the ALW report available to every one of our members and encourage them to use it when evaluating their own operations. I would venture to say that a great deal of those providers are already using the recommendations and putting them in place in their operations. Where they can make changes to improve quality, ASHA members should do so with or without regulation because it is the right thing to do. Our best regulators, after all, are our residents and our families.

An example would be the recommendation to require assisted living operators to allow their residents to form resident councils. This is a practice that we have done for over 27 years in our company and we strongly encourage residents to be involved in how their community operates. The ability of residents to meet independently allows them greater flexibility in the community operations. It definitely improves quality and resident choice and autonomy at the same time. When I go to communities and I have to meet with resident councils and I have to meet with groups of hundreds of residents, believe me, I am held accountable for the quality of services that I provide.

ASHA will continue to seek collaboration with consumer organizations, such as AARP, the Alzheimer's Association, and with the Consumer Consortium on Assisted Living to help ensure the views of consumers and family members are heard by our members and that the highest level of quality in assisted living can be achieved at every residence.

The relationships that were built around the Assisted Living Workgroup table will not be abandoned or allowed to fade away. As I stated earlier, ASHA encourages State regulators to solicit the input of assisted living consumers, providers, families, and address changes in their current regulations, and use the ALW report as an important reference guide, which was originally intended, to issues that should be considered in oversight structure of assisted living. The ALW provided the blueprint for such collaboration.

In conclusion, I would like to thank Senators Craig, Breaux, and the entire committee for the opportunity not only to speak to you today, but for the continued efforts on behalf of America's seniors. Rest assured, ASHA and its members and the committee's commitment to improving the lives of assisted living residents nationwide. Thank you.

The CHAIRMAN. And thank you very much.

[The prepared statement of Mr. Madsen follows:]



Testimony of

Dan B. Madsen
President & Chief Executive Officer
Leisure Care, Inc.
Bellevue, Washington

On behalf of the
American Seniors Housing Association

*"Assisted Living: Examining the Assisted Living
Workgroup Final Report"*

Before the
U.S. Senate Special Committee on Aging

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Good morning, Chairman Craig, Senator Breaux, and members of the Committee. My name is Dan Madsen and I am President and Chief Executive Officer of Leisure Care, Inc. Leisure Care is a privately owned family business headquartered in Bellevue, Washington. We currently manage 33 retirement communities and assisted living residences in 9 western states housing over 4,700 residents. Since 1976, Leisure Care has grown from managing just one community to become the 4th largest privately owned assisted living company in the country. We plan to expand into other states in the future.

I am here today on behalf of the American Seniors Housing Association (ASHA) which represents the interests of over 250 companies involved in the management, ownership, financing and development of seniors housing. ASHA's members currently house over 500,000 seniors nationwide in settings that include assisted living and Alzheimer's residences, independent living communities, senior apartments, and continuing care retirement communities. The Association was proud to have been asked by this committee to participate in the Assisted Living Workgroup – the topic we are here to discuss today. ASHA's approach, from the outset of this process, has been to work in a consultative manner with our colleagues on the Workgroup in order to balance our residents' strong desire for choices, options, and quality in the provision of seniors housing services with the requisite level of regulation needed to assure that only high quality, service oriented providers thrive in the marketplace. As a member of the Assisted Living Workgroup's Steering Committee, ASHA and its members are committed to improving quality in assisted living residences nationwide and we feel that the Assisted Living Workgroup Report – *Assuring*

Quality in Assisted Living: Guidelines for State Regulations, Federal Policy, and Operational Models – provides information that will be helpful to consumers, operators and state policymakers in promoting quality in assisted living.

The Assisted Living Workgroup

The most positive aspect of the Assisted Living Workgroup has been the opportunity for interaction between organizations and people from all sides of the assisted living spectrum. Perhaps for the first time in one room at the same time, the interests of consumers and family members, assisted living providers, state regulators, and other professionals were represented. For over 18 months, as many as 50 organizations researched, debated and reached consensus on over 100 recommendations to states and assisted living operators on how to promote quality on such vitally important topics as resident rights, medication management, activities, and Alzheimer's and dementia care.

The spirited debate and interaction between such a diverse group of people that occurred at the monthly meetings of the full Assisted Living Workgroup, as well the more frequent topic group meetings, will lead to more communication, better policy and in turn, improved quality for assisted living residents. It has been a tremendously healthy dialogue. Our participation in the Assisted Living Workgroup reaffirmed the need for providers to have a dialogue with consumers in order to serve them better. While not all of the groups involved in the Assisted Living Workgroup agreed all the time on every recommendation in the report, the spirit of consensus and coalition building will help state policy makers understand what issues are the most important when they examine and revise their current regulatory schemes for assisted living.

In the end, while the Report produced by the Assisted Living Workgroup is not perfect, the process used to bring all the relevant stakeholders together was a positive experience and will only help improve communication between assisted living consumers and operators. As you are well aware, the history of healthcare regulation in this country too often reflects an "us against them" mentality. ASHA commends our colleagues on the Workgroup for their vigorous efforts to find common ground and also ground our disagreements in respectful divergences of opinion. We will continue to work with policymaking bodies in this spirit in the future. Mr. Chairman, we commend you and Senator Breaux for your leadership on this issue

Quality for Each and Every Resident

I started in the business of caring for older people in 1988 as a property manager for Leisure Care at Cottonwood Creek located in Salt Lake City, UT. That experience, as well as my continued work with Leisure Care over the years and now as President and CEO, has taught me that assisted living quality starts not at the state level or even the property level for that matter. It begins with understanding the individual needs of every single resident. In addition to the duties I have running Leisure Care as President and CEO, I still personally oversee two communities in Tucson, AZ as Operations Manager, which allows me to stay close to the day-to-day business of caring for our residents. This also allows me to communicate directly with residents, their families and our employees.

As a member of ASHA's Executive Board and its Assisted Living Workgroup Task Force, Leisure Care assisted Association staff in reviewing, editing and perfecting Workgroup recommendations as they were developed here in Washington, DC. This Task Force was comprised of a number of talented professionals from a diverse range of assisted living companies -- including Emeritus Assisted Living, Brookdale Living Communities, Hearthstone Assisted Living, LifeTrust America and Marriott Senior Living Services. We were able to objectively review the recommendations to determine if they would be effective in promoting quality for our residents.

Did we agree 100 percent with all the recommendations? Of course not. On some occasions the ASHA Task Force felt that a certain recommendation would not have an impact on quality or would dramatically alter the way that assisted living services are provided. We also carefully took into account the effect that some recommendations would have on accessibility of assisted living to low and moderate-income individuals. If the impact on quality was negligible, but implementation of the recommendation would result in a significant increase in costs to residents, ASHA's Task Force opted to vote against the recommendation. It is true that many things should be done regardless of cost (i.e. adherence to building and life safety codes, providing a secure environment for residents with Alzheimer's disease or dementia). Nonetheless, we must note that some of the recommendations included in the Assisted Living Workgroup Report did not meet a reasonable cost-effectiveness standard and ASHA joined other groups in opposing them. A good example of this is a recommendation from the Direct Care Topic Group that would have required assisted living operators to contract with a number of external professional consultants such as medical directors, clinical social workers, and activity consultants. ASHA feels that the specific assisted living residence should determine whether contracting with certain professionals would impact the quality

of care its residents receive. It would be cost prohibitive, unnecessary and duplicative, for instance, for an assisted living residence to employ a medical director when residents are under the care of their own primary care physicians.

We also voted against some recommendations that appeared to micro-manage administrative procedures of assisted living operations that really did not have a direct impact on quality. For instance, a recommendation from the Staffing Topic Group included a 23-point checklist for the training curriculum of personal care assistants. We felt that this recommendation was overly prescriptive. And finally, we voted against some recommendations because we simply did not feel that they were consistent with what ASHA's members believe to be vital issues related to quality. The best example of this is ASHA's opposition to the language included in Part B of the definition requiring assisted living operators to only offer private, single occupancy apartments. Many of ASHA's members offer shared-room environments for residents who either choose to share because of a desire not to live alone, or because they simply would not be able to afford assisted living were they required to live in a private apartment. Requiring operators to only offer private apartments would (1) significantly limit accessibility to assisted living for moderate and lower income individuals, (2) undermine consumer choice and affordability, (3) be cost-prohibitive for many providers of assisted living and (4) would in the end have very little impact on quality.

As with any process involving as many as 50 organizations, disagreements occurred and occasionally consensus was not achieved. That being said, ASHA and its members feel that the majority of the recommendations included in the final Assisted Living Workgroup Report will indeed help assisted living providers across the country identify areas that need to be considered when they address quality within their residences. In the end, ASHA voted for more than 100 of the 127 recommendations included in the report. The assisted living industry has changed a great deal over the past 15 years and is continuously striving to improve the quality of care provided to its residents. It is still evolving and I suspect that it will change as much in the next 15 years as it has since I first began my career at Cottonwood Creek in 1988. The Assisted Living Workgroup Report is an important Mile Marker along that road.

State Oversight of a Growing Industry

The Assisted Living Workgroup did not operate in a vacuum. Over the past 10 years, states have been aggressively monitoring and licensing assisted living providers and have regularly updated and modified their regulation of assisted living. As the assisted living industry grew dramatically in the mid-to-late 1990s, state governments took the lead in setting forth guidelines for assisted living operators to protect

their senior populations. Since 1997, ASHA has published the *Seniors Housing State Regulatory Handbook*, a reference guide providing information on assisted living regulations in all 50 states and the District of Columbia. During this period, 49 of the 50 states and the District of Columbia have made significant changes and updates to their regulation of assisted living – many more than once. More than just technical changes to regulatory jargon, these updates have remained flexible enough to allow assisted living operators to adapt and innovate, while at the same time have provided meaningful oversight of an industry caring for a population whose average resident is over 80 years old.

According to the National Academy for State Health Policy in its most recent review of assisted living (*State Assisted Living Policy: 2002*, November 2002), between 2000 and 2002 legislative and executive branch activity occurred in nearly every state and at any given time, more than half the states were working with a task force to develop and/or revise assisted living regulations. The review also states that more than half the states are currently reviewing assisted living regulations. The same NASHP report highlights an important trend in assisted living oversight – the specific regulation of assisted living providers who provide care and services to residents with Alzheimer’s disease or related dementia. Currently, 36 states have Alzheimer’s-specific provisions in assisted living regulation for such residences. Other important areas that states are focusing on include defining assisted living, medication management, admission and retention criteria, resident agreements, staffing and staff training, activities, quality assurance and public financing for low-income residents. The very same topics addressed by the Assisted Living Workgroup.

State legislatures are also involved in a significant way. In fact, since the start of the 2003 legislative sessions, 30 states have at least one bill introduced in their state legislatures pertaining to assisted living. These bills concern a wide-variety of topics that were discussed at the Assisted Living Workgroup including, administrator training, background checks for employees, hospice services, consumer disclosure and resident agreements.

States and localities are best able to regulate assisted living and they are working to do so. ASHA and its members support the aggressive enforcement of state regulation and in the rare occasions where persistent and serious quality-of-care problems arise, we urge states to exercise their existing authority to put the few “bad apples” out of business.

The presence of state regulators at the Assisted Living Workgroup table was a significant benefit to the assisted living industry. We hope that in the years ahead, as states continue to monitor and, where

appropriate, make more changes to their laws and regulations, that they will implement a process that involves a wide variety of stakeholders to offer input, as this Committee has done with the Assisted Living Workgroup. Using the Assisted Living Workgroup Report as a reference guide to issues that should be considered, states can create "state-based ALWs" that will help assure quality in assisted living across the country. As I stated before, assisted living quality is a community-by-community, resident-by-resident endeavor. Assisted living residents and their family members are best served by state- and local-based regulations that can truly meet the unique needs of the residents and culture of a certain state.

Leisure Care operates in nine states, and while the core of what is required is very similar in those states – and indeed what is provided in our buildings is as well – it is the variation of assisted living regulations between states that allows assisted living to be able to best meet the needs of its residents. Residents living in our assisted living community in Idaho Falls, Idaho have many of the same needs that the residents of our communities in Beaverton, Oregon and Rio Rancho, New Mexico, but they also have a unique culture and way of life. For instance, Leisure Care offers regional menus for all of our dining services. Residents typically move-in to assisted living located within the communities in which they were born and raised. Their culture and tastes move-in with them. The residents in our community in Oceanside, California outside San Diego particularly enjoy fresh Mahi Mahi and roasted vegetables for dinner. If we tried to serve fresh Mahi Mahi to a resident in Great Falls, Montana, I am not sure that it would go over quite so well! Another example would be the staffing patterns we employ on Sundays. Again, different cultures and values determine how we provide services to our residents. Residents in our Los Angeles community expect fully-staffed activities to occur seven days a week, while the residents of our Idaho Falls community have actually requested that we allow our employees to stay home with their families on Sunday and only staff a skeleton crew those days. This regional flexibility would not be possible with a national standard.

An Industry Committed to Quality and Consumer Education

When Senators Breaux and Craig created the Assisted Living Workgroup in 2001, ASHA and the assisted living industry embraced the idea because we are committed to quality and customer education, service and choice. The ability to engage in discussions on important topics with consumer advocates and state regulators was an opportunity that will help the industry to better serve its population of over 700,000 seniors nationwide. As the assisted living industry evolves and changes over the next decade, ASHA and its members will remain committed to continuing to educate the public about assisted living. An educated consumer is better able to make decisions either for themselves or their loved ones as to what setting is most appropriate and will best meet their needs. Our efforts in consumer education began in earnest in the mid-

1990s when a collaborative effort, initiated in 1995, between ASHA and the American Bar Association's Section of Real Property Probate and Trust Law, Committee on Housing for the Elderly, resulted in the publication of a model *Retirement Community Admission Agreement*. This guide was prepared for attorneys and consumers to help identify issues that should be addressed and options to be considered in admission contracts. Thousands of copies of this publication have been distributed to consumers and their legal advisors in the past eight years.

In 1997, ASHA created a brochure entitled "*Assisted Living Residency Agreements, Key Points to Consider when Choosing a New Home*." This consumer-friendly brochure provides consumers and their families with two-dozen critical questions that should be asked of prospective assisted living providers with respect to services and care; payment and pricing; and other important considerations. To date, more than 50,000 of these brochures have been distributed free-of-charge by ASHA members to prospective residents and their families.

Prior to this Committee's first hearing on assisted living in 1999, ASHA published and distributed to its members an *Assisted Living Consumer Information Statement*. This three-page form serves as a general guide for assisted living consumers and their family members about the care and services provided in different assisted living settings. It provides consumers with uniform information on resident fees and services; move-out and discharge criteria; staffing; and safety features. This brochure allows prospective assisted living residents to easily compare one residence to another in order to help make the most informed decision about which assisted living residence will best meet their needs. Copies of the *Assisted Living Consumer Information Statement* have been distributed to over 5,000 assisted living communities, and remain available to the general public on the ASHA website at no cost.

Most recently ASHA, in conjunction with ASHA Executive Board member Freddie Mac, produced and distributed over 100,000 copies of our brochure entitled, *Housing Options For Seniors* – a brochure describing the different types of seniors housing communities available from coast to coast. Finally, ASHA will soon launch a revised website – www.seniorshousing.org -- that will include a special Consumer Information Section with links to consumer organizations and free-of-charge electronic versions of all the consumer information I just described.

But it is not just ASHA who is educating the consumer about assisted living. A simple search on Yahoo for "assisted living" netted over 800,000 hits. Included in those results are sites such as

www.seniorhousing.net, a website that allows consumers and family members to search for an assisted living residence in the same way that many people search for apartments and single-family homes online. Similarly, the Administration on Aging sponsors a website (www.eldercare.gov) and toll-free phone referral service to assist the nation's seniors find appropriate settings in which to live – including assisted living. Such an online system was very limited when the Aging Committee first started addressing assisted living in 1999. Other groups involved in the Assisted Living Workgroup also have done significant work in educating the public about what assisted living is all about:

- The National Center for Assisted Living has published an excellent guide online entitled: *A Consumer's Guide to Assisted Living and Residential Care* available at www.ncal.org.
- AARP has made assisted living a major part of its "Life Answers" program, which provides an opportunity for consumers to call a toll-free number to help answer questions, find a residence nearby or simply talk with a trained consultant about aging issues.
- The American Association of Homes and Services for the Aging has developed an important consumer brochure entitled "Exploring Care Options for Relatives with Alzheimer's Disease" that it distributes on its website (www.aahsa.org) that receives over 10,000 hits per week.
- The Consumer Consortium on Assisted Living has developed a comprehensive checklist that consumers can use to ask the right questions when visiting assisted living residences in order to determine the best possible setting for themselves or their loved one.

Important Next Steps

We urge this Committee to continue its commitment to improving the quality of life for America's seniors and particularly encourage you to examine one item that is not covered in the Assisted Living Workgroup Report – the cost of financing needed long-term care services. Quality long-term care does not come cheap. Most Americans are woefully unprepared financially if and when they require assistance with the activities of everyday life. We encourage this Committee to continue efforts to educate the American people on the pressing need to be prepared and encourage you to examine legislation like that introduced in the past by Senators Grassley (R-IA) and Graham (D-FL) that would encourage long-term care insurance coverage. We are pleased that President Bush supports similar proposals and ASHA encourages your continued efforts in that regard. Leisure Care, Inc. offers long-term care insurance free of charge to all 2,000+ our employees. We also offer subsidized access to a preferred long-term care insurance plan to the employee dependents and families (including grandparents).

ASHA does not view today as an end to the Assisted Living Workgroup process, but rather as a beginning. To that end, we will make the Assisted Living Workgroup Report available to every one of our members and encourage them to use it when evaluating their own operations. I would venture to say that a great many of the recommendations are already being put into place by ASHA's members, but where process and procedure can be changed to improve quality, ASHA members should do so with or without the presence of state regulation. An example would be the recommendation that would require assisted living operators to allow their residents to form resident councils - a practice that Leisure Care has followed since its inception. The ability of residents to meet independently allows for greater input into community operations - improving quality and resident choice and autonomy at the same time. There are other recommendations in the Assisted Living Workgroup Report like this one that can be implemented at little or no cost to assisted living providers that will improve quality today. So, ASHA will stress the importance of the Assisted Living Workgroup process and Report to each and every ASHA member.

We will continue to seek collaboration with consumer organizations such as AARP, the Alzheimer's Association and the Consumer Consortium on Assisted Living both here in Washington, DC and in the states to help ensure that the views of consumers and family members are heard by our members and that the highest level of quality in assisted living can be achieved in every residence. The relationships that were built around the Assisted Living Workgroup table will not be abandoned and allowed to fade away. We will continue to work hand-in-hand with consumer organizations and state regulators whenever and wherever possible.

We will encourage state regulators to solicit the input of assisted living consumers and providers when they address changes in their current regulatory schemes and to use the Assisted Living Workgroup Report as an important reference guide to issues that should be considered in any oversight structure of assisted living.

In conclusion, I would like to thank Senators Craig, Breaux and the entire Committee for the opportunity not only to speak to you today, but for your continued efforts on behalf America's seniors. Rest assured, ASHA and its members share the Committee's commitment to improving the lives of our assisted living residents.

The CHAIRMAN. Next, let me introduce once again to the committee Robert Mollica, National Academy for State Health Policy, Portland, ME. Robert, welcome to the committee.

STATEMENT OF ROBERT L. MOLLICA, SENIOR PROGRAM DIRECTOR, NATIONAL ACADEMY FOR STATE HEALTH POLICY, PORTLAND, ME

Mr. MOLLICA. Thank you, Mr. Chairman and members of the committee for the opportunity to speak here today. The Special Committee on Aging is playing an important role in the future of assisted living, raising questions about its definition, direction, quality of care, government regulation, and the extent to which the interests of consumers and family members are protected. The committee's interests created the vehicle for stakeholders to discuss and debate important issues.

You extended a challenge to all stakeholders to reach a consensus on a set of standards for policymakers and regulators to consider as they develop State policy. The Workgroup has produced a valuable report after 18 months of hard work by numerous individuals. The issues are complex, as you have mentioned. Current policy is very diverse and there is not enough research to know what works best.

There is consensus on many recommendations and strong reservations about several that did receive the required two-thirds vote for adoption. Differences among stakeholders reflected competing priorities, protecting the health and safety of residents and supporting consumer preferences and decisionmaking.

A number of groups felt the recommendations gave more prominence to consumer and decisionmaking over protection and safety. Consumers may not always have enough information about a specific facility to understand the risks to their health and safety and to make decisions about where and how care will be provided.

On the other hand, control and independence are important to quality of life and self-esteem. Systems that are flexible, offer choice, and emphasize consumer decisionmaking are generally preferred by consumers. Both perspectives are important and it is difficult to find a balance, but balance is what I believe is needed.

The report's value lies, in part, on the presentation of all the proposals, the rationale for them, and the supplemental positions that present alternate views. The array of issues and options presented will help States and stakeholders understand the issues and decide their own approach.

The report offered differing opinions about the value of a philosophy and principles of care. The number of States including a philosophy in their regulations has almost doubled in 6 years, from 15 in 1996 to 28 in 2002. By itself, a philosophy does not specify the requirements for licensing, but it does set a framework and gives us a benchmark for designing rules governing the accommodations, admission and retention criteria, service to be provided, staffing patterns, and training. A philosophy is a very useful way to frame regulations. However, we do not have enough research about how it works in practice and whether one approach or the other has better outcomes.

Recommendations addressing screening and assessment, care planning, resident contracts, move-out protocols, and others offer helpful guidelines to States. The recommendations dealing with medication administration reflect trends among States. Sixty-four percent of the States now allow aides who have completed and passed a training program to administer medications. Ninety-eight percent allow aides to assist with self-administration. Thirty-three percent require facilities to have a consulting pharmacist, and other States require that medications are reviewed by registered nurses.

As facilities serve residents with greater needs, assistance with medications has been cited as a concern by regulators. About half the states reported in 2002 that problems with medications occurred frequently or very often. The frequency of problems was not associated with who may administer or assist with medications. In fact, focus groups conducted by the Rutgers Center for State Health Policy suggest that errors may be less frequent when trained aides are allowed to administer medications, a somewhat surprising finding.

The report contains some excellent discussions of the barriers to expansion of affordable assisted living. Affordable housing programs, such as low-income housing tax credits, HUD 202 programs, and Section 8 vouchers are now being asked to support a product that was not envisioned when these programs were established. Currently, less than 15 percent of assisted living residents are low-income, while the percentage of low-income nursing home residents is far higher. If assisted living is to be a viable option for low-income tenants, Federal policymakers need to consider the changes outlined in the report.

Whether you agree or disagree with the recommendations, the report is an excellent tool to frame policy options and encourage discussion at the State level. There are clearly two distinct approaches to regulation among the Workgroup members. It will be useful for the group to develop a side-by-side set of model standards to fully develop and compare each approach.

The Workgroup also recognized the need to develop outcome measures, update the recommendations, develop practice protocols, and offer technical assistance to States upon their request. There is much that we do not know about assisted living. What is the impact of different regulatory approaches and requirements? How do they affect quality? Do levels of care or general licensing guidelines work best? Do regulations based on philosophy of care produce different outcomes than regulations that do not? Research on assisted living in relation to the regulatory requirements is limited and much more is needed.

While stakeholders disagree about the direction and content of the recommendations, they agree on one thing. We are not where we need to be. We know that regulation alone does not guarantee quality. We know that some facilities offer high-quality care, others are eager to improve that may be lagging, and still others seem unable or unwilling to address quality issues. We hear that facilities are keeping people with needs that they do not have the staff to meet. It is important to distinguish between practices that are not allowed under regulation and practices that may warrant changes

in regulation. We always need to understand when enforcement needs to be improved or regulations need to be strengthened.

The results of the Workgroup will advance the development of State standards that achieve what all stakeholders want, quality of care for people served in these residential settings, and I thank the committee for its work in this regard.

The CHAIRMAN. Robert, thank you very much for that testimony.
[The prepared statement of Mr. Mollica follows.]

Testimony of
Robert L. Mollica

Senior Program Director
National Academy for State Health Policy
Portland, ME

Before

Senate Special Committee on Aging

April 29, 2003

Mr. Chairman and members of the Committee, thank you for the opportunity to testify here today. The Special Committee on Aging has played an important role in the discussion about the future of assisted living, raising questions about its definition, direction, quality of care and government regulation and the extent to which the interests of consumers and family members are protected. The Committee's interest created a vehicle for stakeholders to discuss and debate important issues.

The Committee extended a challenge to all stakeholders to reach consensus on standards for policymakers and regulators to consider as they develop state policy. Despite 18 months of hard work by numerous individuals, unanimous agreement was not possible but I doubt anyone expected it. The issues are complex, current policy is very diverse, and there is not enough research to determine what works best. There is consensus on many recommendations and strong reservations about several that received the required two-thirds vote for adoption.

The report includes all the recommendations that were considered by the Workgroup. The value of the report is its presentation of the recommendations, the rationale for them and the supplemental positions that present alternate views. Including the proposals that were not adopted gives readers a better sense of the approaches that may be considered and their implications. The array of issues and options will help states and stakeholders understand the issues and consider their own approach.

Recommendations

The recommendations and accompanying supplemental positions suggest that we are still unable to agree on what assisted living is, whom it should serve and how it should be regulated. State examples can be found that follow each recommendation and also the alternative, when one is described. The differences among stakeholders were evident in the recommendations describing the components of state oversight. A number of groups felt the recommendation gave more prominence to consumer decision-making over protection and safety. Consumers may not always have enough information about a facility to understand the risks to their health and safety and to make decisions about where and how care will be provided which suggests that regulations be more prescriptive. On the other hand, control and independence are important to quality of life and self-esteem. Systems that are flexible, offer choice and emphasize consumer decision-making are generally preferred by consumers. Consumer centered care is becoming the primary influence in the design of home and community based service programs. Both perspectives are important and it is difficult to find a balance, but balance is what I believe is needed.

Perhaps the most difficult issue is the starting point – what is assisted living? Examples of the recommended definition, and the suggested alternate definition, can be found among the definitions used by states. The recommended definition includes a philosophy and principles of assisted living that set the framework for developing standards and requirements that operationalize it. By itself, a philosophy does not specify the requirements for licensing, but it does serve as a benchmark for the design of rules governing admission and retention, services, staffing and training. Over half the states now include a philosophy of assisted living in statute or regulation. However, we do not have enough research that compares regulations to understand

how it works in practice and whether one approach or other has better outcomes.

One part of the recommended definition would require the use of at least two levels of licensing to differentiate facilities serving lower and higher need consumers. Again, both approaches have been implemented in states but general levels are more common. Ten states license facilities according to their level of care (Arizona, Arkansas, Idaho, Florida, Maine, Maryland, Mississippi, Missouri, Utah, and Vermont). The rest have a single level of care. The advantage of levels of care is that consumers know what to expect from each facility if they are required to provide all the services allowed for its level. The disadvantage is that residents may have to move when their care needs change. Maryland allows facilities to serve a percentage of residents that meet the criteria for the next level of care. Other states use waivers to allow a facility to retain a resident who no longer meets the retention criteria as long as they have the capacity to serve the resident and the resident, family and sometimes a physician agree. Single categories of care place greater importance on the resident agreement to clarify resident expectations. There is no basis for concluding that one approach works better than the other.

One of the many debates in assisted living is whether people who need nursing home care should be served and what the requirements should be if they do. Your position on this issue depends to some extent on your starting point. One starting point may be the services delivered by home health agencies and other providers to a person to help them remain in their single family home. Why shouldn't a person be able to bring services with them as they move from their single family home to an elderly apartment building or a licensed assisted living facility?

If your starting point is a nursing home and the regulatory environment in which services are delivered, you ask why don't we apply the same regulations to settings that provide similar services to the same people?

There are two important variables. It is important to understand who nursing homes serve now and the minimum criteria states use to decide who can enter a nursing home. State level of care criteria vary considerably. States that base the minimum threshold on impairments in activities of daily living historically have found significant percentages of people living in nursing homes who did not need to be there even though they qualify. With the expansion of Medicaid home and community based services waiver programs and assisted living, people have more options and fewer who need help with activities of daily living, medications and supervision are entering nursing homes. Statements in the report that say that assisted living serves people who qualify for admission to a nursing home should not be interpreted to mean that assisted living residents are comparable to the profile of current nursing home residents or are receiving 24 hour skilled care. It means that state criteria allow a broader mix of people to enter a nursing home than may actually live there. Allowing assisted living facilities to serve people who qualify for a nursing home does not mean they are all receiving the highest level of care available in a nursing home.

State Medicaid programs set criteria for admission to nursing homes that also apply to eligibility for Medicaid home and community based waiver services programs. These criteria differ from the assisted living licensing criteria but there is considerable overlap. Only a few states do not allow anyone who meets the nursing home level of care criteria to be served in an

assisted living facility.

State level of care criteria fit into four primary categories:

- Medical conditions or needs;
- A combination of medical conditions/needs and functional impairments;
- Functional impairment alone; and
- Scores from an assessment instrument.

Of the 45 states whose criteria were received for a 2002 study by the National Academy for State Health Policy, two used medical criteria; 13 used a combination of medical and functional criteria; 22 used ADL thresholds, and 8 based their decision on the assessment score. One used professional judgment, and one used a physician's statement. Assessment score approaches included a mix of medical/functional and functional assessment items.

States can be arrayed along a continuum from low to high need thresholds for nursing home admission. (See Table). Admissions based solely on impairments in one or two of five to six ADLs are on the low end of the spectrum, those based on ADLs and medical criteria in the middle, and medical criteria on the high end. The placement of states within this continuum is somewhat arbitrary, and that the actual application of the criteria may be somewhat stricter or more lenient than placement within these categories suggest.

You can see that any statement about nursing eligible residents and assisted living means something very different depending on the particular state you are discussing. It would be clearer to talk about the needs, conditions and functional abilities of residents in relation to the services and staff available to serve them in an assisted living facility than whether they could be in a nursing home. After all, people can receive a very high level of care in their own homes.

Array of Selected States Along Continuum of Nursing Home Admission Criteria						
1 (low)	2		3 (moderate)		4	5 (high)
CA	AR	MS	AK	MO	AZ	AL
DE	IL	NE	CO	MT	NC	HI
KS	IA	OK	CT	NJ	UT	ME
NH	IN	TX	FL	NM		MD
OH	LA	VT	GA	ND		TN
OR	MI	WI	ID	PA		VA
RI	MN		MA	SC		
WA						
WY						

Recommendations addressing the pre-screening process, move out requirement, medication storage, and special care facilities were considered too vague by several groups. These limitations could be addressed by states that may want to specify how an area is addressed such as who conducts the pre-screening assessment and how it is used. The move out recommendation raises the question of whether facilities may or are required to provide all the

services allowed by regulation. As long as facilities with a higher license are able to serve residents who have lower levels of need, aging in place can be accommodated. States that license by level of care may allow or require that the services be available or simply state the staffing requirements for residents based on their ability to evacuate in an emergency. Permissive admission criteria allow facilities the flexibility of establishing a policy based on its business plan, mission, staffing patterns, the skills of the staff and the availability of nursing expertise.

General licensing criteria lead to variations in the needs of residents who will be served, the services provided to meet those needs, patterns, and the skills of staff. In these instances, the resident agreement or contract is the vehicle for describing who will be served, what services are will be provided and when a person may be asked to move.

Recommendations for special care facilities included general descriptions of areas that would be addressed by facility policy, such as staff training, policies, and procedures. Several members of the Workgroup felt the statements were too vague. In 2002, thirty-six states had provisions for facilities serving residents with Alzheimer's disease or dementia, an increase from 28 in 2000. These provisions addressed the philosophy of care, disclosure, staffing patterns and training, activities, the physical environment, family involvement and the cost of services.

The staff training requirement for special care facilities did not specify the hours of training, the topics to be covered or a required curriculum. However, the list does help identify what is important and serves as the minimum threshold. Specific provisions are easier for facilities to implement and for oversight agencies to measure. General provisions give facilities flexibility to vary training based on the resident population, and accessibility to training resources especially in rural areas. They require that oversight staff review each facility's policies and procedures and make a determination about their appropriateness. Again, state rules for staff training in special care facilities vary. Many specify the number of hours, topics for training or both. Arizona requires that 12 of 75 hours initial training cover dementia and 4 hours per year of ongoing training. Florida requires 8 hours of initial training and 4 hours per year. Maine's rules require 8 hours of classroom training and 8 hours of clinical training. Texas requires 4 hours of training and 16 hours of on the job supervision plus 12 hours annual in-service. Given these variations, it is difficult to determine what number of hours is most effective but they set a baseline on which future changes based on experience can be made.

The recommendations support the ability of aides who have completed training to administer medications. The recommendation is consistent with directions in state policy. The NASHP 2002 licensing survey found that sixty-four percent of the states allow aides who have completed and passed a training to administer medications. Ninety-eight percent allow aides to assist with self-administration. Thirty-three percent of responding states require facilities to have a consulting pharmacist. Several additional states require review of medications by a registered nurse.

Affordability

The report contains some excellent discussion of the barriers to the expansion of affordable assisted living facilities. Opposition to the recommendations was based on

disagreement with the regulatory sections and questions about the universal description of assisted living as a less restrictive alternative to a nursing home. Affordable housing programs (low income housing tax credits, HUD's 202 program) are now being asked to support a product that was not envisioned when these programs were established. Currently, less than 15% of assisted living residents are low income while the percentage of low income nursing home residents is far higher. If assisted living is to be a viable option for low income tenants, federal policymakers need to consider the changes outlined in the report.

Another barrier is the amount of income available to pay for room and board. Medicaid waiver beneficiaries in many states have income that exceeds the SSI payment and therefore, depending on state policy, have more income that can be used to cover room and board. However, many do not. Beneficiaries who rely on the federal SSI benefit may not have sufficient income to cover room and board, especially in areas with high construction costs. The recommendations would support the ability of families to contribute to room and board costs, while the supplemental position opposes family contributions based on existing Medicaid rules. In 2002, about 19 states permitted family supplementation for room and board costs. Supplementation is not allowed for services covered by Medicaid. Since Medicaid does not pay for room and board, there are no federal prohibitions against supplementation. There is also concern that family supplementation means people with families who have resources will have access and those that do not will have less access. Family supplementation does reduce barriers for some. However, full access can only be obtained by expanding affordable assisted living or increasing the SSI payment for this setting. Covering room and board under Medicaid does not seem like a reasonable strategy since it would trigger a reduction in the federal SSI payment to the personal needs allowance for people in institutions. In effect, this would shift costs to state Medicaid programs without increasing the amount available for room and board.

Next steps

Whether you agree or disagree with the recommendations, the report is an excellent tool to frame policy options and encourage discussion about change. The report creates opportunities for members of the Workgroup to continue the process. There are clearly two distinct approaches to regulating assisted living. It would be useful for the groups who support the recommendations, and those who would offer an alternative, to develop a set of regulations that implements each approach. A detailed set of side-by-side "model regulations" could be prepared as the next step. It seems clear that stakeholders are not likely to reach full agreement about how assisted living should be regulated. What they can do is develop resources and information that informs the policy development process.

The Workgroup also recognized the need for more work to develop outcomes measures, update the recommendations, develop practice protocols, provide technical assistance to states upon request and other tasks. An additional function could be research on the impact of different regulatory approaches and requirements to see how different regulatory approaches affect outcomes. We do not have data to decide whether levels of care or general licensing guidelines work best. We don't know if regulations based on a philosophy of care produce different outcomes than regulations that do not. Research on assisted living in relation to regulatory requirements is limited and more is needed.

The proposed Center for Excellence is one way to address those needs. However, a group of members questioned whether the Center would be independent and that it might take over the role of government. Individually, states are not likely to have the resources to fund these activities. It may be possible to build a partnership between the federal government, states and a consortium of research organizations to carry out these functions. The consortium might be guided by an advisory board of stakeholders but would not be governed by them. DHHS' Office of the Assistant Secretary for Planning and Evaluation, which has funded research on assisted living in the past, might be an appropriate agency to fund this activity.

The report needs to be disseminated widely to state leaders – legislators, governors, commissioners, regulatory officials – as well as consumers, providers and professional organizations, to bring the discussion to the state level. I believe that the report will be a valuable document for stakeholders at the state level as they continue to refine and develop standards that support quality care for people who need assistance and prefer a residential environment. The Assisted Living Workgroup completed a difficult and ambitious task, requiring an enormous amount of time and work. The commitment and interest of the members of this Committee has certainly advanced our understanding of assisted living, and the different opinions about how it should be regulated.

Thank you.

The CHAIRMAN. We will now turn to questions of our members here and we will adhere to a 5-minute rule and move through the rounds as often as we need until all of our questions or your additional comments to them are dealt with.

Stephen, let me first start with you. I noted that there was apparent difficulty in meeting a common definition of what constitutes assisted living. Will you articulate why they had, collectively, such difficulty?

Mr. MCCONNELL. Again, as I mentioned, there are people who felt that the definition should be more stringent and others that wanted to keep it looser. What we ended up with was a series of, in effect, principles around which many people could agree.

There were a couple of things that were important differences for some of the groups. One was whether assisted living facilities should be required to have private rooms. That is an issue that we felt there isn't enough evidence to suggest that it is necessary. It could increase the cost. But some people felt very strongly about that.

A second issue that got the group tied up was around levels of care. Levels of care exist in regulations in your State, Mr. Chairman, and in several other States. While we think that levels of care make sense, our particular concern about the definitions of levels of care that were being developed by the workgroup is that they weren't specific enough to protect people with dementia. So that was another issue around which the group couldn't agree.

I think part of it, too, is that if we had come up with a very narrow, strict definition, it is entirely possible that this would have ended the conversation in many States because there is such variability out there in how it is defined, and so I think that was at least an argument for why it shouldn't be too tightly defined.

The CHAIRMAN. Dan, there are numerous competing thoughts on the various aspects of care in assisted living, or in that context, even to the extent of licensing requirements of facilities, and yet no definition of what is an assisted living facility. I think of where my mother-in-law lives today, in a large facility in Tucson. She lives on the independent side, but there is also the assisted side. There seems to be a line at which that facility defines and cares for its residents. Can you explain why there is this universe of different viewpoints and are there ways to bring a consensus on such definitions of terms?

Mr. MADSEN. I believe there is more in Part A when we talk about the definition of assisted living and that there has been some controversy about what that is. I know what we do, and I am in that business, and I know that there are domiciliary services that we provide as part of our assisted living and it is very well defined by bullet point.

I think when, using your example in Tucson, where we have two communities, we are seeing the past change a bit in that there were segregated areas for assisted living at one time and we are seeing that become more mainstream and more integrated, which we think is a good thing, because residents are now coming in and looking at services not only for assistance with daily living skills because they need them, but because they want them, and we are seeing resident choices. We are seeing that they want to have

meals delivered at different times. They want certain types of assistance, certain types of services, and served to them in their apartments and where they live versus an area of the building or a place where that is more regulated.

So we look at our programs and we try to ensure the quality of the program itself. We focus on the quality of services being rendered. Or the fine line becomes to what level of service and still respect their dignity and choice and that they are in a home of their own within their environments, that they have choice to bring in outside services, for example, to receive higher levels of care than what we are licensed to do or comfortable in providing.

The CHAIRMAN. You made one other comment that I thought was fascinating because I actually watched it work in this particular community that I am most familiar with, and that is the residents' council. The empowerment of the residents was phenomenal and the changes they brought about within a reasonable spectrum were very satisfying to them and they really did feel they were full participants in a community of common interests and helping guide that particular provider and that facility. I think you are right. That is a phenomenal tool in a regulatory process, or at least in a process of balance and quality of care, when the residents are empowered to participate.

Mr. MADSEN. I believe as well that we pay great attention to family members. We answer to the consumer, and in a very competitive environment that it is today, where we have families that are more educated about retirement communities, assisted living communities, they are shopping, there are higher quality providers today, the highest quality providers today that I have seen ever in the industry that I have been in for 15 years. We are absolutely operating at a higher level because of the competitive environment, and it is the right thing to do. But we raise the bar on each other constantly.

The dialog that we have with residents and their families is extraordinary. We work very closely with resident opinion surveys. We formally do them on an annual basis, but we have secret shops that we perform monthly from an outside company giving us a perspective on the quality of our services that we offer, from the taste of the food to the cleanliness of the building to how they are treated by staff, and we do our own.

Absolutely, we do our own surveys, and when we are onsite or we call residents, we call families. I personally call families every month and ask how we are doing. When in the communities, we meet with families, we meet with residents, and we get their feedback and we make changes. They are telling us what they want and we want to meet our needs.

The CHAIRMAN. Dan, thank you very much.

Now, let me turn to my colleague, Senator Breaux. John?

Senator BREAUX. Once again, I thank not only the witnesses, but everybody who has participated in producing this very elaborate document, the question now is, what becomes of the document? Does it go to a library somewhere and gather dust and 10 years from now, somebody will pick it up and say, you know, they did good work back there a decade ago, but really nothing was ever done to follow up on it.

So the question is, what becomes of this document? Is it something that the various States should pick up and utilize in revising or, in some cases, establishing their rules dealing with assisted living facilities? Is it something that Congress picks up and says, this should be a national standard of what all assisted living facilities should look like in terms of how they are regulated? Give me some discussion as to what you think perhaps should happen to this document.

Mr. McCONNELL. Senator, we think this is a conversation that needs to happen primarily at the State level, and we have already had conversations with our state advocates about the key recommendations that relate to dementia care. We are encouraging them to work on these issues in their own State. This, as has been noted by everybody, is a terrific reference document. You can see where all the various interests lie, and it helps elucidate the issues, not just what a group's perspective is, but what are the kind of both sides, three sides, four sides of an issue.

At the Federal level, it is less clear. I think as Medicaid becomes more a part of financing for assisted living, should that happen, there is more of a stake in this by the Federal Government. But we would still argue that the variability at the State level is not a bad thing entirely, that trying to fit assisted living into one box will reduce some of the flexibility and individuality that is still important in this industry.

Senator BREAUX. Mr. Madsen, what do you think?

Mr. MADSEN. I totally agree. I believe that the one-size-fits-all approach would be difficult to employ. We represent different States, as you do. We have different cultures. I think this is a great, great point of reference. This is a continuing improvement process. That is what it needs to be—

Senator BREAUX. Suppose the States just ignore it.

Mr. MADSEN. I think that the States have obviously—we are seeing many of the States make adjustments in their assisted living regulations most recently, that they are looking for tools. I know the States that were in there looking for some guidance that they can customize to their own States and meet the needs of those residents. They are very active. States are very active in our industry and they are doing a good job.

Senator BREAUX. Some are, not all of them.

Mr. MADSEN. Yes.

Senator BREAUX. Mr. Mollica.

Mr. MOLLICA. I think the report will be used by States. They clearly know about it. They are looking forward to it. I had one State person suggest that having a recommendation supported by the Workgroup might help them adopt it in a State where there might be some opposition. So I think it will be a very useful document.

In terms of the Federal process, I think the first role would be to fund more research. We clearly need to know what works and what doesn't, and whether it is the broad approach, the broad definition that was included in the Workgroup's recommendation or a more narrow definition that was preferred by some members of the Workgroup. We need to know if one set of outcomes is derived from a certain staffing approach or training approach or levels of care

versus non-levels of care. We simply don't know enough about what works to say that it should be one standard or another.

Senator BREAUX. Thank you. I notice one of the recommendations is a Center for Excellence in Assisted Living. I have always felt that when you give consumer choices, that you also have to give them information about what the choices are. Otherwise, bad information produces bad choices. So I have always thought that you ought to be able to go to some type of a national site to look at, whether it is nursing homes or whether it is toaster ovens or whether it is assisted living facilities, a type of consumer report on how the various organizations are doing so that when you make the choice, you know that you make the choice based on a history of performance.

Is this what we are talking about on the Center for Excellence in Assisted Living? Is this a research group, or is this something that would help provide information to consumers as they go out and pick the best assisted living facility for their folks or themselves?

Mr. MCCONNELL. As I understand it, Senator, it is all of the above. It is to conduct the research to help us get to the point where we are looking at outcomes. It is designed to provide feedback to the industry so that what we learn about good care can be fed back and care can improve. It can also provide information and guidance to consumers.

This is a concept that has been around for a while. We were involved in a smaller group several years ago called the Assisted Living Quality Coalition. This concept arose then, as well. I think it is a good idea. There is some nervousness about it, which probably suggests that it really is a good idea— [Laughter.]

Perhaps because consumers would have a role in guiding this, as well as the industry. It is in some ways an embodiment of what you have tried to do by creating the Assisted Living Workgroup.

Senator BREAUX. There are a lot of issues out there. You mentioned the question about who gives out medications in assisted living facilities, whether you are going to have to have a registered nurse or someone with a nursing background or degree to help administer the medications or whether you can have an aide who has been trained to provide the meds. All of these things are very, very important issues of which there are various opinions.

What about, the final thing, licensing according to a degree of care? Obviously, assisted living facilities can range from those who are treating very healthy older Americans who need very little help as opposed to those who need a great deal of help, on the verge of having to require a nursing home facility, and you would think that the degree from a licensing standpoint would be different depending on the degree of services they provide. Can you give me any thought on that, anybody?

Mr. MOLLICA. I think you have to look at the total context of the regulations to know how either approach would work. If you allow a more flexible array of services to be provided and serve people with different needs within the same facility, then, as a regulator, you have to look at the admission agreement and the staffing pattern and your oversight activities might be done a little bit differently than if you were looking at a specific level of care.

I personally think that the general approach is preferred among consumers who want to age-in place. They don't want to have to move when their level of care is no longer appropriate for that facility. On the other hand, as their level of care changes, there is a need for the oversight agency to make sure that the staffing pattern and the training of the staff is consistent with the changing needs of those facilities.

Again, I don't think there is research one way or the other that suggests which is better. The level of care approach might be easier to monitor because you know specifically what you are going to look for. If the staffing patterns for one level or another are different, you know what to count. If the training requirements are different, you know what to look for. On the other hand, it doesn't have the same amount of flexibility that the broader approach does.

Senator BREAUX. I don't want to take more than my allotted time, but I guess the question is who determines whether an assisted living facility can accept Mr. and Mrs. Smith into a facility? I mean, some of them are Ritz Carltons. They run beautiful facilities, but they lack in terms, I think, of the amount of medical care they can give to an individual. How do you regulate that? It is a very difficult question about whether this person qualifies for a given institution. I am not sure how we go about setting those standards. Some people obviously sicker than others. Some need very little medical attention. Others need a great deal. Should there be someone that says, no, you cannot take this couple because they require far too much care, or can a facility take anybody who shows up with the money to pay the bill?

Mr. MOLLICA. Well, I think States are, as expected, feeling a lot of tension in that regard. Some states allow facilities to take care of whomever they have the qualified, trained staff to serve, and others will draw some boundaries barriers, some lines. It is either a list of conditions or the need for 24-hour care or unstable medical conditions.

I think whichever approach a State uses, they have to look clearly at what the facility's capacity is and who the staff are. If the facility isn't making the proper judgments, and that has been a concern among a lot of regulators, then the oversight agency has to be there frequently enough to step in and say, your staffing pattern either has to change or you have to ask this person to move and help them to do so.

Senator BREAUX. I think that this document has been well put together. Nothing we do is the final answer to anything, but I think this really moves the ball down the field in a major way as far as establishing in one comprehensive document a set of guidelines that has been thoroughly discussed, not just by the Federal Government or not just by the State Government, but by the actual utilizers of the services, as well as by the providers of the services.

I would hope that this sets a standard or a pattern that we can utilize on other difficult issues where we bring people to the table and somehow almost force them to do what has been done here, and sometimes they do it voluntarily and sometimes they do it with a little encouragement and sometimes it takes more than a little

encouragement. But this is a good product and put together by good people and I thank them for it.

Mr. MADSEN. Senator Breaux, if I may go back and elaborate a little bit on the Center for Excellence and some of the needs for information for consumers, because I think that is an important issue, is there a catch-all checklist that you are going to be able to go on and seek information regarding each facility or community out there that is going to be standard and allow you to make choices for a family member or yourself? No. I don't believe that is possible.

Should there be an incredible amount of information provided and guidelines and tips and the best ways to analyze any of those situations? Yes. I think we need to do a great job and have done a much better job in that area because we are focusing on something that is very, very important, and as a provider and being out there, it is a life decision. This isn't buying a car. These are people's lives, and there is nothing, there is not a survey, there is not a document, there is nothing that will replace going and seeing the community and talking to staff and talking to residents and talking to families that have received services there.

Nothing will replace going and visiting and getting the feeling and interviewing people and finding out the quality, attending resident council meetings and seeing, does it work in this community, because they are going to vary, and no checklist will replace that, ever. These are lifestyle decisions and I think they need to be taken seriously and I think that is the best way to make those decisions.

Senator BREAUX. I don't disagree with that, but, I mean, a lot of families don't have time to visit ten different facilities.

Mr. MADSEN. I agree.

Senator BREAUX. It would be nice if we could visit every facility within a city or a State and say, here is the best one for Mom and Dad.

Mr. MADSEN. I agree.

Senator BREAUX. That information could be a good starting point. I mean, I have always said that if a facility has had ten fire code violations last year, I would like to know that somewhere, because I would say, whoa, I may go visit and see if they have changed it because it looks pretty bad up front. So I think you need that continuum of information that kind of gives you a parameter so that then you can go out and pick the ones that are really good and exit those who are really bad.

The CHAIRMAN. In other words, it isn't buying a car, but you darn well better kick the tires.

Mr. MADSEN. Exactly. Absolutely. You better drive it, test drive it.

The CHAIRMAN. Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. I think all of you have been excellent, and I think you heard me say at the outset that my goal is to make sure that every single person in an assisted living facility secures a basic level of protection, and at the same time, we look at a way to try to be innovative so as to give industry and providers enough flexibility to avoid some of the problems that we have in nursing homes.

I think probably the best way that we can proceed now is to have you walk us through some of the specific challenges. Let me take the example of dementia as a way to get us into this debate because I think that this is an area where we are clearly talking about a lot of frail people, we are talking about people that certainly consumer groups have advocated for and many in the industry have tried innovative approaches to care for, as well.

Steve, if you would, tell me what percentage of States, or a number of States, are not yet where we need them to be with respect to treating dementia. Give us a sense right now of how serious it is in the United States with respect to the dementia question.

Mr. MCCONNELL. Bob knows the specific numbers, but a number of States have regulations, disclosure requirements for special care units. In other words, those that hang out a shingle claiming to have a special care unit for people with dementia would face disclosure requirements and there are better restrictions for many of those facilities. But as I pointed out in my testimony, most people with dementia are not in special care units, so there is very little protection from them.

Second, one of the challenges with dementia is that we are, with advances in science, able to diagnose people earlier. Someone in the very early stages of dementia needs a whole different set of services and care than someone in the later stages, this relates back to the issue of levels of care. If that is defined simply by a diagnosis, that is a problem. That is like saying you get a diagnosis of Alzheimer's, you can't drive. Well, we know that is not appropriate.

So I think the key is as I said, "That there are requirements that staff be trained to recognize the signs and symptoms of dementia, and that there be basic training and basic protections in place."

Bob, you can straighten out the record on this, but I think there are very few States that provide protections for people with dementia in all assisted living facilities. If they do it at all, it is really only for special care units.

Senator WYDEN. So would you say a third of the States are not where the country ought to expect them to be with respect to the dementia question? What I am trying to do is to give us a sense on a very key question with respect to striking the balance between caring for frail and vulnerable people and at the same time ensuring that we will have the providers we need and the flexibility for them, get a sense of the problem. Then I am going to walk you through what the report says with respect to the dementia issue.

But first, give me a sense, if you would, of how serious the situation is with respect to where the States are on this particular key area of the frail elderly population.

Mr. MCCONNELL. Bob, do you have the specifics?

Senator WYDEN. Mr. Mollica—

Mr. MOLLICA. Between half and 60 percent of the States do have provisions for facilities serving people with dementia and about 40 percent or so do not.

Senator WYDEN. So 40 percent of the States have nothing at all on this?

Mr. MOLLICA. Right.

Senator WYDEN. Of the States that do have protections for those with dementia, do we have any sense of whether they are good, bad, medium? Is this something that the task force looked at?

Mr. McCONNELL. I think most of them, as I said, relate to disclosure requirements so that it is really only a matter of telling people what is provided, and then only if you declare that you have a special care unit. So I think disclosure was a good first step, and is very important. But, it is not enough.

Senator WYDEN. All right. So we have got 40 percent of the States with nothing, then we have 50 or 60 percent of the States with nothing, and Steve and the Alzheimer's Association says that it is fairly modest with just disclosure.

Dan, do you want to weigh in on this? Do you have a difference of opinion on anything?

Mr. MADSEN. I don't have a difference of opinion. I think, again, it is a challenge. It is that balance that you are trying to strike, and that is, I think, a great first step is disclosure and understanding what you are qualified to provide in services. I know in our company, we have chosen not to treat that level of care because that is not where our specialty lies and there are people that are very, very good in that area, in the specialty care and Alzheimer's area. I think the disclosure piece of making sure the consumer doesn't expect to receive care in those areas is a great start.

The identification, to be able to see the signs, I think is good. We should all be trained to a degree of that in all areas of life. But I think we also have the personal physician that is working with the resident and identifying those issues better than we can, and they are making recommendations on levels of care and where they should receive those services.

Senator WYDEN. So using this report, how can we take this document and upgrade what is done in the dementia area? Senator Breaux made the point, for example, with respect to making sure that this just doesn't gather dust somewhere. I think we can get pretty significant agreement among consumer groups and patient advocates and the industry that we need to have a monitoring process, and I assume that you are thinking about that in the context of a national center in some way.

But how do we take this report and use what you have just told us with respect to dementia, a serious area, to make sure that we are putting in place the kinds of policies that bring about the changes we need?

Mr. McCONNELL. It is both to try to get requirements in place that, for example, staff are trained throughout these facilities, not just if you have a special care unit. Any assisted living facility should train staff to recognize the signs and symptoms of dementia. So that is partly a requirement and partly training. The Alzheimer's Association is trying to help in communities around the country by providing resources on how to recognize dementia. So it is both putting some requirements in place and then making sure that the tools are available to facilities.

I listed out a number of other things that should be put into State requirements. Each state will vary on exactly how this plays out.

For example, on the issue of training, we had some very specific requirements we wanted to see in terms of training on dementia care and those didn't survive. The recommendation was watered down to get a two-thirds vote. But those are things that we will push for at the State level.

So some efforts will focus on specific legislative requirements. Some will focus on working with the industry to try to upgrade the level of training.

Senator WYDEN. I want to ask just one other question. However, I really encourage you, in some of these key kinds of questions with respect to services for the frail that we take additional time to sort of walk through how we make progress in those kinds of areas. I think, as much as anything, if we have learned in the past, is if you can get at these questions early on in the formative days of policymaking at the State and the Federal level, you are more likely to prevent the kind of blow-ups down the road.

My last question, as I looked at it, there were areas where it seemed to me we could have some better coordination. For example, when a resident is moving in, apparently, the group came to the conclusion that there ought to be a pre-move-in screening process and then an initial assessment. There is going to be some concern about how you coordinate this so you don't just chew up a lot of time and additional cost. What efforts are underway to try to better coordinate some of the ways to address those concerns? Is that something you brought up in the report, because, I mean, it is in the report.

Mr. MADSEN. Sure. Absolutely. I think that assessment processes is a very viable tool. It is something that—important in a—when a resident moves in, again, it is a life decision and I think it is important to, one, have the disclosure, these are the services we can and cannot provide in the setting, and go through the assessment process, work with the physician, work with the family, work with the resident to identify the services that you can and will provide and are saying you will provide and then to what level of quality and care.

You know, is that something that the States should work with? Absolutely, and they do. You know, several States are working with that very accurately. What is that assessment process? What is that entry process? Again, is that something that comes from the Federal standpoint? No. I think the States are doing a good job.

Senator WYDEN. I would just rather make sure, for example, those dollars that may now get chewed up in a duplicative process are put back into services for people. I think those are the kinds of choices we are going to have to ensure get made Mr. Chairman, you have been gracious with the time for questions and I look forward to working with you and Senator Breaux.

The CHAIRMAN. Well, thank you both.

A couple more questions. Robert, do you think there are any additional areas of concern that should have been included in this study or should be included in future examinations and future studies that this one missed?

Mr. MOLLICA. Well, I can't think of one. They did a— [Laughter.]

The CHAIRMAN. Now, we have got—

Mr. MOLLICA. It is a challenge—

The CHAIRMAN. We have got 110 recommendations here that met the two-thirds requirement, but surely one slipped out that you thought had to be critical and should be there. [Laughter.]

Mr. MOLLICA. I think the ones that didn't meet the two-thirds requirement are still worth considering and I am very pleased that the report included them because it gives stakeholders and regulators an opportunity to look at what is there that they didn't reach consensus on for their own deliberations.

The CHAIRMAN. Dan.

Mr. MOLLICA. There isn't much they have left out.

Mr. MADSEN. I agree. I am glad that we have the supplemental positions in there so that the States can see what was left out or what wasn't approved by the two-thirds so that they can consider all recommendations, consider all opinions when formulating their regulations on a State level. I think it is great.

The CHAIRMAN. Stephen.

Mr. MCCONNELL. It is hard to imagine anything that was left out. If you think about whether this is too prescriptive or not prescriptive enough, most of the groups on the tails of that Bell Curve you talked about argue that it is not prescriptive enough. So I think it is really more a matter of defining these things more clearly. It is too bad we couldn't have come up with a definition we could have gotten two-thirds vote on. But I think the issues are laid out clearly here and now it is a matter of playing them out at the State level.

The CHAIRMAN. Senator Breaux mentioned—another question to all three of you. Senator Breaux mentioned in one of his comments that many studies that are done either at the auspices of the Congress or done by Congress end up on library shelves gathering dust and somebody simply cleans them off a decade or so from now, might look at them, and might just toss them.

How can we help you, or how can we help the industry elevate this in a way that it actually get read, gets looked at, is viewed as a template from which to make decisions, and that we move this industry in the direction that it ought to be moved in, and that is at the State level with State regulation to assure those kinds of quality, some degree of uniformity, as we go through, so that this isn't one of those dust-collecting projects? Recommendations, gentlemen, that we, I say we the Congress, we this committee, might participate in to lift it up?

Mr. MCCONNELL. I suspect that if you threatened legislation— [Laughter.]

There would be a lot of activity on this, because I think there are many groups that are interested in preempting federal legislation. I think there is a genuine interest in addressing this at the State level, and if there was a fear that something might happen federally—I mean, the fact that you asked these groups to get together, my hunch is that many of us came together because we thought, either on one side, gee, maybe they are going to do something about this, or, oh, my God, they are going to do something about this.

So I think keeping that stick there might not be a bad thing, as well as continued oversight by the committee. I think it is very im-

portant you do these kinds of things, where you are asking questions, you are looking into the issues, paying attention. I think that will help everybody keep working on this.

The CHAIRMAN. Surely. Dan.

Mr. MADSEN. I believe it is a living document. It is something that needs to be made available. It should be sent to the States, all interested parties. We certainly will urge all the providers to utilize this when looking at their own policies and procedure manuals, working with the State regulators. I think knowing that it is a continual improvement process, that we need to keep it alive. It is going to change. It is going to evolve. Our market changes and evolves—

The CHAIRMAN. Sure.

Mr. MADSEN. Our residents, and I have seen over the last 15 years change and evolve, and what they are looking for in assisted living is completely different today than it was 15 years ago, and it will be different 15 years from now and I think that we should always have a process in place like this.

The CHAIRMAN. Robert.

Mr. MOLLICA. I think that if you announced that you were going to have a hearing in 2 years or some period of time to look at what has happened to the Workgroup recommendations and what have the States done, that would initiate consideration by states that might feel complacent that their regs are OK the way they are. Even if they are, if they just look at it and compare their regulations with the complaint and survey results and compare what the Workgroup has recommended, it would be worthwhile to make sure the regulations are working well in a State that may not change their regulations.

But I think in many other States, they will look at them seriously. At any given time, about half the States are tweaking their regs or refining them or totally revising them and they will look to the recommendations for suggestions about what they might consider.

The CHAIRMAN. John, the last word, if you wish?

Senator BREAUX. Not necessarily the last word, but I think the observation is correct. I think that while most of the payments for the assisted living facilities are currently private, I think that more and more, you are going to be moving into tax credits to buy long-term health insurance, which would mean that the Federal tax dollar is dramatically involved in it. You will see more and more States with more Medicaid waivers to allow Medicaid to cover the costs of these type of alternative facilities.

There certainly is a legitimate national interest to make sure that the facilities are performing as they are intended to perform, so what we did with this is to say, look, the Federal Government doesn't have all the answers but there is a legitimate Federal concern. So you folks that run the facilities and you folks that utilize the facilities, see if you can get together and come up with some recommendations that make sense. Rather than having us go out into it on our own, we wanted you all to do it as a first cut, and I think the first cut is a very, very good starting point.

But I do think that we are going to be looking to see what happens with this document, and it won't be 2 years from now, it will

be sooner than that. But I guarantee you that to the extent that Senator Craig and I can work together on this, we are going to be saying, we want to know what happens to this wonderful document and that it is not sitting in a library somewhere. Thank you.

The CHAIRMAN. Gentlemen, thank you very much, and for all the groups that participated, we want to thank you for your work effort. We think it is a phenomenal first step and a substantial document.

With that, the committee will stand adjourned.

[Whereupon, at 11:17 a.m., the committee was adjourned.]

APPENDIX



Statement for the Record

U. S. Senate Special Committee on Aging Hearing

Assisted Living: Examining the Assisted Living Workgroup Final Report

April 29, 2003

AARP appreciates this opportunity to offer a statement on quality in assisted living as the Committee receives the final report of the Assisted Living Workgroup (ALW). We commend the bipartisan leadership of the Special Committee on Aging for its ongoing commitment to quality in assisted living, as evidenced by the series of hearings, studies, and other forums sponsored by the Committee. We especially appreciate the role played by the Committee in initiating the ALW process nearly two years ago. AARP has strongly supported the ALW process, and we support the recommendations in the final report. That report would not have been possible without the Committee's leadership and support.

Background

Assisted living has been one of the most rapidly growing of the supportive service options available to older persons with disabilities. From the time the term first was used in the mid-1980s, assisted living has grown from a few pioneering residences to an industry serving nearly 1 million people with disabilities. At least 32 states now use the term "assisted living" in their statutes and regulations. Forty-one states use Medicaid funds to serve over 100,000 persons with low incomes in assisted living or residential care settings.

AARP has been involved in issues related to assisted living for more than a decade through its advocacy and research efforts. In 1993, AARP's Public Policy Institute (PPI) published one of the first national research reports on assisted living. Since that time, AARP has published numerous research reports, issue briefs, facts sheets, consumer guides, and advocacy guides related to assisted living – focusing on privacy, legal rights, affordability, regulation, and other important issues.

In 1995, AARP took the lead in convening the Assisted Living Quality Coalition (ALQC), a group of four provider organizations (American Association of Homes and Services for the Aging, American Health Care Association, American Seniors Housing Association, and Assisted Living Federation of America) and two consumer groups (AARP and Alzheimer's Association). In August 1998, the Coalition issued its final report, "Assisted Living Quality Initiative," representing recommendations on which the six members could reach consensus. Since that time, the report has been used by numerous states, accrediting bodies, and the current Assisted Living Workgroup as they developed standards and quality recommendations. AARP believes that the report is still a valuable resource in outlining a comprehensive system for promoting quality outcomes for the consumers served by assisted living.

The Assisted Living Workgroup (ALW)

The enormous growth in assisted living over the past decade and a half is an indicator of the desire of older persons with disabilities to live with as much independence, privacy, and dignity as possible. But with growth in numbers and the greater degree of disability among the consumers served have also come increased reports of quality problems and confusion about what to expect from assisted living providers. An earlier hearing of this Committee documented some of those quality problems

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and issues related to consumer disclosure. These problems are amplified by the variability in state efforts to regulate and monitor quality in assisted living.

Convened in August 2001, at the request of this Committee, the ALW has involved countless hours of dedicated work by many people representing a wide diversity of interests and perspectives. The process that produced those recommendations was remarkable for its inclusiveness of all national organizations that expressed an interest in assisted living quality, for its democratic rules that required a two-thirds vote to approve all recommendations, and for its comprehensive scope.

AARP supports the recommendations in the final report of the ALW. While we have not achieved unanimity on all issues, the final report should be a valuable resource for states considering reforms to their assisted living regulations, as well as to providers who want to improve their operations. The report includes 111 recommendations that enjoyed two-thirds support, as well as, the rationales for those recommendations. The report also includes numerous proposals that did not achieve such support. In addition, supplemental positions both in favor and against recommendations are included in order to present a more complete picture of the issues involved and the various approaches to those issues.

We will not comment on all recommendations of the report, but the following sections highlight some of the ALW recommendations that address areas of federal responsibility.

A Philosophy of "Privacy, Choice, Dignity, and Independence"

AARP's first publication on assisted living in 1993 was entitled, "Assisted Living in the United States: A New Paradigm for Residential Care for Frail Older Persons?" Much of the discussion and debate that occurred in the ALW over the definition and core principles for assisted living was still trying to answer the question posed in the subtitle of that report. Is assisted living a "new paradigm," a new type of service driven by a new philosophy of consumer independence and choice, or is it just a level of care, a way station between independence and institutionalization? While we recognize that many assisted living residences fall short of the mark, AARP believes that the success or failure of the assisted living movement must be judged by its adherence to the core principles agreed to by the ALW – principles that highlight individual "privacy, choice, dignity, and independence."

So defined, the philosophy of assisted living is part of a much larger movement that is changing the whole direction of supportive services for people with disabilities. Coincidental with the submission of the ALW report, today AARP released the latest in its series of "Beyond 50" reports (available at www.aarp.org/beyond50). This year's report focuses on "long-term independence" for people who are living with disabilities. The report includes the results of the first nationwide survey of people over the age of 50 with disabilities, providing a voice for their hopes, needs, and disappointments. What came through loud and clear was the desire to remain engaged with families, communities, and activities that give life meaning. Equally strong was the desire to remain in charge of the decisions affecting their lives.

AARP's "Beyond 50" report is also premised on the understanding that disability is not simply an attribute of the individual, something wrong that must be cured or treated by medical means. Rather, disability is the relationship between individuals and their social and physical environments – environments that can either be enabling and supportive of independence and dignity or disabling and

destructive of individual dignity. If assisted living is to realize its potential, the social and physical environments must reflect and reinforce individual choice and independence.

AARP believes that the ALW report marks a watershed in the growing consensus among consumers, providers, and professionals of all stripes that the philosophy of "privacy, choice, dignity, and independence" can only be achieved by providing private occupancy rooms or apartments to assisted living residents. In 1928, British writer Virginia Woolf was asked to deliver a lecture on women and fiction. Her rather astonishing conclusion was that "a woman must have money and a room of her own if she is to write fiction." What she recognized was that being in control of one's life, having money and "a room of one's own," were critical dimensions of being a whole, creative person.

As AARP's "Beyond 50" report documents, one might give the same answer today when asked what people with disabilities want and need. Assisted living has led the way among the providers of long-term supportive services in providing private rooms and apartments to the vast majority of its residents. The great obstacle to providing private accommodations to everyone has been the other half of Virginia Woolf's answer – namely money. In some states, public reimbursements, primarily through the Medicaid waiver program, require private accommodations. We at AARP, together with the vast majority of the participants in the ALW, believe it is time to make a national commitment to people with disabilities that they will not be condemned by public policy and reimbursement programs to share living accommodations with strangers in a hospital-like setting.

"Privacy, choice, dignity, and independence" demand a national commitment to private accommodations, just as our housing subsidy programs long ago required private occupancy. A person should not forfeit the right to private occupancy housing simply because he or she has a disability. Moreover, as our colleagues from the Pioneer Network and others in the ALW more directly involved in nursing home issues would remind us, the same principles should apply throughout the system of providing long-term supportive services – including to those who need skilled care in a nursing home. Assisted living may further its philosophy not only by providing private accommodations to its own residents, but also by serving as a model and, indeed, as a competitor driving change in other types of services.

Affordability

As the preceding section notes, the philosophy of assisted living argues for systems that allow for a wider array of options, including consumer direction. Consumers and the decision-makers they designate should make decisions about the settings in which they live, the types of services they receive, and those who provide the services. Many of the recommendations of the ALW Affordability Topic Group relate to providing more reimbursements that support a greater range of consumer options.

The recommendations also relate to making federal housing programs more responsive to the needs of those who have disabilities. As a recent AARP Public Policy report notes, the 1.7 million older households receiving federal housing assistance have characteristics that place them at high risk of needing supportive services – and at high risk of needing Medicaid reimbursements by virtue of their low incomes. The residents in subsidized housing report having disabilities at twice the rate of older homeowners. They also tend to be women living alone with relatively weak informal supports from family.

The Department of Housing and Urban Development has a limited program for converting units in Section 202 elderly housing to assisted living, but no programs provide services in public housing or other types of subsidized housing. A HUD task force is now looking at examples of providing assisted living services in public housing. Such efforts should be encouraged by HUD and by Congress.

Center for Excellence in Assisted Living

Continuing and extending the work of the ALW will require the establishment of a permanent body charged with promoting quality in assisted living. The ALW has proposed a national "Center for Excellence in Assisted Living" (CEAL). As recommended by the ALW, the CEAL would be an independent body with a board appointed to balance the interests of various stakeholders. The CEAL would be an information clearinghouse charged with: 1) developing and validating performance measures, including clinical outcomes, functional outcomes, and resident satisfaction; 2) updating recommendations for state regulation; 3) disseminating the measurement tools developed; and 4) developing practice protocols that address specific problem areas.

The activities of the CEAL would be helpful to a variety of stakeholders. Regular reports on quality issues to Congress should provide better information for decision-making on important policy issues. Quality measures should provide a useful basis for consumer decision-making, state monitoring, and provider quality improvement. Updated recommendations on quality standards should be of use to states, many of which are currently involved in revising their regulations or their statutes. Congress could play a useful role in developing these tools and fostering the development of quality information on assisted living by providing an appropriation to fund the establishment of the CEAL.

Conclusion

Our statement has focused primarily on areas of federal responsibility. But most of the recommendations of the ALW relate to areas of state or provider responsibility. Recommendations for state regulation would greatly improve state oversight of services, medication management, staffing, and resident rights. The Best Practices and Operational Models provided in the Appendix to the report should be useful to providers looking for ways to improve the quality of services they provide residents.

The encyclopedic nature of the report may make it unlikely that states will adopt all of the proposals wholesale, but AARP believes the ALW report will serve as a valuable resource for states as well as a benchmark for progress in realizing the assisted living philosophy. Once again, we thank the Special Committee on Aging for your leadership in creating this process, and we look forward to working with you to implement many of its recommendations.

AARP is a nonprofit, nonpartisan membership organization dedicated to making life better for people 50 and over. We provide information and resources; engage in legislative, regulatory and legal advocacy; assist members in serving their communities; and offer a wide range of unique benefits, special products, and services for our members. These include *AARP The Magazine*, published bimonthly; *AARP Bulletin*, our monthly newspaper; *Segunda Juventud*, our quarterly newspaper in Spanish; *NRTA Live and Learn*, our quarterly newsletter for 50+ educators; and our Web site, www.aarp.org. We have staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.



**American Association
of Homes and Services
for the Aging**

Statement for the Record

American Association of Homes and Services for the Aging

U. S. Senate Special Committee on Aging

"Assisted Living: Examining the Assisted Living Workgroup Final Report"

April 29, 2003

The American Association of Homes and Services for the Aging (AAHSA) appreciates the opportunity to submit this statement for the record of the Committee's hearing on assisted living. AAHSA represents more than 5,600 mission-driven, not-for-profit senior housing and assisted living facilities, nursing homes, continuing care retirement communities, and community service organizations. Every day, our members serve more than one million older persons across the country. AAHSA is committed to advancing the vision of healthy, affordable, and ethical aging services for America.

AAHSA welcomed the opportunity to be involved in the Assisted Living Workgroup (ALW) to develop a roadmap for assisted living and to take responsibility for shaping the future of the field. As a member of the Assisted Living Workgroup, Steering Committee and co-chair of two of the eight topic groups, AAHSA has been committed to furnishing the Committee with a report that will raise the bar in the assisted living field.

As many have noted, assisted living has experienced phenomenal growth over the past 15 years because it provides a desirable, cost-effective and dignified living environment. Consumers like the help they receive with everyday living tasks and with varied challenges to their health status. They love the residential -- rather than institutional -- "feel" of assisted living and appreciate the range of assisted living settings and services from which they may choose. Assisted living residents value and benefit from a wellness model -- a blend of social and health services. Supportive services are provided in a way

that maximizes resident dignity, autonomy, privacy, independence and safety, and takes the approach of “we will help you take care of yourself,” instead of “we will take care of you.” The beauty of assisted living is that it covers a broad array of services and settings to meet the varied needs of residents.

The ALW report, which the Committee receives today, reflects the full complexity of the assisted living field. The strength of the process that produced it was the diversity of the groups and individuals that participated. The importance of the report itself is its portrayal of the view of those groups and individuals that participated. During the past year-and-a-half, the workgroup’s deliberations have been characterized by lively debate, consensus and healthy compromise. Where opinions have differed, the process has provided workgroup participants the opportunity to file supplemental positions, which are reflected in the report.

Nobody who reads this report can escape the conclusion that assisted living serves a varied population with varied needs. The other clear conclusion of those reading the report must be that regardless of the intensity of the divergent views, the resident remained at the center of the process. The need for safe, high quality, and affordable options was paramount in all participants’ views.

AAHSA participated in all topic groups and is supportive of the ALW’s report. As rich as the entire report is, however, AAHSA believes that it especially moves the field ahead in three areas: assessment, disclosure, and accountability and oversight.

Assessment

Facilities must be able to assess someone adequately to ensure that the services that a prospective or current resident needs match the services that a facility offers. This is one of the most important principles of assisted living. Facilities should be able to tailor their service package to the residents they serve. For example, some facilities may decide to have licensed personnel on staff at all times while others may not. In order for assisted

living facilities to maintain that type of flexibility, they must adhere to assessing the needs of people in a timely and appropriate manner. If the services that a resident needs do not match with the services that a facility offers, then the facility should not admit or retain those individuals.¹

Disclosure

Prospective residents must be able to make informed decisions when they are deciding to enter an assisted living facility. All information conveyed by the assisted living residence such as marketing materials should be consistent with the contract. Contracts should be written in simple language and easily understandable. Contracts and agreements should provide a comprehensive description of services offered, all costs, resident rights, and any other information that would affect a resident's stay.²

One of the most misunderstood areas for consumers is criteria for resident transfer or move-out from an assisted living residence. Consumers need to understand before they move in and throughout their stay what reasons may be given for them to leave the facility.³

Accountability and Oversight

The recommendations on state accountability and oversight systems are founded on the principle that state regulatory models should incorporate standards, monitoring, technical assistance and remedies. Regulators, providers and consumers should work together in a participatory fashion when defining regulatory standards. We must move away from a strictly punitive system to a new paradigm that allows for flexibility and innovation while ensuring that residents are cared for in a high quality safe environment.⁴

¹ Recommendations D.01 Pre-Move in Screening Process, D.02 Initial Assessment and D.03 Services Plans

² Recommendations R.01 Consistency in Contracts and Marketing, R.03 Contracts and Agreements: Readability and Pre-Signing Review and R.04 Contracts and Agreements: Required Elements

³ D.04 Reasons for Resident Transfer or Move-out from an ALR, D.05 Protocols for Resident Transfer or Move-Out from an ALR

⁴ AO.06 Components of a State Accountability and Oversight System, AO.09 Licensure of Assisted Living

Next Steps

The ALW recognized that this report is a beginning, not an end. The ALW recommends the creation of the Center for Excellence in Assisted Living (CEAL) to carry forward the work of the group. The CEAL would collect data and move toward developing outcomes that along with minimum regulatory guidelines will assist consumers, providers, regulators, legislators and other interested parties to keep this important level of care in the continuum viable. The CEAL should include broad representation and use the ALW report as a foundation as the field of assisted living continues to evolve.⁵

In addition, the work of the ALW must be modeled at the state level. Assisted living currently is and should continue to be a state-regulated field. It is very important that a process similar to the national ALW be replicated in the states so that all perspectives are presented if a state chooses to review its assisted living regulations.⁶

AAHSA itself has additional plans for the report. With other organizations,⁷ AAHSA developed in 2002 a bold five-year plan to improve the quality of aging services and to ensure public trust in the aging field. The Plan, “Quality First: A Covenant to Achieve Healthy, Affordable, and Ethical Aging Services,” is a promise to the public that aging service providers are taking responsibility for raising the bar in the field.

Quality First is rooted in seven core principles, six measurable outcomes, and a clear path for reaching them. The principles include:

- Continuous Quality Assurance and Quality Improvement
- Public Disclosure and Accountability
- Resident and Family Rights
- Workforce Excellence
- Public Input and Community Involvement
- Ethical Practices
- Financial Stewardship

⁵ AO.01 Center for Excellence in Assisted Living

⁶ AO.03 State-level Public Meetings to Review ALW Recommendations

⁷ AHCA, NCAL, The Alliance for Quality Nursing Home Care

The expected outcomes are:

- Continued improvement in compliance with regulations
- Demonstrable progress in promoting financial integrity and preventing occurrences of fraud.
- Demonstrable progress in the quality of clinical outcomes and prevention of confirmed abuse and neglect.
- Measurable improvements in all Centers for Medicare and Medicaid Services continuous quality improvement measures.
- High rates on consumer satisfaction surveys, indicating improved consumer satisfaction with services.
- Demonstrable improvement in employee retention and turnover rates

As AAHSA continues to implement Quality First, it will look to the ALW report for guidance as it further develops its principles and outcomes in assisted living.

The charge given to the Assisted Living Workgroup by the Senate Special Committee on Aging in 2001 was to (1) describe what a system of quality and accountability would look like for assisted living; (2) be inclusive with respect to participation, and (3) be quick. The ALW has met that challenge. We have described an approach to assisted living that incorporates guidelines for federal and state policy, state regulation, and operations. Our recommendations preserve flexibility for residents in terms of services and setting, while mindful of their other needs for affordability.

AAHSA appreciates the foresight of the Committee and the opportunity to participate in this milestone process. We feel the outcome is a report that will be a blueprint for assisted living for many years to come.

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May 2, 2003

U.S. Senator Larry Craig, Chairman
Special Committee on Aging
Dirksen Senate Office Building
Washington, D.C. 20510-6400

**Re: Assisted Living: Examining the Assisted Living Workgroup
Final Report;
Hearing of April 29, 2003**

**Statement of Nine Participating Organizations
Representing Interests of Regulators, Older Americans,
Long-Term Care Ombudsmen, and Long-Term Care
Facility Employees;
Submission of Policy Principles for Assisted Living**

Dear Chairman Craig:

This letter is submitted on behalf of nine national organizations, representing the interests of state regulatory officials, older Americans (including assisted living residents), long-term care ombudsmen and other advocates for residents, and employees of long-term care facilities. The nine organizations are listed at the conclusion of this letter.

Each of these nine organizations has participated actively in the Assisted Living Workgroup. We thank you and the Special Committee on Aging for convening the Workgroup. Given the ever-increasing use of the term "assisted living" throughout the country, there is an urgent need to clarify for consumers what assisted living is, and what standards an assisted living facility must meet.

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With that need in mind, our nine organizations developed *Policy Principles for Assisted Living*, the policy paper enclosed with this letter. In brief, *Policy Principles for Assisted Living* recommends that assisted living standards be set by regulation, and not be left to the contract used by an assisted living facility. An assisted living regulatory system should license more than one level of assisted living so that, for example, regulatory standards can match residents' health care needs. Given the increasing amount of Medicaid funding used for assisted living services, Medicaid standards should protect Medicaid beneficiaries from discrimination, and guarantee a quality of care that is appropriate to the relatively intensive health care that by definition is provided within Medicaid-funded assisted living services.

The discussions of the Assisted Living Workgroup brought out many of the important issues in assisted living today. The dialogue in the Workgroup's Final Report – between the Final Report's recommendations and the supplemental positions submitted by participating organizations -- is a valuable tool for approaching public policy decisions relating to assisted living.

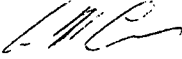
That being said, we believe that the Final Report's recommendations themselves, by and large, are not well-crafted, and are not good guides for future regulation at either the state or federal level. The Final Report includes numerous supplemental positions submitted by our nine organizations. These supplemental positions – generally framed as dissents to the Final Report's recommendations – explain the inadequacy of certain of the Final Report's recommendations.

The inadequacies of the Final Report's recommendations are in part a result of the following:

- The Workgroup never was able to reach a shared definition of “assisted living.” Also, although the defining of assisted living logically would be the first step in setting assisted living standards, definition-setting was not the first but the last item completed by the Workgroup, more than eighteen months after the process began.
- The recommendations of the Final Report generally were made without recognition of the significant quality of care problems that exist in assisted living today.
- The Workgroup gave almost no consideration to states' existing assisted living laws, whether those laws have been successful or unsuccessful, and how those laws could be modified or improved.
- The Final Report does not distinguish between different types of assisted living facilities, even if, for example, one type of assisted living facility provides relatively high-intensity health care services, and another type of assisted living facility provides no health care services whatsoever.

Because the Workgroup's Final Report, in our opinion, fails to address many important issues, we developed *Policy Principles for Assisted Living*. We believe *Policy Principles for Assisted Living* provides an important framework for improving the care provided to the many vulnerable individuals living in assisted living facilities. We look forward to working with you and the Special Committee on Aging toward this important goal.

Sincerely,



Eric Carlson, Esq.
National Senior Citizens Law Center, for:

Association of Health Facility Survey Agencies
Center for Medicare Advocacy
National Association for Regulatory Administration
National Association of Local Long-Term Care Ombudsmen
National Association of State Long-Term Care Ombudsman Programs
National Citizens' Coalition for Nursing Home Reform
National Committee to Preserve Social Security and Medicare
National Network of Career Nursing Assistants
National Senior Citizens Law Center

Enclosure: *Policy Principles for Assisted Living*

Policy Principles *for* Assisted Living

April 2003

- Association of Health Facility Survey Agencies
- Center for Medicare Advocacy
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Acknowledgements

Thank you to the members of the participating organizations for generously donating their time in the development and preparation of this report. Thanks also to the American Bar Association's Commission on Law and Aging for making available the considerable expertise of its staff for consultation.

We are especially grateful for the leadership of the Senate Special Committee on Aging Chairmen – Senator Charles Grassley, Senator John Breaux, and Senator Larry Craig – for recognizing and working to address the existing problems in assisted living.

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Executive Summary

Although the assisted living model can have a vital place among available long-term care services, it will fail if it is allowed or expected to be all things to all people. The vulnerable residents of assisted living facilities deserve regulatory standards that define assisted living in an understandable way, and ensure an adequate quality of care.

Assisted Living Standards Must Be

Strengthened. Recent newspaper stories illustrate the substandard care that too frequently is observed in assisted living facilities. Serious problems often are caused by a dangerous combination – vulnerable physically or mentally disabled residents with significant health care problems, cared for by a staff with minimal knowledge. The management and staff of assisted living facilities often do not have adequate experience or expertise in providing health care, even for relatively routine health care such as the management and administration of medication.

"Assisted Living" Must Be Defined In a Meaningful Way, and Governed By Standards That Guarantee a Reasonable Level of Quality.

Standards should address the types of care provided, staffing levels, staff training, fire standards, and other important issues. The setting of standards should not be left to a facility's admission contract. It is unreasonable to expect an elderly individual in need of long-term care to negotiate the standards that the facility will follow.

States Should Establish More than One Level of Assisted Living Licensure. While a single one-size-fits-all standard may be appropriate for a facility whose residents have minimal needs, a single standard is inadequate to protect the increasing number of residents with significant health or mental health care needs. Far from protecting the most vulnerable, a "one-size-fits-all" system reduces standards to the lowest common denominator. A more effective

system is to license assisted living at more than one level, with levels defined by the type and severity of the physical and mental conditions of residents that the assisted living facility is prepared to accommodate. Such a system is used successfully by a significant number of states.

Assisted Living Facilities Should Be Subject To the Same Non-Discrimination Rules that Govern Nursing Homes, to Assure That Low-Income Medicaid Beneficiaries Are Treated Fairly.

Too commonly the assisted living industry wants the benefits but not the responsibilities of Medicaid reimbursement. Medicaid-participating facilities should be required to accept Medicaid from residents who become financially eligible for Medicaid while residing at the facility. Also, Medicaid-participating facilities should be required to accept Medicaid as payment in full for covered services, and should be prohibited from soliciting supplemental payments from residents' family members and friends.

The Federal Government Should Take an Active Role In Assuring that Assisted Living Residents Receive Quality Care.

The federal government has jurisdiction over numerous important aspects of assisted living, and federal funding is responsible for a significant percentage of assisted living care. In addition, of course, the health and safety of vulnerable assisted living residents is a pressing concern. All of these are compelling reasons for an active federal role in assisted living. It is particularly appropriate that the federal government review the adequacy of state regulation when evaluating a state's application for a Medicaid waiver, given that waiver reimbursement is reserved only for those Medicaid beneficiaries whose medical needs are severe enough to warrant nursing home care.

I. Assisted Living Standards Must Be Strengthened.

Assisted living has much promise and, for some residents, provides a beneficial combination of housing and services. For too many residents, however, assisted living services are inadequate or substandard. We believe that consumers deserve better. Assisted living standards must be raised, and those raised standards must be enforced in a meaningful way.

A. "Assisted Living" Is an Expansion of a Longstanding Residential Care Model.

While the term "assisted living" first appeared fairly recently, the term describes a business that is not necessarily new. At its core, "assisted living" refers to services provided in conjunction with housing, for persons who cannot live independently.

In some states, "assisted living" is a new name for a pre-existing licensure category. In some cases the name change is made formally – in 2002, for example, Colorado renamed its "personal care boarding homes" as "assisted living residences."¹ In other cases the official name is unchanged, but "assisted living" has become the informal designation. California, for example, has licensed residential care facilities for the elderly since 1985, and it is those residential care facilities for the elderly that now are referred to commonly as "assisted living," even though the relevant law still refers to residential care facilities for the elderly.²

There are currently more than a dozen different designations for facilities that could be considered "assisted living," with more than one such designation in some states. For example, New Mexico licenses adult residential care facilities, and operates a Medicaid payment program known as assisted living.³ Michigan licenses adult foster care facilities and homes for the aged, and also sets out requirements for contracts used by "housing-with-services establishments."⁴ New York licenses adult homes, enriched housing programs, and assisted living programs.⁵

For years, residential care/assisted living was understood as a level of care falling between independent living and nursing home care. Appropriate consumers of an assisted living facility were those residents who required some assistance with activities of daily living, but did not have extensive medical problems. The very name "assisted living" suggests that such non-medical assistance was the principal service provided when the term "assisted living" moved into circulation in the early 1990s.

Assisted living has moved beyond its initial identity as a housing option for relatively healthy older people. The assisted living industry increasingly provides health care services, and it provides these services to a population that each year is becoming frailer, more dependent, and more similar to nursing home residents. Some chains and independent operators now contend that they should be allowed to compete directly with nursing homes, especially for the business of private pay residents.

B. Problems Are Mounting In Assisted Living.

Significant care and safety problems are not uncommon in assisted living. Furthermore, because assisted living facilities have less professional staff and fewer regulatory requirements than do nursing homes, and are less closely monitored by the states, it is likely that serious problems are more numerous than is currently known.

Recent news articles illustrate some of the problems. For example, one newspaper investigation of 25 local assisted living facilities found "[s]ubstantiated neglect and abuse cases . . . includ[ing] an outbreak of a highly contagious skin disease that went unchecked for months; a woman who was attacked in her bed by another resident; a man whose toe had to be amputated because of neglect; residents left injured and bleeding on the floors of their rooms; and a senile resident who wandered away unnoticed, collapsed and had to be hospitalized."⁶

In North Carolina, three residents from an assisted living facility were hospitalized within seven hours, each as a result of dangerously low blood sugar. The newspaper report noted that the low blood sugar could have been caused by inadequate food or improper doses of medication.⁷ In Florida, "[m]ore than 25 residents were removed from an assisted living facility after state inspectors found them living with filth, insects and spoiled food, among other hazards."⁸ In another incident from Florida, an owner and administrator of an assisted living facility was charged with criminal abuse or neglect in a death possibly caused by overmedication of an 88 year-old resident.⁹

Sources:

¹ See Colo. Rev. Stat. Ann. § 25-27-101.

² See Cal. Health & Safety Code § 1569.1 (residential care facilities for the elderly); Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy 178 (2002) (identifying residential care facilities for the elderly as California's assisted living facilities).

³ N.M. Admin. Code tit. 7, § 8.2.2; Robert L. Mollica, National Academy for State Health Policy, State Assisted Living Policy 328-332 (2002).

⁴ Mich. Comp. Laws Ann. §§ 333.20101(3) (homes for the aged), 333.26502, 333.26504 (housing-with-services establishments), 400.703(4) (adult foster care facilities).

⁵ N.Y. Comp. Codes R. & Regs. tit. 18, § 485.2 (definitions).

⁶ Donna Calles, *Assisted Suffering*, Daytona Beach News-Journal, March 10, 2003.

⁷ Nichole Monroe Bell, *Assisted Living Center Under Investigation*, Charlotte Observer, April 1, 2003, available at <www.charlotte.com/msl/observer/news/local/5529403.htm>.

⁸ Jay Stapleton, "Nasty" Conditions Prompt Removal of Assisted Living Residents, Daytona Beach News-Journal, March 15, 2003, available at <www.news-journalonline.com/NewsJournalOnline/NewsLocal/areaNS301503.htm>.

⁹ Kathy Ciolota, *Owner of Keystone Heights Nursing Home Charged in Patient's Death*, Gainesville Sun & Associated Press Newswires, November 3, 2002. Although the headline refers to a "nursing home," the text of the article identifies the facility as an assisted living facility.

Serious problems often are caused by a dangerous combination – vulnerable elderly residents with significant health care problems, cared for by a staff with minimal knowledge. For example, many assisted living facility residents suffer from significant and progressive dementia,¹⁰ involving memory loss, altered awareness, diminished judgment or decision-making capacity, and difficulty with articulating needs. When individuals with significant dementia reside in a congregate assisted living setting with inadequate staffing and supervision, there is a constant risk of neglect, serious injury or adverse medical consequences from, among other things, falls, malnutrition, weight loss, wandering from the facility, resident-on-resident physical and sexual abuse, staff-on-resident abuse, and medication errors.¹¹

The average assisted living resident is more than 80 years old and needs assistance to take medication or accomplish certain basic activities of daily living.¹² Because of advanced age, many residents have several chronic ailments and take a number of medications. They are likely to be susceptible to infections, dehydration, loss of appetite, and depression, all of which can lead to system imbalances. They can rapidly develop life-threatening conditions that require prompt recognition and treatment by medical professionals.

Risk factors can be reasonably controlled if a facility operator both understands the need to address these risk factors, and commits the resources to doing so. A facility must have competent professional nurse involvement in resident care, and appropriate numbers of well-trained and supervised personal assistance staff. But reports from around the country indicate that assisted living facilities often do not anticipate or respond to these risk factors as they should.

The problems facing the assisted living industry, and those trying to safeguard the interests of assisted living consumers, are serious and complex. Among the factors that make solving these problems difficult are the following:

- The management and staff of assisted living facilities often do not have adequate experience or expertise in providing health care, even for relatively routine health care such as the management and administration of medication.
- Assisted living facilities tend to rely excessively on minimally supervised direct care workers who, in the absence of professional nursing guidance, are inadequately prepared to assess residents' health status and care needs, or to perform complex tasks of care.
- Residents are sicker and require more care, as compared to assisted living residents five or ten years ago. The increased acuity level is the result of, among other things, shortened hospital stays, and in-home care options and health care technologies that delay long-term care entry.
- Assisted living facilities increasingly are used as residences for individuals with mental illness or developmental disability, but without recognition of those individuals' particular needs, and without adequate social service or mental health support.
- There is a need to more closely monitor health status changes and incidents involving residents, but assisted living facilities often are not prepared to do such monitoring.

Although the assisted living industry can have a vital role to play in the needed array of long-term care services, it will fail if it is allowed or expected to be all things to all people. This is a situation that cries out for more precise regulatory standards than we see in most states, coupled with meaningful enforcement.

Sources:

¹⁰ See, e.g., Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey (2000)* (nationwide survey of more than 1,500 assisted living facilities, commissioned by U.S. Dept. of Health and Human Services), available at <<http://aspe.hhs.gov/dattoc/reports/fshoes.htm>> (executive summary).

¹¹ A pilot study was conducted of 5 assisted living facilities from April 1, 1997, to March 31, 1998, under the joint supervision of the Alabama Department of Public Health and the Alabama Department of Mental Health and Mental Retardation. The 5 facilities were permitted to admit residents with dementia to locked units. Changes in resident conditions were reported monthly and were closely monitored by both agencies. Almost from the outset, significant problems were noted in 4 out of 5 facilities in the areas of weight loss, falls with fractures, elopements, and resident on resident abuse and staff on resident abuse. The results of the study have not been published.

¹² Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey (2000)*.

II. "Assisted Living" Must Be Defined In a Meaningful Way, and Governed By Standards That Guarantee a Reasonable Level of Quality.

A. Standards Are Needed To Assure an Adequate Quality of Care.

An older person generally moves into an assisted living facility because he or she no longer feels safe at home, or a family member believes that the older person is not safe at home. For example, this older person may have progressive dementia, suffer from urinary incontinence, or be partially paralyzed. He or she may need assistance in dressing, eating, toileting, or bathing, or have diminished sight or hearing. As is common, he or she may suffer from a chronic and potentially disabling disease such as diabetes, hypertension, or arthritis, and as a result would benefit from regular monitoring by a nurse.

Most likely, the older person never has lived in an assisted living facility, and knows little or nothing about long-term care options. More specifically, he or she likely knows little of what to expect from "assisted living."

For the benefit and protection of these vulnerable individuals, "assisted living" should be defined in a consistent and meaningful way, and assisted living law should establish standards that guarantee a reasonable level of quality. Following are examples of standards that should be set in law: it should be noted that this list is not all-inclusive and does not address resident rights and numerous other important areas of concern.

Levels of Care: As is explained in more detail in this paper's "level of care" discussion, assisted living law must specify the types of care that are mandated or prohibited in an assisted living setting. Vulnerable individuals seeking long-term care deserve a guarantee that certain services must be provided in an assisted living facility, and also deserve a clear explanation of what services cannot be provided. Some flexibility can be provided in the law – for example, different standards can apply to different levels of care within the assisted living category.

Staffing: Assisted living staffing too frequently falls at or below a bare minimum. A national study involving nearly 1,500 assisted living facilities found that "fewer than half of the residents reported that adequate numbers of staff were available at all times. . . . One third of the [facilities] had no registered nurse on staff, and one quarter had a ratio of one personal care assistant for each 23 or more residents."¹³ Assisted living law should set standards for staffing and staff expertise, make those standards dependent upon residents' care needs, and require appropriate participation by nurses and other health care professionals. Alabama, for example, has specific standards for assisted living facilities that specialize in the care of residents with dementia. In Alabama's "Specialty Care" assisted living facilities, a physician

coordinates medical care provided in the facility, and a registered nurse assesses resident needs. Alabama regulation sets minimum staffing levels to make sure that residents always have at least a respectable minimum of direct-care assistance.¹⁴ Such standards can be – and should be – extended beyond dementia to assure that the care needs of all residents are met consistently.

Training of Direct Care Staff: Assisted living law should set requirements for basic training of direct care personnel. These requirements should include standards for trainer qualifications, as well as standards for course curriculum and competency testing.

Fire Standards: In just the past few months, several fires in long-term care facilities have killed and injured residents who were unable to escape due to physical disability or mental impairment.¹⁵ Standards should be set that protect those residents who cannot protect themselves.

B. The Setting of Standards Should Not Be Left to a Facility's Contract.

Many assisted living providers claim that important assisted living issues should be determined by the facility's contract, rather than by regulation. Under such a model, a state's law would set few substantive standards, and instead would require that certain important issues be addressed in a facility's individual contract with a resident.

Such a contract-reliant model is wholly inadequate. It is grossly unfair to consumers.

The term "assisted living" becomes meaningless if it represents something different in each individual contract between a facility and a resident. Under a contract-reliant model, the contract of one "assisted living" facility could state that a dementia diagnosis is a reason for eviction, while the contract of a second "assisted living" facility could state that the facility can provide around-the-clock nursing care. For the benefit of consumers, there should be different terminology for facilities so dramatically different – for example, under the level-of-care system used in Florida, an assisted living facility can

Sources:

¹³ Catherine Hawes, Charles D. Phillips & Miriam Rose, *High Service or High Privacy? Assisted Living Facilities, Their Residents and Staff: Results from a National Survey 61-62* (2000).

¹⁴ Ala. Admin. Code r. 420-5-20-04.

¹⁵ See, e.g., Associated Press, *Nursing Home Fire Search Warrant Issued*, Feb. 27, 2003 (ten persons killed in fire in nursing home in Connecticut); Nancy Wride, *Torrance Rest Home Fire Kills Two*, L.A. Times, Dec. 31, 2002.

be licensed for Limited Nursing Services or, in order to provide additional nursing services, can be licensed for Extended Congregate Services.¹⁴

Providers claim that assisted living contracts are "negotiated" with consumers but, in the real world, assisted living facilities prepare standard contracts, and those contracts are presented to incoming residents on a take-it-or-leave-it basis. In any case, it is unreasonable to expect an elderly individual in need of long-term care to negotiate the care that is needed and must be provided, or the standards that the facility should follow. This is particularly true in relation to the unknown and unpredictable needs that the resident likely will have in the future.

The danger of the contract-reliant model is shown by the continued emphasis by assisted living providers on the waiver-of-liability contractual provisions which euphemistically are known as "negotiated risk" or "shared responsibility."¹⁵ Although providers suggest that these "negotiated risk" agreements are benign documents that allow a facility to honor a resident's preferences, "negotiated risk" actually refers to an agreement that allows an assisted living facility to admit or retain a resident whose needs the facility cannot meet, and that has the resident release the facility from any liability arising from the facility's inadequate care.¹⁶ A public policy director for an

assisted living corporation claims "that negotiated risk can protect [the] facility from regulatory action and/or litigation, and can justify non-intervention on the part of staff members."¹⁷

Source:

¹⁴ Fla. Admin. Code Ann. r. 58A-5.030- 5.031.

¹⁵ See, e.g., Kenneth L. Burgess, *Negotiated Risk Agreements in Assisted Living Communities* (1999) (manual produced by Assisted Living Federation of America); Allen A. Lynch & Sarah A. Teachworth, *Risky Business: The Enforceability and Use of Negotiated Risk Agreements*, 1 *Seniors Housing & Care Journal* 3 (2002) (defense of negotiated risk agreements, authored by provider attorneys).

¹⁶ See, e.g., Joel S. Goldman, *Potential Legal Roadblocks Ahead for Assisted Living* in ALFA Fall 2001 National Conference & Expo Conference Proceedings 299 (Oct. 21-23, 2001), as cited in Allen A. Lynch & Sarah A. Teachworth, *Risky Business: The Enforceability and Use of Negotiated Risk Agreements*, 1 *Seniors Housing & Care Journal* 5 n.11 (2002); see also Eric Carlson, *In the Sheep's Clothing of Resident Rights: Behind the Rhetoric of "Negotiated Risk" in Assisted Living*, *NAELA Quarterly*, Spring 2003 (upcoming), available at <www.nslc.org>.

¹⁷ *Why Your Facility Should Have Negotiated Risk Agreements*, Briefings on Assisted Living, June 2000, <www.safinfo.com/articles/BAL060001.cfm>, reviewed on Internet on April 3, 2003.

III. States Should Establish More than One Level of Assisted Living Licensure.

A. "One-Size-Fits-All" Does Not Fit Well.

States license assisted living facilities in order to protect the health and safety of residents, yet some state licensure systems apply "one-size-fits-all" standards to all assisted living facilities, regardless of the needs of the facility's residents. While a single standard may be appropriate for a facility whose residents have minimal needs, a single standard is simply inadequate to protect the increasing number of residents with significant physical and mental health care needs. Indeed, far from protecting the most vulnerable, a "one-size-fits-all" system reduces standards to the lowest common denominator.

In states with a single set of standards, assisted living providers set the range of services they will offer beyond those required for licensure, within any parameters (e.g., restrictions on the provision of certain services in assisted living) set by the state. Some providers offer only the minimum services required for licensure — meals plus limited supervision and assistance with routine activities of daily living. Others may serve residents with significant needs, including those with severe dementia and those whose care needs could justify nursing home care. Still others offer services somewhere between the two extremes, carving out certain services that they choose not to provide.

As discussed above, this model creates a system of standards set by contract and offers little protection to the consumer. In practice, consumers have no way of knowing whether providers have adequate staff to provide quality care, and no guarantee that the standard of care or the services offered will continue. Consumers are frequently frail, perhaps suffering from dementia, and their families are anxious and stressed. They generally are in no position to inquire about staffing or to understand the information they are given, to compare one facility to the next, or to understand pre-printed contracts that are long and complex.

B. Level-of-Service Licensing Enables Consumers to Make Meaningful Comparisons, and Facilitates Establishment of Appropriate Standards.

A more effective system is to avoid the "one-size-fits-all" model and instead license assisted living at more than one level, with levels defined by the type and severity of the physical and mental conditions of residents that the assisted living facility is prepared to accommodate. In a level-of-service licensure model, the

state establishes two or three levels of licensure, each with certain requirements that providers must meet in order to be licensed at that level. Idaho and Maryland have established three levels of licensure based on services offered;²² Arkansas, Florida, Mississippi, and Utah each have two levels.²³

The most significant distinction between levels is in the health care provided. In Arkansas and Maryland, for example, Level I facilities are not permitted to administer medications; in Arkansas, only Level II facilities may house or provide services to residents whose medical needs would qualify them for nursing home care.²⁴

Level-of-service licensure provides information that consumers otherwise would lack. By informing consumers what conditions a facility is or is not licensed to accommodate, a level-of-service system allows the consumer to choose a facility from the desired licensure category and, in deciding among facilities, to compare "apples with apples." Level-of-service licensure also allows states to establish appropriate standards for staffing levels and staff qualifications, special care or services, participation by health care professionals, and fire safety.

Level-of-service licensure benefits assisted living facilities by allowing them to choose what kind of services they will provide. Some may prefer not to offer a high level of services. Those opting to limit their services to meals, supervision, and limited assistance with activities of daily living would be licensed at a lower level. On the other hand, facilities desiring to continue serving residents whose needs increase could license at a higher level, allowing the facility to offer a full range of services from relatively low to high, under standards that help assure that a resident's needs will be met adequately.

Level-of-service licensure also can promote affordability in assisted living. It can limit the operating costs for facilities that choose not to offer more complex services. It also can limit expenses for private-pay consumers with fewer care needs, by allowing them the option of selecting (and paying for) a facility that offers only a lower level of service.

Sources:

²² See Idaho Admin. Code § 16.03.22.400; Code Md. Reg. tit. 10, §§ 10.07.14 et seq.

²³ See Ark. Code Ann. §§ 20-10-1701 et seq.; Florida Stat. §§ 400.401 et seq.; Fla. Admin. Code Ch. 58A-5; Missa Code Ann. § 43-11-1; Code Miss. R. 1202.1 et seq.; Utah Code Ann. §§ 26-21-1 et seq.; Utah Admin. Code 432-1-1.

²⁴ Ark. Code Ann. §§ 20-10-1701 et seq.; Md. Regs. Code tit. 10, § 10.07.14.04(F)(2)-(4).

In addition, level-of-service licensure can improve access to assisted living for low-income consumers, by encouraging facilities to participate in the Medicaid program. In most states, Medicaid funding can pay for assisted living services provided to Medicaid-eligible residents whose care needs could justify nursing home care. Licensure levels help a state to identify facilities appropriate for Medicaid payment, to assess whether residents in question will be provided the Medicaid-funded services. In Maryland, for example, Medicaid payment for

assisted living services is available only to residents of Level 2 and 3 facilities.²¹ In Arkansas, Medicaid payment is available only to residents of Level II facilities.²²

Sources:

²¹ While state policy does not specifically require Level 2 or 3 licensure as a condition of facility certification, as a practical matter only Level 2 and 3 facilities are licensed to provide the level of care required by the state Medicaid waiver program. See Md. Regs. Code tit. 10, § 10.09.54.16.

²² Ark. Code Ann. §§ 20-10-1701 et seq.

IV. Assisted Living Facilities Should Be Subject To the Same Non-Discrimination Rules that Govern Nursing Homes, to Assure That Low-Income Medicaid Beneficiaries Are Treated Fairly.

A. The Medicaid Program Covers an Increasing Number of Assisted Living Residents.

Assisted living is moving rapidly beyond its initial identity as a housing option for relatively healthy and financially secure older people. The assisted living industry increasingly provides health care services, not just housing and personal care services, and it provides these services to a population that is becoming more frail and more similar to nursing home residents each year.

Under the banner of "affordable assisted living," and with the goal of extending the option of assisted living to a less wealthy clientele, the assisted living industry calls for public reimbursement of assisted living services. In practice, "affordable assisted living" translates into reliance on the Medicaid program to pay for health care services in assisted living facilities. Pursuant to federal Medicaid law, these Medicaid funds are used to pay for the care of residents suffering from medical conditions significant enough to warrant admission into a nursing home.

In fact, use of Medicaid money for assisted living care is expanding at a breakneck pace. Medicaid beneficiaries receiving assisted living as a Medicaid-funded service grew 70 percent between 2000 and 2002, from 60,000 to 102,000 individuals.²¹ By October 2002, 41 states authorized their Medicaid programs to pay for assisted living services.²²

B. Facilities Voluntarily Accepting Medicaid Payments Must Comply With Medicaid Requirements.

Participation in the Medicaid program is voluntary for a health care provider. In agreeing to accept Medicaid reimbursement, a health care provider promises to comply with program participation rules, including rules prohibiting discrimination against Medicaid beneficiaries, and protecting beneficiaries' limited income and savings.

Too commonly the assisted living industry wants the benefits but not the responsibilities of Medicaid reimbursement. But fairness to Medicaid beneficiaries – who, by definition, have few resources and limited incomes – demands that these standards be applied to and enforced in assisted living facilities.

C. Medicaid-Participating Facilities Should Be Required To Accept Medicaid From Residents Who Become Financially Eligible For Medicaid While Residing At the Facility.

A Medicaid-participating nursing home must accept Medicaid payment on behalf of a resident who becomes financially eligible for Medicaid during his or her stay.²³ A similar rule must apply in assisted living. It would be unconscionable to allow a Medicaid-participating facility to refuse Medicaid payment from a resident whose new

Medicaid eligibility is the result of spending the last of his or her financial resources for assisted living care. If a facility were to be allowed to refuse Medicaid payment under such a situation, the resident inevitably would be evicted for nonpayment.

D. Medicaid-Participating Facilities Should Be Required To Accept Medicaid As Payment in Full for Covered Services.

To assure that Medicaid beneficiaries have full and independent access to care, longstanding Medicaid rules require Medicaid-participating health care providers to accept Medicaid as payment in full for Medicaid-covered services.²⁴ As a result, a Medicaid beneficiary can be required to pay only the deductibles and co-payments authorized by law.²⁵ In addition, Medicaid rules prohibit health care providers from soliciting or receiving payments from a beneficiary's family members or friends.²⁶

These provisions establish a commonsense framework for public payments. By definition, Medicaid-eligible individuals are poor, and Medicaid rules require them to spend all their income – aside from a subsistence-level allowance – as a monthly deductible for Medicaid coverage. Without the legal protections, Medicaid-participating health care providers could restrict admission and services only to those Medicaid beneficiaries able to obtain supplemental payments from a family member or friend. If a beneficiary were unable to obtain supplemental payment, she would be denied necessary care and services.

These important protections must be extended explicitly to Medicaid-participating assisted living facilities. A Medicaid-participating facility must accept Medicaid payment as payment in full for Medicaid-covered services, and must accept a Medicaid beneficiary's available income – including federal and state income supplements under the Supplemental Security Income program – as sufficient payment for room and board. Once a facility has agreed to accept Medicaid reimbursement, the facility must not discriminate against Medicaid beneficiaries or Medicaid payment.

Sources:

²¹ Robert L. Mollica, *Coordinating Services Across the Continuum of Health, Housing, and Supportive Services*, *Journal of Aging and Health*, vol. 15, no. 1, at 165, 172 (Feb. 2003).

²² Robert L. Mollica, *National Academy for State Health Policy, State Assisted Living Policy # (2002)* (within executive summary).

²³ 42 U.S.C. § 1396r(c)(4), (5)(A)(i); 42 C.F.R. § 483.12(c), (d)(1).

²⁴ 42 C.F.R. § 447.15.

²⁵ 42 U.S.C. § 1396a(a)(17).

²⁶ 42 U.S.C. §§ 1320a-7b(d), 1396a(e)(28), 1396r(c)(5)(A).

V. The Federal Government Should Take an Active Role In Assuring that Assisted Living Residents Receive Quality Care.

A. A U.S. Senate Committee Has Recognized the Need to Protect Assisted Living Residents.

In April 2001, the Senate Special Committee on Aging held a hearing entitled "Assisted Living in the 21st Century: Examining Its Role in the Continuum of Care." During the hearing, Senators repeatedly voiced questions and concerns about the well-being of vulnerable assisted living residents. For example, Senator Larry Craig (now Chairman) stated: "We must ask whether the States and the industry are doing enough to protect the elderly who rely on assisted living facilities." In a hearing a year later, Chairman John Breaux (now Ranking Member) noted many "unanswered questions" involving assisted living facilities "in terms of even what we call them, how we classify them, whether they are going to be State approved, federally approved, [and] whether States will have rules and regulations about the quality of care in these facilities."

During the 2001 and 2002 hearings, Senators have thought it premature to draft federal legislation governing assisted living. The Senators have noted, however, that if consensus on standards is not reached, it might be incumbent on Congress to act to ensure sufficient regulatory standards.

The April 2001 hearing was the genesis of the Assisted Living Workgroup which, despite a laborious process, has been unable to reach consensus on meaningful, enforceable standards for the assisted living industry.²¹ Thus, many of the Senators' questions and concerns remain unresolved.

B. Existing Law Establishes Federal Jurisdiction Over Important Aspects of Assisted Living.

The federal government already has jurisdiction to address many problem areas in assisted living. For example, the Federal Trade Commission has authority to protect consumers from the false advertising and unfair and deceptive contractual provisions that have been observed in the assisted living industry.²²

Some government jurisdiction is based on the significant amount of federal money paid for assisted living services. The housing costs of assisted living often are subsidized by payments or below-market loans from the Department of Housing and Urban Development, or the Department of Agriculture. The service costs of assisted living increasingly are funded by Medicaid or Medicare. Medicaid payments generally are made through "waiver" programs in which Medicaid covers all service costs (except for the resident's monthly deductible); other Medicaid programs pay only for certain health care provided to residents. Medicare payments generally cover certain health care reimbursable under Medicare Parts A and B.

C. The Federal Government Should Exercise its Authority to Ensure the Quality of Assisted Living Services Funded Through Medicaid Waivers.

As explained immediately above, the federal government has jurisdiction over numerous important aspects of assisted living, and federal funding is responsible for a significant percentage of assisted living care. And, of course, the health and safety of vulnerable assisted living residents is a pressing concern. All of these are compelling reasons for the federal government to take an active role in assisted living.

It is particularly appropriate that the federal government more diligently exercise its discretion in evaluating Medicaid waiver applications. The "waiver" of Medicaid law allows states to establish assisted living facilities as an alternative to nursing homes. Waiver reimbursement is reserved only for those Medicaid beneficiaries whose medical needs are severe enough to warrant nursing home care.²³ Currently federal Medicaid waivers pay for assisted living services for 102,000 residents in forty-one states, establishing the federal government as a major purchaser of assisted living services.²⁴

Under existing law, the federal government has broad discretion that can be exercised to respond to the vulnerable condition of residents receiving assisted living services under a Medicaid waiver. The relevant federal statute requires states to establish "necessary safeguards . . . to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services."²⁵ The corresponding federal regulation requires "adequate standards" along with enforcement of the relevant state licensure rules.²⁶ Under this federal law, the federal government has authority to be more discriminating in evaluating the state standards applicable to the more health-impaired population that receives assisted living services through a Medicaid waiver.

Sources:

²¹ See Assisted Living Workgroup Final Report to the U.S. Senate Special Committee on Aging (April 2003), available at <www.alworkgroup.org>.

²² See 15 U.S.C. §§ 45, 52-54, 57a, 57b (FTC authority); see also General Accounting Office, Quality-of-Care and Consumer Protection Issues In Four States, Report No. HEHS-99-27 (1999) (vague and misleading advertising and contracts in assisted living).

²³ See 42 U.S.C. § 1396n(c).

²⁴ Robert L. Mollica, *Coordinating Services Across the Continuum of Health, Housing, and Supportive Services*, *Journal of Aging and Health*, vol. 15, no. 1, at 165, 172 (Feb. 2003); Robert L. Mollica, *National Academy for State Health Policy, State Assisted Living Policy #* (2002) (within executive summary).

²⁵ 42 U.S.C. § 1396n(c)(2)(A).

²⁶ 42 C.F.R. § 441.302(a)(1), (2).

VI. Conclusion.

"Assisted living" is an attractive and appealing term. But to this point the reality of assisted living has fallen far short of the images evoked by the term.

Assisted living standards must be strengthened so that the term "assisted living" has real meaning. These standards should define levels of care within the broad category of assisted living, so that consumers can choose

among like facilities. Within each level, these standards should ensure that the staff is adequate in numbers and expertise to address residents' needs. Also, these standards should require that low-income Medicaid recipients be treated fairly, and pay particular attention to the needs of those health-impaired individuals whose care is reimbursed through Medicaid waivers.



Statement of
Bill Southerland
President, Idaho Assisted Living Association

Before the
U.S. Senate Special Committee on Aging
April 29, 2003

Chairman Craig, Ranking Minority Member Breaux, and Members of the Committee:

On behalf of the Idaho Assisted Living Association (IDALA), I want to thank you and your staff for the passion, conviction, and leadership to protect our senior citizens. IDALA shares your commitment and has enjoyed working closely with you to provide a safe, home atmosphere for the elderly and disabled that provides dignity, independence, and choice.

I am proud to report that Idaho has been in the forefront of assisted living regulations, balancing safety and health with the resident's desires to retain their independence and freedom of choice. While some states are still in the process of defining assisted living, Idaho has a mature set of statutes and rules ensuring a safe and nurturing environment for residents. Idaho was the first state in the United States to require administrator certification. All assisted living administrators in Idaho must take an assisted living training course and then pass the nationally recognized NAB exam for residential care providers. The Bureau of Occupational Licensing then requires an FBI background check before issuing a Residential Care Administrator's license.

Most recently, in an effort to save consumers and providers money, the Idaho Assisted Living Association sponsored a concurrent resolution in our state Legislature that allows unopened, unused medications to be returned to pharmacies for credit by either Medicaid or the individual payer. I wanted to inform you of Idaho's current regulatory status because it directly relates to the Committee's concerns about the level of quality provided under different state regulations.

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Please allow me to submit a short list of state government agencies who currently have oversight of assisted living in the state of Idaho:

- a) Bureau of Facility Standards (Health and Welfare)
- b) Idaho Board of Occupational Licensing
- c) Idaho Board of Pharmacy
- d) Idaho Board of Nursing
- e) Universal Building Code Commercial Requirements
- f) Idaho Health District

The very ingredients that have created such success here in Idaho will be undermined by additional regulations recommended by the ALW. For example:

1) Rural health care. In Idaho, rural health care would likely become cost-prohibitive. In some instances, the recommended education and training are completely unavailable. Of our 265 facilities in Idaho, 122 homes have 15 beds or less. Some are new, state-of-the-art buildings, and others converted homes or renovated schools. They may be operated by non-profit or for-profit companies. Many of the recommendations seem to be more suited to large corporate facilities than the smaller rural facilities such as those in Idaho. What this means to the elderly widow is that the only care provider available will be in a larger town, often far from her friends, family, and community support system.

2) Rising cost of health care. It has been our experience in Idaho that increased regulations often bring with them more costs. Requiring significant additional training above present Idaho requirements for caregivers means the owner of the facility will pay even more for these sessions with no guarantee that the employee will even stay and work at the facility. Once again, in Idaho, the travel to a training facility alone may be cost-prohibitive, especially for rural care providers.

3) States' rights. In reading through the recommendations thus far, the group appears to take a national approach as the best way to achieve quality care. IDALA members are concerned that

the ALW report does not address differing lifestyles, varying state geographies, or state urban/rural mixes.

4) Customer Choice. The most important difference between assisted living and other long-term options is choice. A typical resident is a widowed or single woman in her eighties. However, Idaho assisted living residents can be young or old, affluent or impoverished, mentally ill or brain injured, developmentally or physically disabled. Residents may suffer from Alzheimer's disease or other memory disorders. Residents may also need help with incontinence or mobility. As such, flexibility and choice, for both the consumer and provider, must be preserved. If only large corporate assisted living communities in our highly populated areas can afford to implement added regulations brought on by the recommendations, it will eliminate much of the choice among small facilities that Idaho residents presently enjoy.

IDALA understands that the ALW report is simply a first step in a very important dialogue that needs to take place. Both the Senate Special Aging Committee and the ALW are to be commended for bringing the stakeholders together and moving the dialogue forward. However, as suggestions become initiatives, and initiatives often become proposed legislation, I implore you to consider our comments before implementing any federal mandates. Your decisions and recommendations affect not only the care providers themselves but, more importantly, the hundreds of thousands of elderly and disabled who consider assisted living facilities their homes. In Idaho, we can tell you what works and what won't, based on over 30 years of experience.

We see the ALW recommendations as another huge government document that limits consumer choice, especially in rural areas. It could potentially increase the cost of health care through over-regulation and unfunded federal mandates to states. Over 6,000 residents in over 250 facilities in Idaho choose to call assisted living their home. Please do not limit these choices by trying to fix something that isn't broken. Thank you.



**Statement of
Tom Grape**

**Chairman and CEO, Benchmark Assisted Living
Chairman, Assisted Living Federation of America**

Before the

**United States Senate
Special Committee on Aging
April 29, 2003**

Chairman Craig, Senator Breaux, and members of the Committee, my name is Tom Grape, and I am the Chairman and Chief Executive Officer of Benchmark Assisted Living, headquartered in Wellesley Hills, Massachusetts.

I also serve as Chairman of the Assisted Living Federation of America (ALFA), the largest association exclusively dedicated to the assisted living industry and the population it serves. With more than 40 state affiliates nationwide, ALFA represents over 6,000 for-profit and not-for-profit providers of assisted living as well as a diverse range of organizations involved in the assisted living industry.

On behalf of ALFA, I would like to extend our thanks and gratitude to the Committee for its leadership and commitment to improving quality care in assisted living. We commend the Committee and staff for proposing the formation of the Assisted Living Workgroup — a milestone undertaking in the history of assisted living and one that will serve as a reference point for state regulatory activities in the years ahead.

On the occasion of the release of the Final Report of the Assisted Living Workgroup, it is my privilege as Chairman of ALFA to reaffirm our industry's commitment to fostering the highest quality care for the residents entrusted to our homes.

I can also speak from experience as a provider of assisted living services on a daily basis to approximately 1,500 residents in seven northeastern states. Over 200 of our residents receive reimbursement through Medicaid in my home state of Massachusetts. In my

company, we sum up our values in three words, by saying that at "**Benchmark, It's PERSONAL.**" This simply means we are in the business of personalizing services for our residents by respecting them as individuals with different values, needs, desires, and life experiences. We know what time our residents like to get up in the morning and what time they like to go bed. We know their hobbies and interests so we can provide them with an array of opportunities to enjoy their lifelong pursuits. We know that in most cases, the families and residents view us as the closest thing to family they have outside of their own. And, of course, we know what it takes on a day-to-day basis to help each of our residents live their lives with dignity, respect and a true sense of independence. In sum, knowing and thinking about our customers is what drives our business.

The same commitment to a resident-centered focus in operations is true in the overwhelming majority of assisted living communities across the nation. At the same time, we are aware that there are some bad apples in the bunch. And to that I say, on behalf of ALFA, **we fully support strong and effective state regulations to safeguard frail and vulnerable seniors from care that does not meet recognized standards for quality.**

ALFA shares the Committee's concern with what constitutes those recognized standards of quality across the states. And that brings me to the central point of my statement: **It is ALFA's strongly held principle that quality improvement starts with consumer choice and state flexibility.** Our Supplemental Position to the Final Report of the

Assisted Living Workgroup, which is attached to my statement, elaborates on this point in more detail.

However, I wanted to share with the Committee my personal view on what I believe quality means to residents and families, as well as to the continued success of assisted living as the consumer's preferred alternative to institutional long-term care.

A generally accepted view is that quality in assisted living can be seen from different but equally important perspectives. One perspective is that quality can be viewed in terms of regulatory compliance with specific licensing requirements — whether care is provided to a resident in a timely fashion and in accordance with accepted or prescribed standards of practice. Another perspective on how we define and evaluate quality is to look through the eyes of the residents we serve.

Residents in assisted living communities make real choices every day about the care they want to receive and how it will be provided. Residents also make the sort of common, everyday choices with which we all are familiar in our daily lives: As a provider, I can attest that having the flexibility to find creative ways to respond to each resident as an individual is what makes assisted living such a successful model of care for thousands of seniors.

I asked a few of our staff in the hallway the other day for examples of how they felt they had recently served residents in a personal or meaningful way. The responses came fast

and furious — ranging from knocking out a wall to give a resident the living space he wanted to observing a tearful daughter hugging an employee because she was so appreciative of the dignity and support her legally-blind mother was given in adapting to a new environment. One staff member described giving a dying resident's daughter the chance to live in a room next door to her mother in the last few months of her life.

I was perhaps even more struck by the examples thrown out to me as more “mundane” and “typical,” such as staff and residents working together to build a work bench for a resident who loved fiddling with tools or the immense satisfaction staff get from seeing a resident dramatically transform in her physical and emotional well-being after she has settled in from moving.

In an assisted living community it is not uncommon for residents to inquire, “If I was doing this in my own home, can I do it while I am living here?” I hope to be living testimony to the answer to this question, when the time comes, and it is, “Absolutely, you can do it here. This is your home!” And it is for that fundamental reason that residents, and in some instances their surrogates, should have equal, shared authority to say what constitutes an evaluation of quality in their assisted living homes. **Respect for consumer choice is synonymous with ALFA’s call for quality standards to be more consumer-centered.**

The concept of consumer choice is not merely a nice-sounding catch phrase. It has real meaning and importance for how quality is defined and evaluated in a regulatory system.

Obviously, the consequences of poor care can amount to more than just a dissatisfied customer. We agree that some process standards must be followed to avoid disastrous results. But as a provider, and as an industry, our continued growth and success depends very much on how well and how quickly we can respond to our customers' changing needs. Plus, our customer base is changing, as the demographics in America clearly show. New generations of seniors bring with them new life experiences and expectations. Consider for a moment the profound impact the Baby Boom generation has had on all aspects of our culture. Then you can appreciate why assisted living in the future must continue to be able to adapt and respond to new customer expectations and demands.

This point underscores the importance of state flexibility. There are substantial benefits to be gained by allowing each state the flexibility to design assisted living to fit the unique and individual circumstances of its culture and its system of long-term care. This principle of state flexibility extends down to the provider as well, so we, in turn, also have the flexibility to respond to our residents' individual needs.

I mentioned earlier that Benchmark operates assisted living communities in seven states, each with its own set of regulations. As a multi-state operator, Benchmark has successfully adapted our commitment to customer-centered care within each state's regulatory structure. The fact that states differ in the scope of their regulations does not mean we provide a different level of quality in each state. A quality provider is a quality provider, regardless of differences in state regulations.

An underlying premise of our Supplemental Position is that each state will be conscientious in its duty to protect frail and vulnerable populations. Therefore, we can respect a state's choice in determining how to meet the needs of its citizens in alternative ways — thereby assuring quality without compromising accountability.

Admittedly, not all states have adequate budgetary resources for survey and enforcement activities, but that problem will not be solved by uniformity of standards.

Rather, what will truly improve quality is the provider's commitment to meet or exceed residents' expectations with regard to what is most important to their quality of life. And a great way to inspire that kind of commitment is by promoting industry "best practices" that can be applied within any state's regulatory structure.

For years, our industry has been showcasing best practices at meetings of ALFA's state affiliates and at our national conference. Through ALFA's state affiliates, we have access to a wealth of best practice materials from every state and from every size of provider. These best practice materials already exist and have been put to the test in real-life circumstances by some of the most innovative providers in the business. This is the critical piece to add to the discussion about how to improve quality.

People who understand what it really means to be customer-focused have developed the industry's best practices. Applying these best practices in day-to-day operations on a

wide scale and leaving the door open to continued innovation is what will ultimately raise the bar for quality in assisted living.

And while I am on the subject, I would like to note that there are also best practices from the related field of consumer-directed care that can offer important and valuable guidance for assisted living. Many states already are pioneering programs that help people with disabilities maintain a strong sense of independence, control, and self-determination. They accomplish this while recognizing the state's duty to protect vulnerable citizens and enforce standards of accountability. Our Supplemental Position cites specific examples of these state-run programs.

These new models of quality improvement and quality assurance strike the appropriate balance between the state's duty to protect residents from harm and poor care with respect for consumer choice and autonomy.

The key word here is balance. ALFA's advocacy for a more consumer-centered approach to quality improvement, coupled with state flexibility, is not an argument against the standards that are vital and necessary for residents' health and safety.

In our view, fair consideration should also be given to how states might integrate, substitute, or give equal weight to the role that measures of performance and consumer satisfaction can play in improving quality of care.

For example, one of the resident and employee survey tools we use in my company measures our success in living our *personal* values. Action plans are built around the outcomes of these surveys and can result in changes as simple as holding more informative resident meetings, evaluating menu selections, or improving staff training to support the philosophy of encouraging residents to do all they can for themselves whenever possible. These surveys also let us look at ourselves as leaders, by giving employees an opportunity to evaluate management in order to ensure that they have the right support in serving residents every day. I think it is fair to say that no regulatory body can compel you to be a better performer than your own staff feedback!

All stakeholders in assisted living must accept the challenge to think “outside the box” and consider new ways of measuring and defining quality from the consumer’s perspective. While there is more work to be done to fine-tune quality measurements in consumer choice programs, **these state models of consumer choice can be helpful in our efforts to develop a regulatory system for assisted living that ultimately incorporates the consumer’s definition and evaluation of quality.**

Before I close, I want to refer back to what I said earlier in my statement — that the industry takes our commitment to quality very seriously. Our commitment is not just in words alone. Indicative of ALFA’s commitment to quality has been our sustained leadership in developing educational and training materials to help providers deliver quality care every day.

What will be of interest to this Committee is how many of ALFA's training materials closely track with the topics in the Final Report of the Assisted Living Workgroup. Attached, as an appendix to this statement, is a partial listing of the training resources produced by ALFA University, the training arm of our association.

In summary, I want to leave this Committee with the assurance that ALFA remains steadfast in our commitment to quality while preserving consumer choice. We are committed to continuing our collaboration with state policymakers, consumers, and other stakeholders to develop balanced regulatory systems that improve quality care. We support full and complete disclosure of all terms, conditions, and costs associated with residency in contracts. And finally, ALFA is committed to helping develop new approaches for measuring and improving quality by focusing on what the consumer needs and wants.

Thank you for the opportunity to present this written statement for the record. We would be pleased to provide the Committee with additional information or answer any questions.

Appendix A

ALFA University was established by the Assisted Living Federation of America seven years ago. Since then, the University has developed comprehensive assisted living training that currently is used by over 9,500 assisted living providers nationwide and offers national certification in many programs. The quality of the programs has been recognized with more than 37 national and international awards for training excellence.

Many of the education and training materials from ALFA University track closely with topics in the Final Report from the Assisted Living Workgroup:

- **Administrator Certification Course**, a 47-hour self-study course, is recognized by the National Association of Boards of Examiners.
- **Consumer Education Videos**, a collection, helps staff educate consumers about assisted living; addresses the decisionmaking process a family experiences in choosing assisted living; and offers helpful hints to families to ease the transition of their loved ones as they move into their new home and adjust to new surroundings.
- **Managing Activities and Recreation Services**, a certificate program, focuses on ways to encourage family and intergenerational participation, including activities for dementia residents.
- **Supervising Front-Line Staff** features best practices for training, motivating, and retaining staff; improving care delivery; and reducing turnover.
- **End-of-Life Care in an Assisted Living Residence** provides a sensitive in-service guide to dealing effectively with the challenges and stresses felt by caregivers as they provide end-of-life care for residents.
- **Job Descriptions** provides job descriptions and responsibilities for the many different roles of assisted living employees.
- **Emergency Planning**, a manual, outlines potentially hazardous situations and explains disaster planning and other life-saving issues.

- **Assisted Living Policy Manual**, a comprehensive two-volume set of policies and procedures, covers all operational aspects of assisted living, including:
 - Activities
 - Communications
 - Dementia care
 - Dining services
 - Emergency response
 - General administrative
 - Human resources
 - Infection control
 - Marketing and public relations
 - Physical environment
 - Quality management
 - Resident care

- **HIPAA Compliance Manual for Assisted Living Providers** includes an overview of HIPAA standards and comprehensive policies and procedures that can be used to develop a community's compliance program.

- **New Employee Orientation** covers everything a new staff needs to know to get started on the right foot, including:
 - What is assisted living?
 - Caregiver's role in resident's rights
 - What do residents need?
 - What do families of residents need?
 - Your role in customer service
 - Assisting with meals
 - Introduction to dining and food service
 - Understanding nutritional requirements for residents
 - Understanding fluid requirements for residents

- **Caregiver Risk Reduction Training Program** includes modules on aging sensitivity; observing and reporting changes in condition; monitoring vital signs; reducing resident falls; an introduction to Alzheimer's disease; managing wandering behaviors; helping residents and families understand the factors involved in making a decision transfer from an assisted living community.

- **Alzheimer's/Dementia Care**, a training program for direct caregiver staff, covers understanding the disease; providing care for a confused resident; communication skills for residents with Alzheimer's Disease; managing challenging behaviors; and supporting family members.

- **OSHA and Safety Training**, a set of educational materials, covers what is OSHA; ergonomics; preventing back injuries; transferring a resident; preventing slips and falls; infection control; kitchen safety; and creating a safe environment.

- **Medication Training**, a practical “how-to” course, covers monitoring the resident’s health and medication use; preparing to assist with medications; assisting with medications; assisting the diabetic resident; reporting medication assistance; and medication storage, disposal, and inventory.
- **The Role of the Nurse in Assisted Living**, a 30-hour course, includes the assisted living philosophy and nurse care; the role of the family and resident in care decisions; managing direct care staff; and training direct care staff.
- **Activities of Daily Living**, practical written guides and training videos, include real-life examples of ways to assist residents at mealtimes, steps to take when toileting, proper body mechanics, methods for transferring, and assisting with mouth care.

A Supplemental Position to the Report of the Assisted Living Workgroup

Assisted Living and the Quality Imperative: Ensuring Consumer Choice and State Flexibility

Submitted to the
U.S. Senate Special Committee on Aging
April 29, 2003

On behalf of:
Assisted Living Federation of America
National Association for Home Care & Hospice



EXECUTIVE SUMMARY

The Assisted Living Federation of America (ALFA) and the National Association for Home Care & Hospice (NAHCH) are privileged to respond to a call to the assisted living community by the U.S. Senate's Special Committee on Aging "to work together to develop proposed recommendations for what quality assisted living should look like." (1)

We have worked diligently with our colleagues throughout the past 18 months to achieve agreement on a set of recommendations that would provide meaningful guidance to the states to improve the quality of assisted living. There are recommendations within the Assisted Living Workgroup (ALW) Report that we, as individual organizations, helped to develop and continue to support.

On the occasion of the release of the ALW Report, we want to summarize our commitment to ensuring quality in assisted living:

- We remain firmly committed to fostering the highest quality care for assisted living residents.
- We support strong and effective state regulatory systems to ensure accountability to the highest standards of care.
- We support full and complete disclosure of contractual obligations, including all fees and costs associated with available services.
- We support efforts to improve consumer access to information to help choose an appropriate assisted living community that will best meet their needs.

In addition to the aforementioned commitments, we assert one strongly held and overarching principle for ensuring quality in assisted living:

Quality improvement in assisted living starts with consumer choice and state flexibility.

First and foremost, consumer choice is respected when quality standards take into account the consumer's perspective. This includes incorporating the consumer's values and experiences, as well as individual lifestyle preferences, into the definition of quality of care.

***Quality
improvement in
assisted living
starts with
consumer choice
and state
flexibility.***

Respect for consumer choice is synonymous with our call for quality standards to be more consumer-centered.

Secondly, because states have consistently proven to be effective laboratories for innovation in assisted living, clear acknowledgment should be given that the states retain the ultimate authority and flexibility to decide how they can best meet the intent of an appropriate recommendation. Further, states should be encouraged to explore alternative approaches and methods to provide a safe environment for residents while maximizing respect for their right to exercise meaningful lifestyle choices.

As a form of long-term care, assisted living stands at a critical juncture, where decisions made in the public and private sectors will profoundly shape its future. We believe the Senate Special Committee on Aging has presented us with an historic opportunity to make a lasting contribution to the national dialogue about improving quality of care and life in assisted living. In the following pages of this Supplemental Position to the ALW Report, we detail the key points that must be addressed to ensure the highest quality care for all consumers of assisted living.

KEY PREMISES OF THE SUPPLEMENTAL POSITION

- A strong national movement currently exists, creating systems of accountability that promote and ensure quality based on consumer choice and consumer protections enforced through appropriate state regulation.
- Regulatory systems for assisted living can effectively accommodate quality standards based on the consumer's perspective as well as process and structure requirements. Supportive evidence for the success of state regulations is found in numerous state-based home and community-based programs that integrate performance measures and consumer satisfaction.
- The recommended consumer-centered approach to quality improvement in assisted living, coupled with state flexibility, does not preclude the need for specific process standards vital to residents' health and safety.
- States are conscientious in their duty to protect frail and vulnerable residents and therefore can decide how to meet the needs of their consumers in alternative ways that assure quality without compromising accountability.

Key Recommendations of the Supplemental Position

- It is recommended that states work toward developing regulatory systems integrating measures of performance, results, and consumer satisfaction.
- The consumer's preferences should be emphasized in the definition and evaluation of the quality of care and life in assisted living communities.
- States should retain the authority and flexibility to consider a range of equally effective approaches to meet the intent of an appropriate recommendation.

WHAT IS QUALITY ASSISTED LIVING?

The Senate Special Committee on Aging directed the ALW to specifically address the question of what defines quality in assisted living and to make recommendations that help ensure consumers have consistent access to quality care regardless of the state in which they reside.

The challenge in such an undertaking consists in encompassing the multi-dimensional nature of what defines quality. Quality must be considered not only with regard to the effectiveness, efficiency, timeliness, and appropriateness of standard operating procedures; it also must include the evaluation and acceptability of services and care as defined by consumers, which may include very different priorities.

From its inception, the core principle of assisted living has been *choice* — respecting, preserving, and enabling residents to exercise meaningful choice in their lives in ways that promote independence, autonomy, and dignity. The resident in an assisted living residence must be considered as having equal and/or shared authority, along with the state and provider, to judge key aspects of his or her life that are beyond the capacity of the state or the provider to assess.

In practice, this means that quality standards and criteria for successful achievement must reflect the resident's individual perspective on quality, freedom, control, and the assurance of health and welfare: Was the resident, in the course of receiving the appropriate procedure, satisfied with the service? Were his or her expectations met? Does the resident feel that his or her choices are being honored and respected?

In advocating for a regulatory system that focuses beyond process standards, we do not intend to suggest that process standards are unimportant. Nor does describing a consumer-centered perspective in defining quality standards exclude the prescription of structure and process standards when outcomes are non-negotiable (e.g., life safety, infection control, food handling, etc.).

Rather, we are suggesting only that an evaluation of process standards should not be the sole determinant of what constitutes quality care. In assisted living, where consumer choice must be emphasized, the "what" (the result and/or performance) is often more important than the "how" (the process or procedure that achieved a result desired by the consumer).

Results, not the methods by which the community achieved those results, must be the initial indicator of quality. Processes should be a primary focus only when they have been validated as essential and are, indeed, uniquely predictive of desired outcomes. In sum, regulatory systems for assisted living should be able to accommodate quality measures based on customer preferences as much as on standards of process and structure.

THE IMPORTANCE OF STATE FLEXIBILITY TO QUALITY ASSISTED LIVING

The pace of change in state policy on assisted living has been nothing short of extraordinary. Already in the first four months of 2003, over 100 bills pertaining to assisted living have been enacted in state legislatures around the country. During the same period of time, there has been a considerable amount of regulatory activity as well. Notices of final rulemaking or pending rule changes have been filed in more than 30 states.

Significant trends can be identified in areas of consumer disclosure, Alzheimer's care, background checks for staff, abuse reporting requirements, sanctions and penalties, and provisions to allow residents to bring in additional care as needed, such as nursing care and hospice, to supplement the services and staff of the residence.

It is important to note that this volume of assisted living legislation and regulatory activity is just a snapshot from the early part of 2003. Looking back over the past three years, the volume of assisted living reform is even more impressive. Since June 2000, 46 states have completed or are currently working on revisions to their assisted living regulations (2). As a result, there is a growing movement toward greater consistency in the way assisted living is regulated at the state level.

The point is that state policymakers, consumers, and providers have collaborated successfully in many instances to fashion a system of regulation that is responsive to the needs of residents and makes sense as well for the state and the provider.

Our Supplemental Position, therefore, suggests that guidance to states should include a suggested range of consumer-centered alternatives to improve quality of care that each state can tailor to fit its unique system.

The next section will highlight the importance of state flexibility regarding health policy with analogies drawn to assisted living.

**...there are
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■ The Importance of State Flexibility to Health Policy

The importance of state flexibility with regard to health policy is best illustrated in a recent letter from the National Governors Association on the subject of Medicaid managed care:

The proposed Medicaid managed care rule provides states with significant flexibility while maintaining our shared commitment to quality care. ... This policy approach is not only right for states operating Medicaid managed care programs, but for beneficiaries and providers with whom states work at the local level to develop state-specific programs that best fit local needs (3).

What is striking in this letter is the call by the nation's governors to allow states the flexibility to design state-specific programs that best fit local needs. We strongly endorse a similar position regarding assisted living. States and providers should be held accountable for meeting quality goals, but we need not prescribe in minute detail the step-by-step approach that must be followed in every instance.

An accepted premise of our Supplemental Position is that a state will be conscientious in its duty to protect frail and vulnerable populations. Therefore, we can respect a state's choice in determining how to meet the needs of its consumers in alternative ways — thereby assuring quality without compromising accountability.

To further illustrate the importance of state flexibility to health policymaking, we will offer the another example from the new privacy rule requirements. Lastly, we will stress the critical importance of state flexibility to preserving the role of the small assisted living provider.

■ The Importance of State Flexibility to Privacy Rule Compliance

New federal regulations governing the transmission, security, and privacy of healthcare information developed under the Health Insurance Portability and Accountability Act went into effect in April 2003. In response to a request for public comments on the proposed level of detail in implementation features, the U.S. Department of Health and Human Services (HHS) received numerous comments expressing the view that security standards should not be overly prescriptive because the speed of evolving technologies could make requirements obsolete and might, in fact, deter technological progress. Accordingly, HHS wrote the final standards in terms that are as generic as possible and which generally could be met through various approaches (4). A similar conclusion could be made with respect to the ALW recommendations — that an overly prescriptive approach discourages discussion of alternative and equally effective means of quality improvement that could stifle innovation and continued evolution of a consumer-centered regulatory system.

■ The Importance of State Flexibility to the Small Provider

The vast majority of assisted living residences (ALRs) in this country have between 11 and 50 beds. For example, in Alabama, one-third of the licensed ALRs are 16-bed facilities. In Arizona, there are more than 1,000 assisted living homes classified as having 10 or fewer beds. Assisted living continues to flourish because states have been allowed to design a regulatory structure that fill gaps in their long-term care systems and recognizes their own unique circumstances. Long-term care policies and programs are determined in the United States by 50 separate state governments, each with different demographics, economies and political philosophies (5)

Regulators, consumers, and providers all have a large stake in seeing that small ALRs not only operate high-quality communities, but also are able to continue playing an important role in each state's long-term care system. Most small towns cannot support facilities the size of today's "purpose-built" communities. The challenge of preserving the few small providers that do exist in rural areas is of particular concern. Seniors with long-term care needs might have no option other than moving far from home to access higher-priced nursing home care.

The continuing viability of small ALRs is questionable if many of the proposed recommendations were to be required of all providers. For example, recommendations for relationships with clinical psychologists, medical directors, consultant pharmacists, and dietary consultants are simply not compatible with the business plans of many small ALRs. Although the recommendation for consultant relationships did not achieve the required votes necessary for adoption, the fact remains that the Workgroup did not appear to fully grasp the nature of operations for small ALRs in forming many of its recommendations.

While there may be overarching considerations for quality standards that transcend the cost of implementation, the economic impact of a proposed rule or standard on small businesses is a legitimate consideration in regulatory decisionmaking. State flexibility allows states to weigh alternative and perhaps more cost-effective approaches to meeting the intent of an ALW recommendation, thereby preserving the viability of the small provider.

SUPPORTIVE EVIDENCE: STATE FLEXIBILITY HAS RESULTED IN SUCCESSFUL MODELS OF CONSUMER-CENTERED PROGRAMS

In the past decade, states have made great strides in developing a wide range of programs designed for people with disabilities that integrate consumer choice and control within a system of public accountability. Many states have made significant changes to licensing requirements to become more consumer-centered without compromising safeguards designed to protect persons receiving support (6). Policymakers now have empirical evidence to cite in support of making consumer and family caregiver empowerment the cornerstone of quality assurance strategies (7).

States' interest in developing service models of consumer choice reflects a groundswell of public support for creating systems of accountability that assure quality and value based on the choices and preferences of the individual as well protections enforced through appropriate government regulations (8).

This national movement toward greater consumer choice and control in home and community based programs adds substantial weight to our call for consideration of ways states might integrate, substitute, or give equal consideration to the role that measures of performance and consumer satisfaction can play in improving quality of care.

Our advocacy for a more consumer-centered approach to quality improvement, coupled with state flexibility, is not an argument against the specification of standards that are vital and necessary for residents' health and safety.

Clearly, process-centered standards are important and can point directly to specific areas needing performance improvement, which is a fundamental aim of quality improvement. On the other hand, consumer input into quality measures is equally critical in a service setting that espouses a philosophy of care based on consumer choice, autonomy, and independence. Regulatory systems for assisted living should be able to accommodate quality measures based on the consumer's perspective as well as process and structure requirements.

By looking at these state models, we can show that there are practical and achievable steps states can take, over time, to incorporate a more consumer-centered perspective of quality standards for the purposes of both regulatory compliance and provider-initiated programs of continuous quality improvement.

While many of these state models have been developed under Medicaid Home and Community-based Services Waiver programs targeted to populations of working-age adults with disabilities, these approaches are equally applicable and transferable to residents in assisted living communities:

- **Colorado's** survey tools focus on person-centered and organizational outcomes and requirements that directly affect an individual's well-being (9).
- **Indiana** is applying customer-oriented quality assurance strategies successfully used in business to a state-funded long-term care program (10).
- **Kansas** has developed the Kansas Lifestyles Outcomes Assessment (KLOA) tool to ensure the level of quality provided to consumers in its Home and Community-based Services Waiver for persons with developmental disabilities. The KLOA tool assesses 10 outcomes. Five of these outcomes relate to state licensing standards. The other five outcomes assess responsiveness to the consumer's preferred lifestyle and the availability and use of choice-driven supports (11).
- **New Hampshire** has a quality assurance component of its HCBS waiver program that includes an adult consumer survey that seeks not only to measure the consumer's satisfaction with services, but also to assess his or her functional status (12).
- **Minnesota** has piloted a model that focuses on disclosure and informed consumer decisionmakers. Although a traditional regulatory system covers the licensing of health-related services in assisted living programs, this model permits great flexibility in the types of residential settings where assisted living programs may be provided and in the types of service packages that a provider may offer. While it is preliminary at this time, there is interest in a consumer-driven accountability model for assisted living adapted from one being demonstrated in a program for people who are developmentally disabled (13).
- **South Carolina** has established Community Long Term Care (CLTC) Program Standards and Indicators. As part of its program, the state conducts annual client satisfaction surveys for CLTC-waivered service clients in all 11 service areas in the state (14).
- **Tennessee** has incorporated customer satisfaction into its quality review process (15).
- **Wisconsin's** Community Options Program emphasizes a consumer-oriented definition of quality, with a focus on respectful relationships, empowerment, and enhancement of self-worth, community involvement, and independence (16).
- **Vermont** has implemented a satisfaction interview with a quarter of adult HCBS recipients, and has mailed a satisfaction questionnaire to families of persons receiving services (17).

While there is still more work to be done to perfect the quality measures used in consumer choice programs, these state models can be helpful in ultimately working toward a system of continuous quality improvement that both incorporates the consumer's definition and evaluation of quality

and fosters a regulatory system for assisted living best suited to fit the local needs of a state. We must not become complacent that process-centered standards can serve as adequate “placeholders” for measures of results and consumer satisfaction.

The states already have demonstrated their leadership in this respect. With appropriate guidance, their pioneering efforts can lay the foundation for the consumer-focused regulatory systems that must be constructed to provide high-quality assisted living choices for elderly Americans nationwide.

One State's Perspective

One state's perspective is particularly instructive. Family Care is Wisconsin's redesigned system of long-term care for elderly individuals and individuals with physical or developmental disabilities. The Wisconsin Department of Health and Family Services (DHFS) recently undertook a multi-year initiative to measure and assure quality in the Family Care program. In the final report of its 2001 Assessment, DHFS made the following observation:

Traditional methods of monitoring quality focus on compliance with standard procedures and organizational processes, and emphasize documentation and compliance with regulations. These traditional systems typically depend upon the judgment of professional inspectors. The result is the identification of deficiencies leading to required plans of corrections, and administrative sanctions that may involve threats of loss of funds or fines.

In contrast, a focus on assessing consumer outcomes will better enable providers to know and understand their clients as people with goals similar to their own and will provide incentive to adapt services more creatively to the needs of each unique individual. No longer will it be acceptable to provide services that do no more than meet minimum licensure standards; providers will be expected to support the achievement of desired results for the individuals. Knowledge about outcomes enables consumers and their families to reject services that are ineffective, and allows policy makers to redirect resources to programs that do a better job of improving the health

ALW RECOMMENDATIONS AND ALTERNATIVE APPROACHES: FOCUSING ON CONSUMER CHOICE AND STATE FLEXIBILITY

The following are a few examples of approaches that could achieve the results intended by a particular regulatory focus without necessarily adhering to the specific processes recommended in the ALW Report for achieving those results. It is critical that we not limit states in terms of the means by which they might integrate, substitute, or give equal weight to measures of *results* and consumer satisfaction in improving the quality of care and life for assisted living consumers.

■ Recommendation D.14 : *Care for People with Cognitive Impairment or Dementia*

ALW Model

- ALRs are required to have certain procedures in place, including procedures for staff training, assessment, specialized activities, designating and working with a surrogate decisionmaker, protecting residents who wander, monitoring, and involving family members.

Supplemental Position: Focus on Consumer Choice

We recognize and respect that residents with mild to moderate dementia can nevertheless participate in care decisions and express lifelong values and wishes regarding the care they currently are receiving.

However, we do not attempt to prescribe the specific procedures a state must require ALRs to follow to serve people with cognitive impairments. We acknowledge that states must have the flexibility to determine, in concert with other stakeholders, the most appropriate policies and procedures to put in place.

Our recommended guidance to states and ALRs is to consider a quality monitoring component that focuses on the perspectives of the resident and other responsible parties to look beyond the procedures and determine whether the resident and other affected parties feel their choices are being respected, their needs are being met, and their assessments of service quality are being sought.

Examples of suggested areas for quality monitoring could include the following:

- Does the resident communicate having opportunities to exercise lifestyle preferences (dining, receiving visitors, activities, directing provision of services)?
- Does the resident communicate as to his or her satisfaction with the quality of care and services?
- Is the staff willing and able to communicate with the resident and respond to his or her preferences?
- Does the surrogate decision maker acknowledge that he or she is encouraged to be involved in the development and implementation of the resident's service plan?
- Do family members report having opportunities for involvement in the resident's care?
- Does the resident acknowledge being able to make decisions about services to be provided to the extent possible and the involvement of his or her family as appropriate?

■ Recommendation O.17: Assisted Living Resident Councils

ALW Model

- ALRs should provide opportunities and space for Resident Councils, schedule meetings, and encourage residents to attend meetings.

Supplemental Position: Focus on Consumer Choice

While we in no way object to the concept of Resident Councils, the real issue at stake here is how effectively the ALR promotes the concept of resident autonomy in the sense that resident input into the operation and house rules of the community is valued, considered, and acted upon as appropriate.

Our Supplemental Position recommends areas for quality monitoring to determine whether the *desired result* of promoting resident autonomy is being achieved. For example:

- Do residents report having opportunities to provide input into development and implementation of existing house rules and community decisionmaking?
- Do residents report that requested changes to rules have been accepted or acted upon by management?
- Do residents acknowledge receiving an explanation for maintaining current policy upon request for a change?
- Do residents acknowledge management or staff responsiveness to grievances or complaints?
- Do residents acknowledge receiving requested clarification of existing rules?
- Do residents acknowledge being informed of community governance events (Resident Council, committee meetings, etc.)?

■ Recommendation O.16 : *Environmental Management*

ALW Model

- ALRs must be maintained in compliance with applicable federal, state, and local laws.
- Buildings and outdoor areas must maintain effective utility capacity.
- Common areas must accommodate residents using assistive devices for mobility.
- ALRs must be kept clean and free of potential hazards and hazardous substances.

Supplemental Position: Focus on Consumer Choice

The general thrust of this recommendation is that ALRs must comply with existing laws and regulations. As such, this recommendation provides no guidance to states on how to improve quality in assisted living.

However, the degree to which a resident feels that his or her assisted living community is a safe and homelike residential environment is of vital importance to a resident's perception of his or her quality of life. Therefore, our recommended guidance to states and ALRs is to consider a quality monitoring focus from the perspective of the resident and to examine how well the residential environment is supporting consumer choice, autonomy, independence, and privacy.

For example:

- Does the resident acknowledge that the assisted living setting feels homelike?
- Does the resident acknowledge having opportunities to control private space:
 - Food storage and preparation?
 - Individual temperature control?
 - Roommate provision consultation?
 - Use of personal vs. ALR furnishings in unit?
 - Modifications to unit?
 - Availability of personal key to unit?
- Does the resident acknowledge availability of staff assistance to help the resident use inaccessible public areas?
 - Dining rooms, activity room, library, TV room; limitations to areas within/outside setting due to: cognitive limitations or physical barriers (steps, doorways, etc.).
- Does the resident report a lack of access to a private phone or key to a mailbox?
- Is the staff able to demonstrate knowledge regarding methods to promote a homelike setting, address resident lifestyle preferences, and/or protect resident privacy?

■ Recommendation S. 08: *Qualifications for Administrators***ALW Model**

- Assisted living administrators who are not qualified nursing home administrators *must* complete a state-approved ALR licensure course and pass a state-approved exam.
- Minimum qualifications that *states must require* for licensure course and examination are specified.
- The required number of continuing education hours that *states must require* is specified.
- The time period in which *states must require* ALR administrators to take the examination is specified.
- The minimum education and experience levels that *states must require* of an individual prior to taking the administrator examination are specified.

Supplemental Position: Focus on State Flexibility

The primary issue related to care quality is not whether the administrator has passed an examination or has a certain college degree, but rather whether there is evidence that the resident's care needs are being met. States can determine this through comparison of assessed needs with the service plan, accuracy of the resident's existing service plan relative to observed need, and measures of consumer satisfaction.

Absent data that correlate the ALW's prescribed requirements with improved care quality, states should retain the flexibility to decide the best combination of administrator requirements and care monitoring to achieve high standards of care.

■ Recommendation: *Definition of Assisted Living*

One of the components for a definition of assisted living deals with a requirement that the state must establish at least two assisted living licensure categories based on the types and severity of the physical and mental conditions of residents.

Supplemental Position: *Focus on State Flexibility*

While we do not object if a state chooses, as a few states have done, to establish a “levels of care” licensing system, we do take issue with the assumption that a “levels of care” licensing system is intrinsic to a definition of what constitutes assisted living. States understand how to design licensing systems for assisted living in ways that they deem most appropriate to the needs of their citizens while being conscientious of their duty to protect frail and vulnerable residents.

Further, there is no evidence-based research showing that a “levels of care” licensing system necessarily improves quality or affords greater protections to residents. Consumer protections and safeguards can and do work just as effectively in other state licensing models.

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A Report to the
US Senate Special Committee on Aging
April 2003



**the
Assisted
Living
Workgroup**

**Assuring Quality in Assisted Living:
Guidelines for Federal and State Policy,
State Regulation, and Operations**

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**A Report
To The
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From The
Assisted Living Workgroup**

April 2003

A special thanks to Amy E. Waye and Carmen Diaz of the National Center for Assisted Living and Bradley Schurman of the American Association of Homes and Services for the Aging for designing and producing the ALW report.

April 2003

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Cover artwork, titled "*All American*," was done by Lamberto Hechanova a resident of a long term care residence in Jamaica, New York.

Assisted Living Workgroup Participating Organizations

ACCREDITING ORGANIZATIONS

CARF-CCAC
Joint Commission on Accreditation of
Healthcare Organizations

AGING/LONG TERM CARE ORGANIZATIONS

American Geriatrics Society
National Academy of Elder Law Attorneys
National Adult Family Care Organization
National Association of Professional Geriatric
Care Managers
National Council on Aging
Pioneer Network

CONSUMER ADVOCATES

AARP
American Bar Association Commission on Law
and Aging
Alzheimer's Association
Consumer Consortium on Assisted Living
Center for Medicare Advocacy
National Association of Local Long Term Care
Ombudsmen
National Association of State Ombudsman
Programs
National Association for Continence
National Citizens' Coalition for Nursing Home
- Reform
National Committee for the Prevention of Elder
Abuse
National Committee to Preserve Social Security
and Medicare
National Senior Citizens Law Center
NCE Development Corporation, The Coming
Home Program

DISABILITY COMMUNITY

National Multiple Sclerosis Society
Paralyzed Veterans of America
United Cerebral Palsy

HEALTH CARE PROFESSIONALS

American Academy of Home Care Physicians
American Assisted Living Nurses Association
American College of Health Care Administrators
American Medical Directors Association
American Occupational Therapy Association
American Physical Therapy Association
American Society of Consultant Pharmacists
Consultant Dietitians in Health Care Facilities
National Association of Activity Professionals
National Association of Social Workers
National Network of Career Nursing Assistants
National Conference of Gerontological Nurse
Practitioners
National Hospice and Palliative Care
Organization

PROVIDER ASSOCIATIONS

American Association of Homes and Services for
the Aging
American Association of Service Coordinators
American Seniors Housing Association
Assisted Living Federation of America
Catholic Health Association of the United States
National Association for Home Care
National Center for Assisted Living

REGULATOR ASSOCIATIONS

Association of Health Facility Survey Agencies
National Association for Regulatory
Administration

STATE/LOCAL GOVERNMENT

National Association of State Units on Aging

OTHER

American Institute of Architects

***Assisted Living Workgroup
Steering Committee***

AARP

American Assisted Living Nurses Association

American Association of Homes and Services for the Aging

American Medical Directors Association

American Seniors Housing Association

Assisted Living Federation of America

Association of Health Facility Survey Agencies

Consumer Consortium on Assisted Living

National Association of State Ombudsmen Programs

National Center for Assisted Living

National Citizens' Coalition for Nursing Home Reform

The NCB Development Corporation/Coming Home Project

Pioneer Network

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Introduction

As a result of the April 2001 hearing held by the U.S. Senate Special Committee on Aging, committee staff members asked assisted living stakeholders to develop recommendations designed to ensure more consistent quality in assisted living services nationwide. The primary directive was to be inclusive and permit any interested national organization to participate in the endeavor. Shortly thereafter, a core group of assisted living stakeholders extended invitations to numerous national organizations. Subsequently, the Assisted Living Workgroup formed with nearly 50 organizations representing providers, consumers, long term care and health care professionals, regulators and accrediting bodies. Meetings on assisted living and the development of recommendations began in Fall 2001.

The ALW identified overarching interests or principles that all topic groups were to consider. Those interests were:

- Quality Indicators
- Dementia Care
- Outcome Measures
- Accountability
- Regulations & Legislation
- Facility Size
- Research
- Best Practices
- Affordability

Much of the ALW's early work focused on developing the rules and processes under which the ALW would operate, including a four-stage approval process for recommendations. After much discussion, it was decided that a two-thirds majority vote of the participating organizations present (or through written proxy) at a full ALW meeting was necessary to move a recommendation forward to the next stage of the ALW's four-stage approval process. Many recommendations were significantly modified as they moved through the development stages. Each approved recommendation was voted on at least three times by the organizational representatives present at the full monthly ALW meetings.

The chapters in this report are organized by ALW topic group. In each chapter, both recommendations that received a two-thirds majority vote of the ALW participating organizations voting at the meeting and those that did not are included. Recommendations receiving two-thirds majority support appear first in each chapter; recommendations that did not receive two-thirds majority support follow.

Voting records are included for all approved recommendations and for those that failed in the last stage of the ALW voting process (on the third and final vote). Recommendations that failed earlier in the ALW process are included but do not have voting records. Finally, it should be noted that an organization was allowed to change its initial vote on a recommendation after the full report was compiled. However, the ALW determined that such vote changes would not affect whether the recommendation is listed as receiving a two-thirds majority.

The ALW also allowed participating organizations to submit supplemental positions on any recommendation published in this report. Supplemental positions were limited to 500 words and required a minimum of two organizational signatories.

Finally, the appendices at the end of the report include three additional resources. Many topic groups made recommendations for operational models or best practices that have been included as Appendix A. These recommendations were not voted on by the full ALW, but are included for the reader's information. Appendix B is a list of recommendations by topic group. Appendix C is a glossary of terms used in the report.

This report was requested by the U.S. Senate Special Committee on Aging, but is intended to be useful to a broad range of stakeholders, including:

- policymakers at the federal and state levels;
- agencies at the federal and state levels that are involved in service delivery, regulation, quality monitoring and enforcement, and providing public subsidies;
- consumers and their families;
- assisted living providers;
- health and long term care professionals, such as nurses, medical directors, pharmacists, social workers, activity directors, nutritionists, etc.;
- insurers, both public and private;
- financiers, both public and private; and
- public policy researchers.

Contact Information

For further information about the ALW, please check the Web site, alworkgroup.org, or send an e-mail with questions to info@alworkgroup.org. Written inquiries can be addressed to Assisted Living Workgroup, 2519 Connecticut Avenue, NW, Washington, DC 20008.

Topic Group Recommendations

Definition and Core Principles

In its August 15, 2002 letter to the ALW Steering Committee, the Senate Special Committee on Aging emphasized the importance of the ALW developing a uniform definition of assisted living that would "provide consumers a clear understanding of what kinds of services they should expect in assisted living." The letter reiterated that the "Committee members' primary goal is that the consumer knows what he/she is getting when signing a contract to enter an assisted living facility. Further, the letter specified: "the Committee expects the definition the Workgroup ultimately chooses to have sufficient detail to ensure that those facilities that are not providing a minimal level of service do not receive the classification 'assisted living.'"

With the Senate Committee on Aging letter as a guide, the ALW focused its attention on agreeing to a consumer-oriented, consumer-friendly definition of assisted living, rather than a more technical definition targeted to an audience of state regulatory or licensing agencies.

The challenge to the ALW in crafting a consumer-friendly definition was this: how to incorporate into the consumer-friendly definition elements that many in the ALW felt were important to assuring quality and raising the bar in assisted living. Such elements ranged from issues around private rooms to issues of levels of service and requirements for state licensing. The ALW was unable to craft a single definition that was supported in full by 2/3 of the participating organizations

To address this challenge, the ALW chose to develop a multi-faceted definition of assisted living, targeted to the consumer that includes supplemental elements that some in the ALW felt were critical to a definition that would ensure quality in assisted living. The ALW participating organizations were then offered the option of approving each of the elements separately or in various combinations.

Definition of Assisted Living

Part A: Services and Regulation

Assisted living is a state regulated and monitored residential long-term care option. Assisted living provides or coordinates oversight and services to meet the residents' individualized scheduled needs, based on the residents' assessments and service plans and their unscheduled needs as they arise.

Services that are required by state law and regulation to be provided or coordinated must include but are not limited to:

- 24-hour awake staff to provide oversight and meet scheduled and unscheduled needs
- Provision and oversight of personal and supportive services (assistance with activities of daily living and instrumental activities of daily living)
- Health related services (e.g. medication management services)
- Social services
- Recreational activities
- Meals
- Housekeeping and laundry
- Transportation

A resident has the right to make choices and receive services in a way that will promote the resident's dignity, autonomy, independence, and quality of life. These services are disclosed and agreed to in the contract between the provider and resident. Assisted living does not generally provide ongoing, 24-hour skilled nursing.

Rationale

Assisted living is distinguished from other residential long term care options by the types of services that it is licensed to perform in accordance with a philosophy of service delivery that is designed to maximize individual choice, dignity, autonomy, independence, and quality of life. The definition includes core services that must be offered by any assisted living residence. Many of the recommendations that follow provide more specificity as to what services should be offered and how they should be monitored by state regulatory agencies.

Within the range of what residences are licensed to provide and state regulations regarding what services must be provided, providers and residents* must agree on individual service packages. The recommendations that follow also provide more specificity about how contracts and service plans should be developed with residents* in a manner that is respectful of their preferences and fully discloses the terms, costs, and implications of the residents* (see definition in Appendix C, Glossary) choices with regard to services.

Voting Record for Part A

1) Organizations Supporting Part A Without Qualification

Alzheimer's Association, American Academy of Home Care Physicians, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association, Consultant Dietitians in Healthcare Facilities, Consumer

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Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Coming Home Program, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Association, Pioneer Network

- 2) **Organizations Supporting Part A Only With Part B**
AARP, National Association of Professional Geriatric Care Managers
- 3) **Organizations Supporting Part A Only With Part C**
American Medical Directors Association
- 4) **Organizations Supporting Part A Only With Parts B & C**
National Academy of Elder Law Attorneys
- 5) **Organizations Opposed to Part A**
Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center
- 6) **Organizations Abstaining From Voting on Part A**
American Occupational Therapy Association

Part B: Private Units

Assisted living units are private occupancy and shared only by the choice of residents (for example, by spouses, partners, or friends).

Rationale

The requirement for private occupancy units is essential to operationalizing the assisted living philosophy. Dignity, autonomy and independence will not be achievable without private personal space that is controlled by the resident. Quality of life in assisted living will be greatly diminished without dignity, autonomy, and independence. Assisted living (a residential setting for person with physical and cognitive disabilities) should mirror the current environmental standards for subsidized independent senior housing; i.e., people should not give up the right to privacy simply because they need services for a disability.

Voting Record for Part B

- 1) **Organisations Supporting Part B Without Qualification**
AARP, American Academy of Home Care Physicians, NCB Coming Home Program, National Association of Activity Professionals, National Association of Social Workers, Consultant Dieticians in Healthcare Facilities, National Senior Citizens Law Center
- 2) **Organisations Supporting Part B Only With Part A**
American Association of Homes and Services for the Aging, Consumer Consortium on Assisted Living, National Adult Family Care Organization, National Association of Professional Geriatric Care Managers, National Center for Assisted Living
- 3) **Organizations Supporting Part B Only With Part C**
Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman, National Association of State Ombudsman Programs, National Citizens' Coalition for

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Nursing Home Reform, National Committee to Preserve Social Security and Medicare,
National Network of Career Nursing Assistants

- 4) **Organizations Supporting Part B Only With Parts A & C**
National Academy of Elder Law Attorneys
- 5) **Organizations Opposed to Part B**
American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association for Regulatory Administration, Catholic Health Association, National Hospice and Palliative Care Organization
- 6) **Organizations Abstaining From Voting on Part B**
Alzheimer's Association, American Assisted Living Nurses Association, American Occupational Therapy Association, Joint Commission on Accreditation of Health Care Organizations, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Multiple Sclerosis Association, Pioneer Network

Part C: Levels of Care

A state must establish at least two assisted living licensure categories, based on the types and severity of the physical and mental conditions of residents that the assisted living residence is prepared to accommodate. The licensure category shall determine licensure requirements relating to important concerns such as staffing levels and qualifications, special care or services, participation by health care professionals, and fire safety.

Rationale

Licensure categories are necessary because currently there is great divergence in the level of services available within assisted living residences. Some assisted living residences provide no more than limited assistance with routine activities of daily living. At the other end of the continuum, some assisted living residences serve residents with significant needs and make available health care services that are almost comparable to those found in nursing facilities. If only one category is used, either the licensure standards are too onerous for those assisted living residences providing a relatively low level of service, or more commonly, the licensure standards fall to a lowest common denominator that is inadequate to protect the residents who have significant health care needs.

Licensure categories benefit assisted living residences by allowing them to limit their services by licensing at a lower level, or to offer a full range of services from low to high by licensing at a higher level (which still gives the facilities the capacity to serve residents with fewer needs). Licensure categories benefit consumers by providing them with lower cost options as well as options that can accommodate increased future care needs, and by giving consumers clear information on what a facility is required by law to do or is prohibited by law from doing.

Voting Record for Part C

- 1) **Organizations Supporting Part C Without Qualification**
American Academy of Home Care Physicians, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, Consultant Dietitians in Healthcare Facilities,

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National Association of Activity Professionals, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

- 2) **Organizations Supporting Part C Only With Part A**
American Medical Directors Association
- 3) **Organizations Supporting Part C Only With Part B**
National Association of Local Long Term Care Ombudsman, National Association of State Ombudsman Programs
- 4) **Organizations Supporting Part C Only With Parts A & B**
National Academy of Elder Law Attorneys
- 5) **Organizations Opposed to Part C**
AARP, American Association of Homes and Services for the Aging, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association, Consumer Consortium on Assisted Living, NCB Coming Home Program, National Center for Assisted Living, National Multiple Sclerosis Association
- 6) **Organizations Abstaining From Voting on Part C**
Alzheimer's Association, American Assisted Living Nurses Association, American Occupational Therapy Association, Joint Commission on Accreditation of Health Care Organizations, National Adult Family Care Organization, National Association of Social Workers, National Hospice and Palliative Care Organization, Pioneer Network

Voting Summary for Definition of Assisted Living

Vote	Definition Part		
	Part A	Part B	Part C
Support without qualification	18	7	11
Support only with Part A	n/a	5	1
Support only with Part B	2	n/a	2
Support only with Part C	1	6	n/a
Support only with other two parts	1	1	1
Oppose	10	8	10
Abstain	1	8	8

Supplemental Position on Parts A, B, and C

1) The undersigned strongly support Parts A and B of the definition and support an alternative version of Part C. We feel that Part A, together with the recommendation on the principle of assisted living, describe the unique model of care that assisted living provides, including essential service components as well as focusing on consumer independence and dignity. The requirements in Part A clearly raise the bar for what qualifies as assisted living currently and bring it into alignment with the goal of providing the services consumers need in a way that they can control, to the maximum extent possible.

Part B, the requirement for private occupancy units in assisted living, is critical to realizing the goals of assisted living – resident control, autonomy, and dignity.

Part C, as currently written, requires a state to license two or more assisted living licensure categories. We do not think that licensed levels of care within an assisted living category is helpful to a consumer's understanding of assisted living and may even be detrimental by requiring discharges and transfers from lower to higher levels of care. As an alternative, we recommend that a state develop or maintain the separate categories of care that they likely already have (e.g., board and care, residential care, group adult foster care, skilled nursing) to allow existing and new models of care and housing types to be developed as needed for various groups' needs and preferences. We believe that assisted living should be established as a discrete licensing category, as defined in Parts A & B, with a regulatory system designed to: 1) support its unique philosophy and mission, 2) implement minimum standards, and 3) allow a flexible approach to service levels, within the established parameters, to allow residents and providers to increase and decrease services to meet the needs of their current or target residents. We feel that the recommendations in the report support this approach to licensing assisted living.

AARP, American Association of Homes and Services for the Aging, NCB Development Corporation, Consumer Consortium on Assisted Living, Paralyzed Veterans of America

Supplemental Positions on Part A

1) We oppose Part A of the assisted living definition. Part A fails to meet the primary request of the U.S. Senate Special Committee on Aging – that a definition “offer consumers a satisfactory understanding of what services they will be guaranteed should they choose to live in an assisted living facility.” (Letter From Senate Special Committee on Aging to Assisted Living Workgroup, August 15, 2002) Although Part A intimates that assisted living provides a comprehensive level of service, Part A and other report recommendations actually guarantee relatively little.

We believe that a regulatory system – including a regulatory definition of “assisted living” -- must set forth clearly the types of services that must be provided. Consumers deserve a definition of “assisted living” that has real meaning.

By contrast, Part A relies on a model in which a resident's right to services is defined almost exclusively by the facility's admission contract. We emphatically reject this

model. In almost all instances, an admission contract is a form contract signed by the resident or the resident's representative. For many, entry to assisted living occurs during an unsettled and stressful time.

The pivotal question is whether a resident receives health care services in an assisted living residence. Part A states only that an assisted living residence provides "[h]ealth related services (e.g. medication management services)." But "health related services" is never defined, and "medication management" is a limited service: as defined in the report's glossary, medication management "[i]nvolves storing medication, opening medications for a resident, reminding residents to take medication and other assistance *not involving the administration of medications.*" (Emphasis added.)

Although requiring little or nothing in health care capability, Part A nonetheless defines "assisted living" to include facilities that provide significant levels of health care. The only health care limitation in Part A is a statement that assisted living does not provide "on-going, 24-hour skilled nursing," and even this limitation is accompanied by the qualifier that assisted living "generally" does not provide such care.

The end result of Part A is total confusion as to what kind of health care might be provided in an assisted living residence. Under Part A's definition, an assisted living residence might not be capable of administering medication or, on the other hand, might be prepared to provide extensive nursing care including, on certain occasions, "ongoing, 24-hour skilled nursing."

Part A's reference to "scheduled and unscheduled needs" does not clarify the health care services provided, because an assisted living residence as defined could be unable to meet many resident health care needs, either scheduled or unscheduled. Similarly unhelpful is Part A's reference to a resident's "right to make choices and receive services in a way that will promote the resident's dignity, autonomy, independence, and quality of life." Without specifics, this feel-good language does nothing to inform a consumer as to the services that he or she can rely upon in an assisted living residence.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

2) We dissent. The fundamental essence of assisted living is consumer choice. Further, state regulatory scenarios must incorporate the necessary flexibility that addresses these consumer needs and preferences for long-term care. By discussing only specific services and offerings, this component of the proposed definition overlooks one essential—and often overlooked—aspect: Assisted living is a philosophy of care.

This philosophy embraces the need to:

- Foster resident independence,
- Promote the individuality of each resident, and
- Nurture each resident's spirit.

Further, vital resident issues such as the preservation of resident privacy, choice, and dignity cannot be mandated—or even addressed—by specific service requirements. Rather, these key concepts must be recognized at the outset as being an integral part of the consumer-centered nature of assisted living.

Assisted Living Federation of America, National Association for Home Care

Supplemental Positions on Part B

1) We concur with Part B of the definition primarily because we strongly support the goal of giving all people requiring residential long-term care services the option of residing in private quarters. However, our concurrence is not free of serious concerns about the difficulties of pursuing that goal through the vehicle of a definition. Definitions steer regulatory policy.

Two competing and contradictory trends that are difficult to reconcile are at play. First, the vast majority of residences being built as assisted living have private units. If private units are the norm for new construction, then non-private units in existing facilities could be grandfathered as assisted living. Second, however, some states have renamed all residential living "assisted living." In these states, private units are not required.

Our primary concern is assuring that regulations are based on the needs of the individuals receiving services and the types of services they are provided. We do not want to encourage different rules for different residential long-term care facilities, based on the wealth of the residents.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

2) We dissent. The Assisted Living Workgroup could not reach agreement on whether a definition of assisted living should include a requirement that private units must be required in assisted living settings as part of state minimum standards.

While we agree that residents should have the right to choose whether to share a room or not, that choice is eliminated with regulatory language that requires private units. In effect, such language would require providers to build all private units in case no potential residents choose to share a room. Regulatory language needs to state that shared units are permissible in order to give providers the flexibility to respond to marketplace factors that gives consumers more options rather than less.

The rationale for the proposed language asserts that resident dignity, autonomy and independence will not be achievable without private personal space that is controlled by the resident. The proponents of the proposed language are making a statement concerning their knowledge of how a resident's quality of care and quality of life is affected without the benefit of asking residents who currently share units as to whether they agree with the statements that are being made on their behalf.

Quantifying how the values of dignity, independence and autonomy are achieved in the eyes of a resident in assisted living is a multi-faceted and complex undertaking. It is not reducible to a single assertion that the operationalizing of these values in the eyes of a consumer hinges on a requirement for private units. Dignity, independence and autonomy can be operationalized in a variety of choices made each day by the resident, even in ALRs where the resident shares a unit.

Assisted Living Federation of America, Joint Commission for Accreditation of Health Care Organizations, National Association for Home Care

Supplemental Positions on Part C

1) We dissent. The rationale for why a state must require two levels of assisted living licensure categories has no basis in fact related to improving quality of care in assisted living.

No evidence is offered to support the statement that a state that has only one licensure category that the licensure standards are too onerous for ALRs providing a relatively low level of service or that the licensure standards will be inadequate to protect residents who have significant health care needs.

No evidence is offered to support the statement that levels of licensure offer a more affordable option to consumers. Issues surrounding what makes assisted living more affordable to consumers are considerably more complex and intertwined with public policy decisions affecting housing subsidies and services subsidies than this rationale acknowledges.

Finally, no evidence is offered to support the statement that levels of licensure provides consumers with clearer information on what the ALR is required by law to provide.

Assisted Living Federation of America, Joint Commission on Accreditation of Health Care Organizations, National Association for Home Care

Core Principles

These core principles of assisted living should be reflected in the setting's mission statement, culture, policies, and procedures:

- 1) To create a residential environment that actively supports and promotes each resident's quality of life, right to privacy, choice, dignity, and independence as defined by that resident.
- 2) To offer quality supportive services, individualized for each resident and developed collaboratively with the ALR.
- 3) To provide resident-centered services with an emphasis on the particular needs of the individual and his/her choice of lifestyle incorporating creativity, variety, and innovation.
- 4) To support the resident's decision-making control to the maximum extent possible.
- 5) To foster a social climate that allows the resident to develop and maintain relationships within the ALR and in community-at-large.
- 6) To make full consumer disclosure, including what services will be offered and their associated costs, before move in and throughout the resident's stay.
- 7) To minimize the need to move.
- 8) To foster a culture that provides a quality environment for the residents, families, staff, volunteers, and community-at-large.

Organizations Supporting the Core Principles

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association, Consultant Dieticians in Health Care Facilities, Consumers Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organizations, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposed to the Core Principles

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining from a Vote on the Core Principles

Assisted Living Federation of America, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Network of Career Nursing Assistants

Supplemental Position on Core Principles

1) We dissent. While the core principles adopted may be appropriate to inspire assisted living staff members, the core principles contribute nothing to the discussion in the ALW report. At best, the core principles are aspiration statements. They are marketing principles that do not reflect actual practice in many assisted living residences. Moreover, the core principles do not distinguish assisted living from other health care settings. They describe neither the assisted living industry today, nor the recommendations that follow in this document.

The core principles misleadingly promise more than the recommendations deliver. For example, a purported core principle is "minimize[ing] the need to move." Yet the majority recommendations allow an assisted living residence to force eviction simply by refusing to provide a service that the resident needs, even though the residence could provide that service under its license. (See our dissent to D.04) Also, under the majority recommendations, an assisted living residence can force eviction by refusing to accept Medicaid reimbursement, even though the residence has Medicaid certification, and even though the resident has become Medicaid eligible by spending his or her life savings for care at the assisted living residence. We proposed requiring that a Medicaid-certified assisted living residence accept available Medicaid reimbursement, but our proposal was voted down. (See our opposition to failed recommendation R.20)

We believe the core principles are misleading. They should not have been included in the report.

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Citizens'
Coalition for Nursing Home Reform, National Committee to Preserve Social
Security and Medicare, National Network of Career Nursing Assistants,
National Senior Citizens Law Center*

Topic Group Recommendations Adopted by 2/3 Majority of the ALW

Accountability & Oversight

Purpose

The Accountability & Oversight Topic Group developed recommendations for regulatory systems designed to provide oversight to assisted living residences.

Issues

The group worked on two primary issues: 1) developing regulatory system guidelines for states and 2) establishing a mechanism to develop outcome measures and quality improvement methods that can be integrated with traditional systems to provide state-of-the-art measurement systems to ensure consumer safety and satisfaction. Related to the goal of providing guidance regarding current regulatory systems, the topic group made recommendations in the following areas: components of a state accountability and oversight system; state-level assisted living stakeholder groups; consumer reports; licensure of assisted living; supply constraints; pre-licensure review; funding for long-term care ombudsmen; and public access to statutes, regulations, survey and inspection reports.

To develop valid outcome measures and improved quality improvement systems, the topic group made recommendations to create a National Center for Excellence in Assisted Living (CEAL), including the tasks to be undertaken by that entity. CEAL would be an on-going effort at the national level to review, research, evaluate and validate methods that will promote quality in assisted living. An additional recommendation made by the topic group is the creation of state-based assisted living workgroups, comprised of assisted living stakeholders, that evaluates the final recommendations of the national assisted living workgroup from the viewpoint of each particular state.

Participants

This topic group was co-chaired by Lyn Bentley of the National Center for Assisted Living and Rick Harris of the Association of Health Facility Survey Agencies.

Topic group participants included Doug Pace of the American Association of Homes and Services for the Aging, Paul Willging and Ed Sheehy of the Assisted Living Federation of America, Karen Love and Jackie Pinkowitz of the Consumer Consortium on Assisted Living, Marianna Grachek of the Joint Commission on the Accreditation of Healthcare Organizations, Donna Lenhoff and Christopher Havins of the National Citizens' Coalition for Nursing Home Reform, Dorothy Northrop of the National Multiple Sclerosis Society, Toby Edelman of the Center for Medicare Advocacy, Don Redfoot of AARP, Bill Reynolds of the Pioneer Network,Carolynne H. Stevens of the National Association for Regulatory Administration, Robert Jenkins of the NCB Development Corporation's Coming Home Program, Josh Allen of the American Assisted Living Nurses Association, Janet Kreizman and Meg LaPorte of the American Medical Directors Association, and Nancy Coleman of the American Bar Association's Commission on Law & Aging.

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<u>Accountability and Oversight</u>

AO.01 Center for Excellence in Assisted Living**Recommendation**

A national Center for Excellence in Assisted Living (CEAL) should be formed and funded to continue the work of the Assisted Living Workgroup and serve as an ongoing information clearinghouse and shall include a governing board comprised of key stakeholders.

The CEAL should foster and develop the following: 1) performance measures, including measures of clinical outcomes, functional outcomes, staff and resident* satisfaction; 2) updated versions of the ALW recommendations and report; 3) dissemination of these tools that are developed; 4) practice protocols to deal with identified problem areas. The CEAL should also develop capacity to provide technical assistance to states, at their request, for integration of outcome measures and the ALW recommendations; identify and promote areas for research AL; and utilizing objective quality measures and data, provide a regular report to Congress and the nation regarding the state of the assisted living industry.

An additional role of the CEAL is to develop a means of reporting quality information about ALRs in ways that are useful to various constituents.

The governing board of the CEAL should include balanced representation ensuring no one group dominates the board. The groups represented should include: 1) consumers and their advocates, 2) providers, 3) state officials, 4) other professionals working in long term care.

Implementation

Guideline for Federal Policy

Rationale

Promoting quality in assisted living requires developing better information tools for all constituents—to foster autonomy for consumers, innovation among providers, and informed decision-making among government officials.

Consumers: Consumers and their families considering assisted living need information about quality that would allow them to make informed choices among alternatives. Those consumers who live in assisted living need a mechanism to express their satisfaction or dissatisfaction in ways that feed into management practices, state enforcement, and quality reports for other potential consumers.

Supervisory and Direct Care Staff: Quality services are a function of able and committed staff. Staff satisfaction and retention of staff are vital to the continuity of services. Supervisory and direct care staff should be consulted on structure and performance measures and process considerations, including staff scheduling, the appropriateness of workload standards, the availability of supplies and equipment, continuing education for staff.

Providers: Providers shall focus on quality outcomes in their day to day management and

Accountability and Oversight

operations. Outcomes measures developed by the CEAL should be useful to providers in evaluating their performance and identifying areas for improvement. Practice protocols could help providers develop more effective interventions in problem areas.

State Enforcement Agencies: States have the primary responsibility for overseeing quality and enforcing minimum standards for assisted living. The CEAL would have responsibility for updating the guidelines for states on minimum standards. Over time, the effectiveness of these standards should be measured against outcomes measures validated by the CEAL. Quality indicators may be one type of outcomes measure that the CEAL could validate for use by state regulators to ensure more continuous monitoring and more timely and effective interventions.

State and Federal Funding Agencies: State and federal governments have shown increasing interest in providing public reimbursements to assisted living, especially through the Medicaid program and various housing programs. Outcomes measures and the guidelines for state minimum standards should provide benchmarks to evaluate state efforts to assure quality—making sure that increased federal funding is used appropriately.

State and Federal Elected Officials: Members of Congress and state legislators have a responsibility to oversee assisted living and to develop policies affecting the industry. An annual report on the state of quality identifying areas for policy development would help policy decision-makers do their jobs, based on accurate and timely information. The CEAL could serve as an ongoing source of information on quality issues for elected officials as well as other constituents.

Governing Board: Broad acceptance of the recommendations of the CEAL will require broad and balanced representation on the governing board. Further, the governing board should be an independent decision-making entity rather than affiliated with a governmental body.

Funding by Congress: The independence of the CEAL will be critical to its credibility. Congressional funding of the core operations of the CEAL would enable the organization to begin offering services sooner and would help guarantee the independence of the organization. The CEAL may, with approval of its board, seek other funding to sponsor research, help disseminate information, and carry out other functions that it may identify.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

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American Seniors Housing Association, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Senior Citizens Law Center, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.01

1) We dissent. This recommendation would establish a private group to perform many functions that are now tasked to public regulatory agencies. We oppose this recommendation because its full implementation would transfer a government function to a private organization with a nebulous governing structure.

The recommendation also would allow the CEAL to solicit contributions for its work, but has no requirements prohibiting conflicts of interest. The provider community would clearly be in a position to make contributions, thus directing the areas of research and potentially affecting research outcomes.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The undersigned strongly support Accountability and Oversight A0.1 as written for the following reasons:

- To address the on-going quality of assisted living, a national organization is necessary to research and disseminate information and best practices. The CEAL's role as an objective resource to develop and/or validate outcome measures is especially important if these measure are to assume a significant role in quality monitoring.
- A national resource is necessary to continually update standards as better methods of delivery and quality monitoring (e.g., outcome measures) are developed or problems are identified.
- A national organization is needed to develop and disseminate technical assistance to states regarding best practices in regulation and monitoring and to providers regarding operations.
- The products of the CEAL (e.g., regulatory updates, outcome measures, best practices in operations) will benefit all consumers and providers but will be especially useful to affordable assisted living residents and providers. The replacement of process oriented requirements with outcome measures holds great promise to allow greater flexibility in meeting consumers' needs and preferences while allowing providers to run the most affordable operation possible. Likewise, best practice technical assistance will allow states and providers to deliver high quality affordable assisted living.
- Public funding is necessary and appropriate for this function, especially as more federal funding is directed to ALRs.

AARP, Alzheimer's Association, American College of Health Care Administrators, NCB Development Corporation, Consumer Consortium on Assisted Living, National

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3) The rationale for this recommendation specifies: "States have the primary responsibility for overseeing quality and enforcing minimum standards for assisted living." We support states continuing their current role of overseeing assisted living. We support and encourage the creation of Centers for Excellence in Assisted Living (CEAL) in each state and adopting the goals outlined above.

American College of Health Care Administrators, American Seniors Housing Association, National Center for Assisted Living

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Accountability and Oversight

**AO.02 Increased Funding for Long Term Care
Ombudsmen**

Recommendation

Congress and the states should provide adequate funding for the Long-Term Care Ombudsman Program to fulfill its responsibilities under the Older Americans Act.

Implementation

Guideline for Federal and State Policy

Rationale

Ombudsmen have legislative authority to resolve complaints and represent resident interests in licensed ALRs. Long-term care ombudsmen have the unique opportunity to negotiate agreements and resolve problems before they become enforcement issues. Equally important, long-term care ombudsmen are resources for consumer education on a wide variety of issues related to assisted living, including resident rights, the difference between nursing-home and assisted-living care, community resources, etc. Providing adequate funding would result in more frequent visits to assisted living residents, increased capacity to provide consumers with much-needed education on assisted-living services, and training to effectively carry out the ombudsman responsibilities in this setting.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.02

None Submitted

Accountability and Oversight**AO.03 State-level Public Meetings to Review ALW
Recommendations****Recommendation**

States should convene public meetings attended by regulators, consumers, consumer advocates, assisted living provider representatives, and professionals working in the assisted living setting. At these meetings, states should consider the recommendations of the Assisted Living Workgroup, as well as other local issues that are relevant to the assisted living industry. Similarly-constituted groups should be convened from time to time to consider new issues and to evaluate the impact of decisions made previously. Particular care should be taken to assist consumers and consumer advocacy organizations in obtaining the resources necessary to participate in this effort.

Implementation**Guideline for State Regulation****Rationale**

The members of the Assisted Living Workgroup believe that the discussions we have had about various questions are at least as valuable as the conclusions and recommendations that we have reached. We do not expect that states will or should adopt the recommendations of the ALW in wholesale fashion. Decisions involve weighing competing values. Inevitably, states will find balance points that differ from one another and from the ALW. We think it is critically important, however, to articulate the values that underlie decisions, including the values that prevail and those that do not. It is no less important to keep the books open on controversial questions, revisiting from time to time decisions that have been made, evaluating once again the underlying value choices, and determining, to the extent possible, whether adoption of a particular recommendation has had its intended effect.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Association for Regulatory Administration, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

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Accountability and Oversight

None

Supplemental Positions for AO.03

1) We agree that states should seek maximum public input when considering assisted living standards. We fully endorse the concept that care should be taken to include input from consumers and consumer advocates.

We dissent because we believe that most of the recommendations from the Assisted Living Workgroup are not appropriate for adoption by the states. For states that have recently revised their assisted living regulatory approach, adoption of the recommendations in the Assisted Living Workgroup report would in nearly every case be a step backwards, increasing the risk of adverse outcomes to thousands of consumers. Rather than follow the report's recommendations, those states seeking to revise their current assisted living regulations should consider measures adopted by other states in recent years. In several dissents published in this report, and in a separately published paper, we will identify several promising, recently-adopted state regulatory approaches to a number of serious care and safety problems within the assisted living industry.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We support this recommendation. We support the concept of convening state meetings to discuss quality improvements in Assisted Living. We recommend that stakeholder meetings be brought together with a vision statement affirming that consumer-centered perspective will be considered in defining all standards.

A consumer-centered perspective is respected when consideration is given to the consumer's values and experiences, as well as individual preferences into the definition and evaluation of quality of care and quality of life.

It is critical that state level discussions to improve quality not be limited solely to consideration of processes, but rather, give equal weight to alternative approaches that might integrate or substitute measures of results and performance, including consumer satisfaction.

Assisted Living Federation of America, Consumer Consortium on Assisted Living, National Association for Home Care, National Center for Assisted Living, Joint Commission on Accreditation of Health Care Organizations

Accountability and Oversight**AO.04 Pre-licensure Review****Recommendation**

A state review of applicants prior to licensure shall focus on both provider capacity and past performance in assisted living and related fields. For applicants without a relevant performance history, in addition to the capacity review, states should exercise heightened oversight until the applicant demonstrates the capacity to operate the residence in compliance with the regulations for one year.

Implementation**Guideline for State Regulation****Rationale**

An effective tool for promoting quality in assisted living is a pre-licensure review. State licensure review should include two parts: a capacity review and a performance review. The capacity review would determine the applicant's ability to meet minimum standards and assess its financial soundness. The performance review would focus on a provider's history of providing quality assisted living or similar services. The performance review should include any records of past performance, records of complaints, past business practices, and specific experience a provider brings to serving older persons and persons with disabilities. States should not grant licenses to providers that have unacceptable performance records or show inadequate capacity to provide quality services. States should expedite requested records and reviews of past performance, including information requested by licensing agencies in other states.

New providers are necessary in many locations. States may also want to use provisional licensure for providers with limited experience. Lack of relevant performance histories should not be an obstacle to licensure or limit entry into the assisted living field. Instead, an approach combining a rigorous capacity review and heightened oversight should be adopted for applicants new to the assisted living field until a performance record is established.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

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Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.04

None Submitted

Accountability and Oversight

AO.05 Supply Constraints

Recommendation

States should not use certificates of need, license moratoria, or any other means to limit the supply of assisted living residences.

Implementation

Guideline for State Regulation

Rationale

Constraints on the supply of assisted living (such as certificates of need or license moratoria) can negatively affect the quality of services by keeping marginal performers in business while limiting the entry of new providers. Licensure should be used to improve quality, not to limit the supply of assisted living residences. Because they reduce competition, supply constraints drive up costs and diminish quality and innovation. Therefore, states should not use certificates of need, license moratoria, or any other artificial constraint on the supply of assisted living residences.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Supplemental Positions for AO.05

1) We dissent from the majority's recommendation to ban supply constraints and from its view that these inevitably preserve substandard facilities while preventing market entry by other providers.

We believe it is equally true that unrestrained growth can and sometimes does result in over-supply with high vacancy rates that force facilities to divert resources from resident care to pay debt

Accountability and Oversight

burdens and other fixed costs. We have seen:

- Facilities, stressed by high vacancies, make ill-advised admissions of high-acuity residents they could not adequately serve or residents who would be inappropriately placed in a home for frail elderly people;
- Abrupt closures that displaced residents;
- Reduced staffing, unmet payrolls with real/threatened walk-outs, and real/threatened cut-offs of services and utilities in over-extended facilities during time-consuming appeal proceedings related to regulators' forcible closure actions and lender foreclosures;
- Some areas dangerously over-built while others remain grossly under-supplied.

Thus, consumers can and do suffer as much from over-supply, voracious competition by large chains, and market volatility as from under-supply.

The wiser course is to allow states the flexibility to adopt, or not adopt, methods and tools according to their prevailing conditions. States are responsible for protecting residents and preventing harmful conditions. States should not be hampered in choosing methods to perform this mission.

Regardless of the states' choices, residents would fare better if:

- States streamlined their appeals processes to reduce the time residents are exposed to high-risk conditions during forcible closure actions;
- States and the federal government generated better planning data and offered planning assistance to promote better, more agile decision-making by providers, lending institutions and states;
- States that establish a certificate of need process assured opportunities for public input; and,
- States that employ market-restraint methods avoided creating unduly thin supply margins that can result in a reduction of healthy competition or consumer options.

Association of Health Facility Survey Agencies, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Network of Career Nurse Assistants

Accountability and Oversight**AO.06 Components of a State Accountability and Oversight System****Recommendation****Part I**

The regulatory system for assisted living is founded on these principles:

- A regulatory system for assisted living is responsible for abating harm and supporting the resident's decision-making control.
- The regulatory system ensures that there is meaningful assisted living stakeholder participation, especially resident* participation, when defining regulatory standards.
- The regulatory system specifies that the practices, protocols and methods by which care is provided are respectful of, and responsive to individual resident preferences, needs and values and that resident values guide care and service delivery decisions.
- Regulatory requirements should be periodically re-evaluated to determine whether or not they are achieving their intended effect.

Part II

Each state shall have adequate survey staff to enforce its assisted living regulations and should have an accountability and oversight system (otherwise referred to as a survey and enforcement system) that includes the following elements:

1. **Standards for Licensing – Quality assurance begins with the licensing or certification of the ALR. Standards for licensing should include: documentation of competent management; performance history; criminal background checks; financial soundness; required policies and procedures; compliance with specific building and life safety code requirements; appropriately trained staff, food safety, service planning, dietary oversight.**
2. **A Monitoring Element – Includes a system of no less than annual unannounced inspections, and a responsive complaint investigation process.**
3. **A Technical Assistance Element – The Technical Assistance Element may be used by a state agency as a third component of its integrated oversight of ALRs; the other two components are surveys and complaint investigations. The state agency may provide technical assistance to ALRs on its own initiative or in response to an ALR's request. The technical assistance includes explanation of regulatory requirements and standards.**
4. **A Remedy and/or Sanction Element – In the Remedy and/or Sanction Element, a range of remedies and/or sanctions may be employed by the state agency, including: directed plans of corrections; fines, reduced capacity; required training, stipulations on admissions, relief of administrative control of the facility, and license revocation. The remedy and/or sanction component should be based on clear regulatory standards that detail the basis for the licensing sanctions. In some instances the state may require a management consultant to be paid for by the ALR.**

Regulatory systems should have systems in place designed to timely identify substandard performers, and to quickly and effectively induce satisfactory performance or closure of the

Accountability and Oversight

ALR. There are three approaches that regulatory agencies should consider using:

Track 1: A small number of ALRs having regulatory difficulties are in such dire circumstances that any reasonable person would fear for the immediate health and safety of the residents. Examples of this situation include: residents are not being fed; there is no heat in the building during the winter due to non-payment of utility bills; residents are being denied urgently needed medical care; residents are being abused by staff and management of the ALR has failed to take any action. Under these circumstances, the only solution is to bring legal action asking for immediate injunctive relief. In situations where the deficiencies do not indicate a physical plant emergency, the injunction shall request some type of receivership or other court-approved change of management of the facility in order to protect residents and allow them to remain in their homes under new management. Discharge of residents shall be an available remedy, but this remedy should be sought by the state agency when there is a physical plant emergency or when receivership or other court-approved change of management of the facility is not possible. Regulatory agencies should have ample legal authority to get immediate relief where necessary to protect residents.

Track 2: ALR operators who have been identified as substandard operators should be immediately notified of their status, of the regulatory agency's assessment of the nature of their problems, and of the remedies and/or sanctions imposed by the state survey agency. The message conveyed should be that identified problems shall be immediately corrected or the ALR will be the subject of additional remedies and/or sanctions and adverse licensure action. In situations involving no harm to residents, the state may give the ALR an opportunity to correct deficiencies before imposing any remedy and/or sanction. Any opportunity to correct problems, if offered, should be limited to a narrow time frame, such as thirty to forty-five days. If problems are not corrected as agreed, the state survey agency shall impose additional remedies and may require the facility to sell or lease the ALR to an unrelated party acceptable to the regulatory agency or bring in an unrelated management company that is acceptable or publicly defend itself at a license revocation hearing. It may be appropriate to conduct a face-to-face meeting with the ALR administrator or with corporate officials to ensure the message is understood and to ensure that any contemplated corrective measures are adequate.

Track 3: License revocation. When Track 2 fails, regulatory agencies shall be prepared to exercise this option.

5. Administrative Procedures Element – Administrative procedures should be expeditious and not unduly prolong or exacerbate the situation that led to the ALR's or State's decision. Administrative procedures should include:

- a. An opportunity for the ALR (including clinical/direct care staff) to discuss survey problems informally with the state agency both during the survey and at the exit conference and to submit a plan of corrections.
- b. The opportunity for the ALR to have an informal conference with the regulatory agency with notification provided to residents*, the ombudsman, or other appropriate consumer advocacy representative.
- c. The right of the ALR to a hearing before an impartial agency officer with a clear set of

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procedural rules. The ALR shall have the right to appeal only deficiencies for which the state agency imposes a sanction.

d. The right of an ALR to appeal the state agency decision to the appropriate state court after a contested case hearing. The ALR shall have the right to appeal only deficiencies for which the state agency imposes a sanction.

The state's rules shall be designed and implemented in a way that:

- Minimizes the time between the identification of deficiencies and final imposition of the remedy(ies); and
- Provides for the imposition of incrementally more severe fines and remedies for repeated or uncorrected deficiencies.

Where the state determines there is an immediate threat to residents' health or safety the state's rules shall authorize the imposition of remedies and/or sanctions during the pendency of an administrative hearing.

Implementation

Guideline for State Regulation

Rationale

This recommendation suggests a framework for an approach to oversight of assisted living. This approach seeks to combine elements of traditional regulatory systems having to do with deterrence and abatement of harm with other modes for monitoring and improving performance and quality of care.

This new approach would align the values associated with assisted living (autonomy, choice, dignity) with the outcomes to be accomplished and the means to evaluate the effectiveness of services within a system that encourages and rewards excellence while retaining traditional state responsibility for vigorous rule enforcement when necessary.

A regulatory system for assisted living serves two primary goals: (1) determining compliance with regulatory standards of care (which include quality of life and residents' rights) and (2) preventing avoidable bad outcomes for residents [California Association of Health Facilities v. Department of Health Services, 16 Cal.4th 284, 940 P.2d 323, 65 Cal.Rptr.2d 872 (1997)].

While it could be beneficial for regulatory agencies to provide technical assistance to facilities to help them provide better care for their residents, that work (1) is not the state's core function and therefore should not be done until the state's core functions are completed; and (2) can be accomplished by other entities (trade associations, private consultants, etc). Facilities engage in quality improvement activities. State survey agencies protect public health and safety. Their roles should not be confused. State agencies should not serve as or become part of an ALR's staff or quality assurance teams.

It should be noted that the sequential listing of the Monitoring, Technical Assistance and Remedy and/or Sanction Components is not meant to imply that the state regulatory

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agency shall follow a linear progression from one component to the next. Instead, each component is a distinct part of the system. A state agency, for example, may take direct enforcement action against a provider without prior technical assistance. Similarly, as part of its monitoring functions, a state agency may provide on-site technical assistance in the way of a suggested best practice or the provider may voluntarily initiate a request for technical assistance.

State oversight programs may consider the clinical staff's medical judgment and decision-making in its examination of care processes. ALR clinicians could have the opportunity to provide adequate clinical pertinent explanations regarding their care decisions as part of a collaborative or consultative process.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, American Seniors Housing Association, Association of Health Facility Survey Agencies, National Association for Regulatory Administration, National Center for Assisted Living, National Committee to Preserve Social Security and Medicare

Organizations Abstaining From the Vote on This Recommendation

National Network of Career Nursing Assistants

Supplemental Positions for AO.06

1) Although we agree with much of this recommendation, we submit this supplemental position to indicate our strong disagreement with #1, the purported principles of a regulatory system. The underlying assumption of the introductory principles is that the most significant problem faced by AL regulators is ensuring that residents have enough decision making control. This assumption reflects the majority's unwillingness to acknowledge significant care and safety problems occurring throughout the assisted living industry-- problems such as abuse and neglect, some resulting in injury or death, elopements resulting in injuries or death, avoidable falls resulting in fractures, and dangerous unplanned weight loss that could be avoided using well-recognized interventions.

The introductory principles, by elevating resident choice above all other concerns would be an impediment to an effective regulatory system. The majority diverts attention from the truly

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important issues. Ignoring the prevalence of care and safety problems in the assisted living setting, it directs regulators merely to make sure that residents have the right to make choices. This is neither useful nor rational as a response to the growing crisis in resident safety and well-being.

Association of Health Facility Survey Agencies, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) As proposed, this recommendation mirrors the current oversight system for assisted living in some states and the federal oversight system for all certified nursing homes. This type of oversight has not proven to be successful and has shifted the main focus of nursing homes from their customers to their regulators. The ALW has an opportunity to propose a new vision for an oversight system and this recommendation does not reflect a new vision.

The oversight system for assisted living should be designed to embrace the following concepts:

- Partnership among providers, residents and regulators to reach the desired goal of quality assisted living;
- Regulators responsible for assisted living should receive specialty training about assisted living;
- The oversight agency should offer technical assistance to the assisted living residences upon request;
- Resident satisfaction should be an integral component for determining quality; and
- Utilize sanctions and fines only as a last resort (sanctions and fines are punishment and do not necessarily relate to long-term improvement of a situation).

American Association of Homes and Services for the Aging, National Center for Assisted Living, American Seniors Housing Association

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AO.07 Public Access to Statutes, Regulations, Survey and Inspection Reports**Recommendation**

State regulatory agencies should make available information that is helpful to consumers and others related to assisted living residences. This availability includes electronic access to statutes and regulations impacting assisted living. The state should also maintain as public records all survey and inspection reports and plans of corrections for a period of at least three years. States should take steps to offer low cost access to these reports, such as by posting the reports on their web page.

Implementation

Guideline for State Regulation

Rationale

Consumers need to have easy access to information that will be useful as they assess assisted living residences.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.07

None Submitted

Accountability and Oversight

AO.08 Federal Jurisdiction Over Assisted Living

Recommendation

The federal government shall exercise its jurisdiction to oversee assisted living and enforce federal law in the following areas:

- To protect consumers from unfair and deceptive acts and practices under the Federal Trade Commission Act;
- Whenever an assisted living provider receives Medicaid funding, the federal government shall adequately enforce its responsibilities for Medicaid waiver for assisted living;
- National abuse registries and criminal background checks;
- Civil rights laws, such as the Americans with Disabilities Act;
- Any other existing federal laws and standards that apply.

This recommendation is not intended to take a position on the need for additional federal authority over assisted living.

Implementation

Guideline for Federal Policy

Rationale

The Senate Special Committee on Aging and GAO have identified consumer disclosure and marketing practices as a problem area for assisted living. These issues are particularly important in the context of an industry whose providers offer a whole range of services with different types of billing strategies, admission and retention policies, and subsidy options. Under the circumstances, it would make sense for the Federal Trade Commission (FTC) to focus attention under its existing consumer protection authority to examine practices in this industry and to take action where problems may persist.

Similarly, CMS should enhance its oversight of states that are using Medicaid waivers and state plan services in assisted living. Since waivers require that recipients be eligible for nursing home services, they require AL providers to offer a higher level of services to a more disabled population than is often envisioned by state AL regulations. CMS should make sure that states are doing an adequate job overseeing quality—not only through having regulations that address higher levels of disability, but also sufficient staffing in state monitoring agencies.

There may be other ways that the federal government can play a more active role in seeing that states do an adequate job with quality—e.g., federal housing programs may play a role. The general goal will be to give states adequate tools, adequate resources, and adequate oversight to make sure they can meet their responsibilities for promoting quality in assisted living.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consultant Dietitians on Healthcare

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Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practicioners, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Catholic Health Association of the United States, National Center for Assisted Living

Organizations Abstaining From the Vote on This Recommendation

American Seniors Housing Association

Supplemental Positions for AO.08

None Submitted

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AO.09 Licensure of Assisted Living**Recommendation**

States shall require assisted living licensing for any entity that meets the state's definition or does the following:

1. Holds itself out as an ALR; OR
2. Offers to provide assisted living services unless licensed under another related category; OR
3. Uses the phrase "assisted living" in its name or marketing materials.

Implementation

Guideline for State Regulation

Rationale

Entities that meet the criteria identified in the above recommendation should be licensed as assisted living. This will provide the states with appropriate regulatory oversight of entities that are providing assisted living. Additionally, it will provide consumers with a broad definition of assisted living and the assurance that there is state regulatory monitoring and oversight.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.09

- 1) We dissent. This definition essentially says that a business only needs to get licensed as an

Accountability and Oversight

assisted living residence if it calls itself, "Assisted living," or if it meets the state's definition of assisted living. It avoids making any recommendations to states on how they should define assisted living.

Licensure requirements should be based on the care needs of the residents that a facility houses, rather than based on the services that it provides. Otherwise, assisted living residences are unlimited in which residents they may admit and retain. Moreover, facilities could lawfully escape having to meet licensure requirements merely by not offering one out of a long list of services. We believe a more rigorous legal definition is required, and propose the following as a guideline to states:

"Assisted living residence" means any business entity, including an individual, that offers housing, meals, and care to ____ [insert here a minimum number to be determined by state law or policy] or more adults who require assistance with activities of daily living or more extensive care, unless the facility is subject to licensure as a different entity, such as a nursing home, or unless the entity is specifically excluded by law from the requirement to be licensed.

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Citizens' Coalition for
Nursing Home Reform, National Committee to Preserve Social Security and
Medicare, National Network of Career Nursing Assistants, National Senior Citizens
Law Center*

2) We dissent. This recommendation goes beyond the mandate to the ALW to focus on recommendations to the states to improve quality in assisted living. Rationale says that adoption of this recommendation will provide the states with appropriate regulatory oversight authority. States already have the requisite authority. Therefore this recommendation provides no new guidance to the states that will improve quality in assisted living. Further, the thrust of the recommendation infringes on state authority to set the terms and conditions for licensure.

*Assisted Living Federation of America, National Association for Home Care, Joint
Commission on Accreditation of Health Care Organizations*

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Accountability and Oversight

AO.10 Stakeholder Involvement in Federal Actions**Recommendation**

Congress and federal agencies shall, in a public and open manner, consult with a diverse representation of stakeholders, including residents* in the review, evaluation and formulation of any assisted living law, policy, regulation or program.

Implementation

Guideline for Federal Policy

Rationale

The development and consideration of any assisted living measure without effective communication with the diverse stakeholders of assisted living will result in outcomes that are not significantly effective.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Social Workers, National Association of Local Long Term Care Ombudsmen, National Center for Assisted Living, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Catholic Health Association of the United States

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.10

None Submitted

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority***

Accountability and Oversight

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote.

The recommendations that do not show a voting record were unable to reach the two-thirds majority during the development process.

Accountability and Oversight**AO.11 Measure of Resident Outcomes****2/3 Maj. Not Reached****Recommendation**

The CEAL (Center for Excellence in Assisted Living) should research, develop and validate measures of resident outcomes including consumer satisfaction and consumer quality of life. When resident outcome measures are available, states may integrate these measures into their regulations and survey process.

The CEAL's designation of outcome measures shall be preceded by research and analysis to identify a limited number of outcome measures that are most useful in evaluating resident quality of life.

Implementation

Guideline for Federal Policy

Rationale

Outcome measures are a powerful tool in enhancing the quality of life of residents. Additionally, outcome measures may be used to focus state inspection and survey activities on issues that are of greatest concern, to act as sentinels for potential problems as they develop and to help consumers choose an appropriate ALR.

Information on outcome measures should be provided to consumers. The information about outcome measures will require analyses with risk adjustments for the ALRs involved, the level of services offered, and the characteristics of the residents served. The CEAL should work on the technical issues so that reports made to consumers and providers are accurate and understandable comparisons that are useful to their respective decision-making needs.

There are substantial costs imposed on both providers and on regulatory agencies involved in a data collection effort such as the one envisioned here. Restricting data elements to only those most useful to consumers, providers, and states in their respective decision-making as identified by the preceding efforts should minimize these costs.

Because of the complicated technical issues in validating quality measures, collecting the data, analyzing the data, and reporting the results, the ALW envisions an extended period of time during which these measures are developed and implemented. As measures are validated and tested, they may be introduced a few at a time rather than as a whole. The ALW urges particular attention to consumer satisfaction and quality of life measures as areas too often ignored in evaluating quality performance.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social

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Workers, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, American Seniors Housing Association, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.11

1) We oppose this failed recommendation because it is not appropriate for a private organization structured like the proposed "CEAL" to develop the outcome measures and a minimum data set. Our objections to the CEAL concept are more fully set out in our dissent to recommendation AO-01.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The undersigned strongly support recommendation AO.11. The ongoing effort to promote quality in assisted living must include research to develop and validate measures of resident outcomes. Particular attention should be paid to measures of consumer satisfaction and quality of life. The CEAL, a national body with representation from a balanced group of stakeholders, is the ideal group to conduct this important work.

The Rationale recognizes the value of outcome measures for consumers, providers, and states. Outcome measures benefit consumers by providing the information needed to develop consumer reports, which provide potential residents and their families with the information they need when choosing an ALR. Outcome measures are useful to providers in their internal quality improvement efforts. Performance-based outcome measures are also valuable for states' survey and monitoring efforts, helping states to focus efforts on improving resident outcomes.

It is the hope of the signatories that as outcome measures are validated, and where determined appropriate and feasible, the outcome measures would replace some of the more prescriptive requirements contained in current ALW recommendations which we support in the interim in the absence of appropriate alternatives.

AARP, Alzheimer's Association, American Assited Living Nurses Association, Consumer Consortium on Assisted Living, NCB Development Corporation, National Multiple Sclerosis Society, Pioneer Network

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3) We dissent. We support in principle the intent of the recommendation, however this recommendation goes beyond the mandate to the ALW to focus on recommendations to the states to improve quality in assisted living.

CEAL is premised on federal funding. Senate Special Committee on Aging did not request recommendations for spending on new federal programs.

Rationale for CEAL calls for federal regulation of assisted living; i.e. Members of Congress have a responsibility to develop policies affecting the industry.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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AO.12 Consumer Reports

2/3 Maj. Not Reached

Recommendation

The CEAL should develop models for states to use in producing assisted living consumer reports and a uniform disclosure form that are easy to read and useful. These reports should be developed with input from assisted living stakeholders and the assistance of experts in the field of assessing consumer preferences and information needs when making major decisions affecting consumers' lives.

Implementation

Guideline for Federal and State Policy

Rationale

Using valid scientific research and state of the art marketing research techniques to determine what AL consumers want to know has never been attempted at a national level.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for AO.12

1) We oppose this failed recommendation because it is not appropriate for a private organization structured like the proposed "CEAL" to develop a model consumer report. Our objections to the CEAL concept are more fully set out in our dissent to recommendation AO-01.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to

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Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The undersigned strongly support recommendation AO.12. A crucial part of the ongoing effort to promote quality in assisted living is the development of consumer reports that will help consumers be more informed about quality outcomes in ALRs. A national model for these consumer reports would help consumers to compare ALRs across states.

A key problem in assisted living has been that consumers are often not informed about important information they need in choosing an ALR. The development of a useful, easy to read uniform disclosure form would ensure that consumers are consistently provided the information they need to make informed decisions.

The CEAL, a national body with representation from a balanced group of stakeholders, is the ideal group to develop models for consumer reports and uniform disclosure forms for the states to use.

AARP, Alzheimer's Association, American Assisted Living Nurses Association, Consumer Consortium on Assisted Living, NCB Development Corporation, National Multiple Sclerosis Society, Pioneer Network

3) Oversight for assisted living is and should remain at the state level. Thus, development of assisted living consumer reports should logically be done at the state level.

States are encouraged to research what consumers want to know about an assisted living residence and develop a report that provides that information for use by consumers. Keeping this at the state level will make it possible to create reports that embrace the differences in assisted living from state to state.

National Center for Assisted Living, American Seniors Housing Association

Topic Group Recommendations Adopted by Two-Thirds Majority of the ALW

Affordability

Purpose

Identify recommendations for federal and state policies that will increase the availability of quality affordable assisted living for Medicaid eligible and moderate-income individuals.

Issues

Affordability in assisted living was examined for two groups: (1) Medicaid eligible residents and (2) moderate-income residents (individuals with \$25,000/year income or less).

Affordability discussions were prioritized, starting with the lowest income residents (Medicaid eligible). Issues impacting access to good quality assisted living were identified for each group and discussed. Recommendations for federal and state policy change were developed as necessary.

The topic group divided discussion topics into five categories: service subsidies, housing development and rent subsidies, operational/services affordability, outside issues' impact on consumer's ability to pay, and related issues. Issues related to each category were generated by the topic group and expanded as additional issues arose through topic group discussions, recommendations of the full ALW, or suggestions of outside experts. Some discussion topics resulted in a recommendation, while others were put aside due to lack of agreement or the belief that the topic area was outside of the group's scope.

Participants

The co-chairs were Robert Jenkins, NCB Development Corporation and Joani Latimer, National Association of State Ombudsmen Programs.

Participants included Kathy Angiolillo, Senior Citizens League; Bill Benson and Alice Hedt, National Citizens' Coalition for Nursing Home Reform; Lyn Bentley, National Center for Assisted Living; Colleen Bloom and Doug Pace, American Association of Homes and Services for the Aging; Virginia Dize and Greg Link, National Association for State Units on Aging; Dina Elani, Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century; Toby Edelman, Center for Medicare Advocacy; Jim Gray, NCB Development Corporation Coming Home Program; Bill Harris and Terri Lynch, Consumer Consortium on Assisted Living; Morris Klein and Brian Lindberg, National Association of Elder Law Attorneys; Diane Lifsey, National Council on Aging; Martha Mohler, National Committee To Preserve Social Security and Medicare; Anne Berman, Lisa Newcomb, Ed Sheehy, Katie Smith, and Beth Singley of the Assisted Living Federation of America; Don Redfoot, AARP; Constance Row, American Academy of Home Care Physicians; Amy Sander, Association of State Medicaid Directors; George Taler, MD, American Academy of Home Care Physicians

Affordability

A.01 Consumer Directed Long-Term Care Benefit**Recommendation**

Create new, consumer directed federal long-term care program that includes assisted living and expands service eligibility to meet the needs of people who are not nursing home eligible.

Implementation

Guideline for Federal and State Policy

Rationale

Consumer-directed federal long-term care program: Federal long-term care policy currently favors institutional care over more residential models of care by providing a benefit entitlement only for nursing home care. Assisted living and other forms of home and community-based programs may be funded at the discretion of the states. The institutional bias in federal funding of long-term care goes against consumers' repeated preferences for home and community-based options.

In light of the various disability statutes and the recent Olmstead decision, the federal government and states should move to a long-term care funding system that provides funding in the least restrictive environment possible. To ensure consumer choice, the system should provide consumers the capacity to direct how and where their funding will be spent. This model of consumer directed care could be similar to the Cash and Counseling demonstration program currently being evaluated by HHS.

Expand service eligibility to meet the needs of people who are not nursing home eligible: Many states define nursing home eligibility at a high level of service need. Often, persons with disabilities do not qualify for nursing home care but require significant services and cannot live independently. These people either suffer without required services or depend on family caregivers to fill in the gaps. The quality of life losses to the person with disabilities who forgo services and the economic and health losses (mental and physical) to family caregivers have substantial negative consequences on our communities. A consumer-directed long-term care program would more effectively lessen these impacts if it were targeted to those who have disabilities which are less than those required for nursing home eligibility.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Catholic Health Association of the United States, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Multiple Sclerosis Society, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

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American Assisted Living Nurses Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, American Medical Directors Association, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Association of Home Care Physicians, National Network of Career Nursing Assistants

Supplemental Positions for A.01

1) We dissent. While we support development and implementation of a national long-term care policy that gives individuals with various needs a variety of choices about where and how to receive long-term care services that meet defined standards of care, we object to the mythology about assisted living that pervades the rationale for this recommendation.

We support individuals' right to live in the least restrictive environment possible. We cannot support a statement that implies that all assisted living facilities are always less restrictive than all nursing homes. Without a common and meaningful definition of assisted living, we cannot agree to this conclusion, which is more a statement of faith than a statement of fact.

Moreover, our experience with the Nursing Home Pioneers confirms that many of the features that assisted living proponents claim most fervently for assisted living are in fact features of care that are implemented by Pioneer facilities under standards set by the federal nursing home reform law. We reject the majority's implication that innovation and good practices lie solely with assisted living.

Under current law, individuals have choice about where they will receive their healthcare. Consequently, the second sentence in the second paragraph of the Rationale states nothing unique. The distinction for purposes of these recommendations is that nursing facilities are entitlements under the Medicaid program, while assisted living is not. We also oppose the Cash and Counseling demonstration model, which would convert Medicaid into a "defined contributions" program, rather than a program of "defined benefits."

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long-Term Care Ombudsman Programs, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

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Affordability

A.02 Home and Community Based Waiver**Recommendation**

Continue to expand funding for the 1915(c) Home and Community Based Services waiver program to provide needed services.

Implementation

Guideline for Federal and State Policy

Rationale

The 1915(c) Home and Community Based Services waiver is the primary Medicaid funding vehicle for low-income persons requiring assisted living services. However, in most states, the waiver funding is quite limited and over-subscribed. As an intermediate strategy to a fully implemented consumer directed long-term care program (see Recommendation A.01), the federal government should encourage states to increase their 1915(c) programs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.02
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1) We dissent. We support individuals' right to remain in their homes and communities. However, expanding Medicaid funding of assisted living through home and community-based waivers is not good public policy in the absence of meaningful quality of care standards. In order to be eligible for home and community-based waivers, Medicaid beneficiaries have sufficiently significant health care needs to require a nursing home level of care. Nursing home-eligible individuals should not be placed in assisted living residences that are neither staffed nor otherwise prepared to meet their needs. The majority recommendations do little to guarantee a high quality of care in assisted living

Affordability

residences.

The expansion of waiver funding of assisted living services is also objectionable because other recommendations, specifically objected to below (e.g., A10 and A.20), would dismantle statutory and regulatory protections that Medicaid and HUD have had in place for many years.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

2) We support this recommendation to provide an immediate, short-term solution for funding needed services for assisted living, but continued band-aid approaches such as this will not help to avert a growing crisis in long term care financing. It is important to understand that our current financing system, rooted in the Medicaid welfare program, will not withstand the huge influx of seniors in the coming decades. Therefore, it is imperative that a permanent comprehensive solution for the funding of the entire spectrum of long term care be developed. Research by the health policy experts at Abt Associates indicates that creation of an insurance-based, public/private program offers a viable alternative to today's unsustainable financing system. Additionally, there must be recognition of the need for personal and family responsibility in the planning for future payment of long term care. State and federal governments, in conjunction with providers of care and services, consumers, researchers, actuaries and other stakeholders should meet and develop a strategy to reach a permanent, multi-faceted solution.

Additional research should be done comparing the cost-effectiveness of in-home care services, assisted living care and services and nursing home care and services taking into account acuity levels and cognitive impairment of individuals.

Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Center for Assisted Living, American Seniors Housing Association, American Association of Homes and Services for the Aging

Affordability

A.03 Additional Federal and State Funding for Affordable Assisted Living**Recommendation**

Additional federal and state funding shall be allocated to meet the needs for affordable assisted living.

Implementation

Guideline for Federal and State Policy

Rationale

Individuals with annual incomes below \$25,000 generally cannot afford to pay for assisted living privately. In fact, in 1997, 40% of all people aged 75 and older had incomes below \$10,000 per year. Nearly two-thirds had incomes below \$15,000 (US Bureau of the Census, 1998). Further, demographic projections indicate that by 2035 the number of seniors in this county will nearly double as a share of the population. Demographic factors suggest that the need for affordable assisted living will not only continue but will likely increase. Federal and state funding will need to be increased to meet the need for assisted living for those who are moderate and low-income older seniors. This increased funding will need to combine increased subsidies for housing costs as well as costs for services.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.03

- 1) We dissent. The recommendation vaguely calls for additional public funding for assisted living.

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arguing, in support, only that older people cannot afford to pay privately for assisted living. We cannot endorse such a broad recommendation for public financing of assisted living when the quality standards approved by the majority are so general and illusive.

The workgroup was unable to reach consensus on a definition of assisted living. In addition, most of the recommendations provide only minimal standards for quality of care as well as minimal guidance on affordability. Many of the quality of care recommendations offer considerably less protection to residents than many states' current rules and guidelines for assisted living. States such as Colorado and Maryland, for example, establish additional staffing standards for facilities that are eligible to receive Medicaid reimbursement.

Without adequate quality standards, we cannot support such broad and open-ended public funding. We are particularly concerned that the recommendation could lead to public payment for a level of care that could essentially be nursing homes without quality of care standards.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Affordability

A.04 SSI Payment for Assisted Living

Recommendation

State shall create a specific SSI "living arrangement" category that will provide SSI recipients living in assisted living a payment sufficient to cover the average unit and board costs (including overhead and profit) associated with developing and operating good quality assisted living projects.

Implementation

Guideline for State Regulation

Rationale

While Medicaid can pay for assisted living services for qualified individuals, room and board in assisted living shall be paid out of the individual's income. For many low-income older persons, their income is limited to SSI or an equivalent amount. The unsubsidized development costs for good quality assisted living projects usually exceed what can be supported by rents affordable to an individual at SSI income levels, even in states that offer SSI supplements. Additionally, the development subsidies that can make rents affordable to individuals at an SSI income level (e.g., low-income housing tax credits or other grant programs) are scarce.

In order to allow sufficient affordable assisted living to be developed to serve low-income individuals at SSI income levels, one of two approaches shall be used:

- Increase the development subsidies available to assisted living so rents may be reduced to what is affordable at an SSI income level, or
- Increase individuals' capacity to pay the assisted living rent associated with unsubsidized development costs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

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Affordability

American College of Health Care Administrators, Assisted Living Federation of America, National Association for Regulatory Administration

Supplemental Positions for A.04

None Submitted

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Affordability

A.05 Government Reimbursement for Services and the Cost of Care

Recommendation

Federal and state reimbursement for required and necessary care should meet the cost of care as required by the state defined program and to meet the principles of the Assisted Living Workgroup's definition of assisted living.

Implementation

Guideline for Federal and State Policy

Rationale

Many observers believe that federal and state reimbursements for assisted living services are often lower than the cost of providing high quality care. While the federal government requires that reimbursements be sufficient to provide access to care and to meet the costs of care, the requirement is not implemented forcefully. Rigorous federal and state methodologies should be developed and implemented to test adequacy. Adequacy should be defined as the costs of care and housing as required by the state program where those program requirements meet or exceed the requirements of the ALW. Where state programs do not exceed the standards defined by the Workgroup, the Workgroup's standards should be used to measure adequacy.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.05

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Affordability

1) We dissent because the recommendation would require public payments to meet "the principles of the Assisted Living Workgroup's definition of assisted living."

A state should pay an appropriate amount to meet the state's definition and requirements for assisted living. It should not make payments to meet an undefined set of "principles" that assisted living residences would not have to meet.

The workgroup did not develop a definition of assisted living and the majority's standards for state regulations are weak. The majority essentially permits each assisted living residence to define for itself which services it will provide and how it will provide them. In the absence of a meaningful definition and standards for assisted living, we cannot support a recommendation requiring full payment to provide unspecified services that would not be required.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We support this recommendation but would provide the following clarifying and qualifying statements:

- The state and federal government need to be held accountable for assuring that the payments for services rendered are sufficient to cover the care being provided.
- Providers of services need to have the ability to protect and reject participation if the payments are not sufficient to provide the services rendered.

National Center for Assisted Living, American Association of Homes and Services for the Aging, American Seniors Housing Association

Affordability

A.06 Medicaid Assisted Living Rate Setting Tool**Recommendation**

CMS shall create a model state rate-setting tool for assisted living services. The tool should be adaptable to state specific Medicaid programs as well as state regulatory requirements. The tool shall be designed to estimate the costs for delivering quality services in accordance with best practices operational models and include reasonable returns for providers. Inputs into the model should reflect regional costs through out the state. The model should be used to reassess rates annually.

Implementation

Guideline for Federal and State Policy

Rationale

Assisted living cannot be a long-term care service choice for low-income persons with disabilities if there is not a Medicaid or state funded program available to subsidize the cost of those services. Even with a Medicaid or state funded program, quality assisted living services will not be available to low-income persons if the state reimbursement rates for assisted living do not cover reasonable costs and provide some return to providers.

Currently, states do not have a clear and proven methodology to set assisted living reimbursement rates that reflect the costs and incentives required to allow good quality providers to enter. Furthermore, state rates rarely have a mechanism to adjust rates rapidly in the face of an unusual price spikes. Without adequate reimbursement and the added danger that cost will rise far more rapidly than state reimbursement, existing providers are very unwilling to take on publicly reimbursed residents and investors and lenders refuse to finance new projects. A fair and rational model needs to be developed to establish, implement, and periodically update required rates.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

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Affordability

Assisted Living Federation of America

Supplemental Positions for A.06

1) We dissent. While we support a "model state rate-setting tool for assisted living services," we oppose adjusting Medicaid rates to meet "best practices operational models" because assisted living residences are not required to comply with "best practices operational models." Models are merely suggestions for residence performance. Medicaid rates should be adequate to meet statutory and regulatory requirements. They should not pay for standards that are neither met nor required to be met.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We oppose the specific language in this recommendation and would propose the following: A payment mechanism for services provided should be developed specifically for use with each state's Medicaid waiver program. This system should be developed by the state agency responsible for the Medicaid waiver program in collaboration with providers with input from stakeholders. The payment for services must assure the following:

- The payment is sufficient to cover the quality and quantity demanded by the client.
- The payment allows access to a variety of providers in all geographic locations.
- The payment is competitive in the overall marketplace.

American Association of Homes and Services for the Aging, Catholic Health Association of the United States, National Center for Assisted Living, American Seniors Housing Association

Affordability

A.07 Retroactive Medicaid Payments in Assisted Living**Recommendation**

Like Medicaid benefits for nursing home care, Medicaid waiver benefits for a resident in assisted living should be retroactive to up to three months prior to the month the applicant submitted an application for Medicaid, provided that the resident was medically and financially qualified to receive services under Medicaid and received allowed Medicaid services. Retroactive coverage is not possible in some cases due to interpretations of Olmstead Letter No. 3, Attachment 3-a. CMS should issue a clarification, providing a procedure that protects the intent of Olmstead Letter No. 3, Attachment 3a, while allowing retroactive Medicaid payments for assisted living residents.

Implementation

Guideline for Federal Policy

Rationale

Medicaid benefits are offered to applicants in a nursing home who meet eligibility requirements by the first day of the month for which benefits are sought. Benefits may be also be approved for nursing home residents up to three months prior to the month of application, if the beneficiary was eligible during the "retroactive" period. For applicants requesting Medicaid waiver services, however, Medicaid coverage may not be available back to the month application or the three-month retroactive period. This is because under Olmstead letter No. 3, Attachment 3-a, the earliest date that benefits may be provided is the last date in which the following eligibility requirements have been met: basic Medicaid eligibility, medical level of care, determination that the applicant is in the group covered by the waiver, signature of a written document that the applicant chooses to be in the waiver, and the establishment of a written plan of care. These requirements make it difficult for an applicant to receive benefits as of the date of application or for retroactive periods.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

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Affordability

Organizations Abstaining From the Vote on This Recommendation
American College of Health Care Administrators

Supplemental Positions for A.07

None Submitted

Affordability

A.08 Governmental Subsidies and Resident Income Calculation**Recommendation**

It should be clarified in all federal and state housing and service programs that when determining an individual's eligibility for federal or state housing and/or services programs, subsidies for one should not be counted as income for the other.

Implementation

Guideline for Federal and State Policy

Rationale

In order for assisted living to be available to people with low-income, significant subsidies are required from multiple sources, including federal, state, and local governments. Under current regulations, the eligibility criteria for one program often requires counting subsidies from other programs as "income," thereby nullifying the benefits of those other programs, and making it impossible for a person to get the care he or she needs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Gerontological Society, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Association of Home Care, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants

Supplemental Positions for A.08
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None Submitted

Affordability

**A.09 Tenant Service Payment and Housing Subsidy
Income Calculations****Recommendation**

When an individual seeking admission to a subsidized housing program licensed as assisted living (or its equivalent) will pay privately for services, the amount that he/she will pay for services (e.g., health care, personal care, meals, home maker, transportation, activities) should be deducted from the resident's income before calculating eligibility for federal and state housing subsidy programs (e.g., tax credits, Section 8, HOME) and the resident's contribution toward rent.

Implementation

Guideline for Federal and State Policy

Rationale

Many individuals require services to avoid institutionalization in a nursing home. Often, an individual's income will be greater than what allows him or her to qualify for a housing subsidy program but insufficient to pay for necessary services and housing. In order to assist lower-income individuals to qualify for a residential setting, the service costs to be paid by a resident should be deducted from the resident's income before his/her financial eligibility and rent contribution are calculated.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Gerontological Society, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Association for Regulatory Administration, National Association of Home Care, National Committee to Preserve Social Security and Medicare

Supplemental Positions for A.09

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Affordability

None Submitted

Affordability

A.10 Medicaid Program Rules: Family Contributions and Room and Board Maximums**Recommendation**

When an assisted living resident receives Medicaid support, family or other private contributions paid directly to a provider for additional services or amenities which are not covered by Medicaid should not be counted as income to the resident for the purpose of calculating Medicaid eligibility. A provider shall accept Medicaid payment, plus applicable beneficiary deductibles, as payment in full for all Medicaid covered services provided to those residents the provider has agreed to serve under the program.

States should set the maximum amount that providers participating in the Medicaid program may charge Medicaid residents for room and board. States shall establish maintenance allowances that permit residents to retain sufficient income to pay for room and board and personal expenses. States shall provide room and board subsidies for Medicaid eligible residents whose income is less than what is established by the state as a room and board payment amount.

The maximum room and board amount shall be established with stakeholder input and calculated to cover the reasonable costs of providing room and board as defined by the ALW recommendations without the assumption of housing or other subsidies. In cases where states do not require private rooms as recommended by the ALW, and the resident nonetheless desires a private room, states shall establish a reasonable maximum for such rooms and shall adjust the maintenance allowance to pay for it. Family or other private contributions should be permitted for any reasonable room and board costs not covered by subsidies and should not be counted as income to the resident for the purpose of calculating Medicaid eligibility.

Implementation

Guideline for Federal and State Policy

Rationale

Many residents of assisted living utilizing a Medicaid program may benefit from services or amenities available to them but not covered by Medicaid. These additional services and options are often beyond their ability to afford. In some instances, families of residents (or others) are willing to pay for these additional, non-Medicaid services or amenities. If direct payments from families (or others) to an ALR or other provider are counted as income to the resident, the added income could disqualify the resident for Medicaid. In order to allow a resident to benefit from additional, non-Medicaid reimbursed services or amenities, payments made by a family member, other person, or organization directly to a provider should not be counted as income to the resident for the purpose of Medicaid program eligibility determination.

By definition, Medicaid-eligible residents have almost no savings, and very limited incomes. To assure that all Medicaid recipients can afford room and board, states should set a maximum amount that a provider may charge residents participating in the Medicaid program and should establish a maintenance allowance that permits residents to pay for

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room and board and personal expenses. To ensure participation by providers and access to services by those residents participating in the Medicaid program, the maximum room and board amount should be based on the fair market costs, including an appropriate profit, of providing room and board services (as defined by the ALW). States should not factor in limited subsidy programs (e.g., low-income tax credits, Housing Choice Vouchers, etc.) when calculating the payment amount if these programs will not be available in sufficient quantity to meet the demand for assisted living by Medicaid eligible residents. States should provide a subsidy program (e.g., a supplemental payment to SSI) to allow individuals eligible for Medicaid assisted living services, but with incomes less than the established room and board payment standard, to pay the room and board charges while retaining an amount established for personal needs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Seniors Housing Association

Supplemental Positions for A.10

1) We dissent. Although this recommendation contains several important protections, what is missing is a clear statement that "[t]he amount charged by an assisted living residence for room and board must not exceed the amount of income allocated to the resident by the Medicaid program." We proposed and supported such language, but it was not adopted by the majority.

By definition, Medicaid-eligible residents have almost no savings, and very limited incomes. Medicaid programs allow Medicaid-eligible residents to retain only a certain amount of income each month. For Medicaid-reimbursed assisted living to be affordable to Medicaid-eligible individuals, an assisted living residence's room and board charge must not exceed the resident's income allocation.

Room and board in an assisted living residence is not covered by Medicaid, and thus is not covered by the recommendation's requirement that an assisted living residence accept Medicaid

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reimbursement as payment in full for "Medicaid covered services." For assisted living truly to be affordable for Medicaid beneficiaries, the assisted living residence must be required to set the room and board charge at an amount that is no more than the resident's income allocation set by the Medicaid program.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long-Term Care Ombudsman Programs, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

2) When the payment is not sufficient to cover the room and board services, providers must maintain the right to determine whether they are able to accept or retain the residents. Requirements or limitations should not be developed that would limit or restrict family or other private supplementation.

American College of Health Care Administrators, National Center for Assisted Living, American Seniors Housing Association

Affordability

A.11 Third Party Service Payments and Housing Subsidy Income Calculations

Recommendation

When determining an individual's eligibility and rent contribution for a state or federal housing subsidy program, payments made by a private, third party (e.g., family member, charity, or non-governmental entity) to a provider for care services (e.g., health care, personal care, meals, home maker, transportation, activities) should not be considered income to that individual for the purposes of federal and state housing subsidy eligibility determination or rent contribution calculations. (E.g., tax credits, Housing Choice Vouchers/Section 8, HOME).

Implementation

Guideline for Federal and State Policy

Rationale

Individuals living in government-subsidized housing are low-income. When they need services to avoid institutionalization, they often need financial assistance to pay for those services. Public subsidies for services may be insufficient or unavailable, necessitating family and/or private charitable assistance to pay for services. However, it is not always clear whether family or charitable contributions to a resident's care shall be counted as resident income for the purpose of calculating eligibility for housing subsidy programs. If service payments from family or charities are counted as income, they may have the consequence of raising the resident's rental payments or disqualifying the resident altogether for the housing that they have made their home and hope to remain in through the use of services. Clarification is needed in all federal and state housing programs that service payments from family or other private sources that are paid directly to providers should not be counted as income to the resident for the purpose of calculating that individual's eligibility for the housing program or his/her rent contribution.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Gerontological Society, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of

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Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Adult Family Care Organization, National Association of Home Care

Supplemental Positions for A.11
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1) We dissent. We agree that public payments for assisted living must be sufficient to pay for the services or housing that they are intended to cover. However, we strongly oppose allowing supplementation from families or other third parties, which this recommendation would permit.

The language of the recommendation allows payments by third parties for a broad range of services. It does not limit these payments in any way. We infer from the language of the Rationale – that “public subsidies for services may be insufficient or unavailable” [emphasis supplied] – that private payments would be permitted to supplement public payments for covered services. We object to such supplementation. The Medicaid program requires health care providers to accept the Medicaid rate as payment in full for covered services and prohibits facilities from requesting or accepting additional payments (i.e., supplementation) from family members or other third parties. Individuals choosing assisted living should not have to give up financial protections for residents and their families that the Medicaid program provides for any other Medicaid-funded service, including nursing home care.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Affordability

A.12 Medicare & Medicaid Physician House Call Payments in Assisted Living**Recommendation**

CMS and State Medicaid agencies should increase access to house calls by physicians for assisted living residents by updating their definition of assisted living and raising payments for house calls to assisted living residents.

Implementation

Guideline for Federal and State Policy

Rationale

Physician house calls to ALR residents are beneficial for many reasons, among them:

1. Allowing physicians to observe the resident in their home environment
2. Ease and cost to ALR and residents
3. Improving lines of communication between physician and ALR staff
4. Decreasing risk to cognitively impaired residents by not moving them from their structured environment

Assisted living residents may enter an assisted living residence with, or develop, functional impairments and chronic diseases that require active medical care management. It is difficult for many residents to travel to physicians' offices. Medicare and Medicaid house call reimbursements are currently inadequate to enable physicians to make house calls in assisted living.

Medicare residents living in their private homes have access to physician house call services. This is because of changes made to the Medicare fee schedule in 1998 that made provision of service economically feasible. To facilitate access to appropriate medical care in assisted living residences, Medicare and Medicaid should establish adequate definitions and reimbursement rates for assisted living. Assisted living currently falls under the Medicare definition for domiciliary care, CPT codes 99321-99333. For similar services in private homes, physicians can bill under Medicare house call codes 99341-99350.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

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Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen,
National Association for Regulatory Administration, National Association of Social Workers,
National Association of State Ombudsman Programs, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National
Committee to Preserve Social Security and Medicare

Supplemental Positions for A.12

None Submitted

Affordability

A.13 Transportation**Recommendation**

Federal and state programs subsidizing assisted living services shall include accessible transportation services for personal and medical needs as a required service within the basic rate. Providers may provide or contract for transportation services.

Implementation

Guideline for Federal and State Policy

Rationale

Transportation is a critical need in affordable assisted living. Without transportation services, residents can not get to medical appointments, shop for personal needs, or maintain community or cultural contacts. Transportation costs are often not included in publicly subsidized service packages in assisted living and may not be available through other subsidies. Including them in basic assisted living packages, with appropriate reimbursement, will assure that publicly subsidized residents have access to transportation for medical, personal, and social needs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudaman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, American Seniors Housing Association, National Association for Regulatory Administration

Supplemental Positions for A.13
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None Submitted

Affordability

A.14 HUD and HHS Collaboration to Deliver Affordable Assisted Living
Recommendation

HUD and HHS should collaborate to craft and fund specific programs to blend housing and service subsidies to enable low-income persons to have access to high quality, affordable assisted living projects.

Implementation

Guideline for Federal Policy

Rationale

Assisted living is a unique model of residentially based long-term care services for frail and cognitively impaired persons. Assisted living requires a distinct combination of physical amenities and service programs to operate successfully. To serve low-income older persons, an affordable assisted living project will typically combine a variety of federally funded housing and services programs. Negotiating these programs is complex and there are areas where they either do not work together well or one is insufficient. Collaboration by HUD and HHS to enable programs within their respective jurisdictions to work better to fund assisted living would remove obstacles, encourage provider participation in affordable assisted living programs, and maximize the efficiency of limited public resources. Among the issues discussed by HUD and HHS should be income and asset related eligibility standards.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of State Ombudsman Programs

Organizations Abstaining From the Vote on This Recommendation

National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

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1) We support collaboration by HUD and HHS to develop and fund programs that combine housing and services for low-income people. We object to the first two sentences of the Rationale. The assisted living workgroup was unable to reach consensus on a definition of assisted living and the majority's recommendations do little to explain what assisted living facilities can and cannot do. As a consequence, it is inaccurate and misleading to say, as these sentences do, that assisted living is a "unique" type of residential living or long-term care or that there is any "distinct combination" of amenities and services that defines assisted living.

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy ,
National Association for Regulatory Administration, National Citizens' Coalition for
Nursing Home Reform , National Committee to Preserve Social Security and
Medicare , National Senior Citizens Law Center*

Affordability

A.15 Federal Housing Subsidy Programs and Assisted Living**Recommendation**

Federal housing subsidy programs, both tenant based and project based, should not change their occupancy standards or requirements for amenities when they are used for assisted living.

Implementation

Guideline for Federal Policy

Rationale

This recommendation seeks to clarify the principle that occupancy standards governing federal housing programs should not be waived simply because the person receiving the housing subsidy has a disability. Occupancy standards for housing subsidy programs, including those administered by HUD, the Rural Housing Administration, and the Internal Revenue Service (the tax credit program) generally require that housing units under their jurisdictions provide units that are shared only by choice. Often, shared units are for married couples or siblings. Rules already clarify that a caregiver may also share the unit. Further clarification will be needed in circumstances where couples are same sex, unmarried, or the resident desires a roommate.

Similarly, occupancy standards also cover the amenities, such as kitchens and bathrooms required for the recipients of housing subsidies. The recommendation clarifies that these requirements should not be waived in those housing projects offering assisted living services. These agencies may need to issue further clarification regarding circumstances under which stoves or other equipment may be disconnected for safety reasons.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

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Assisted Living Federation of America

Supplemental Positions for A.15

None Submitted

Affordability

A.16 Federal Housing Subsidies and the Cost of Common Facilities in Assisted Living**Recommendation**

Federal housing assistance programs, both tenant and project based, should recognize the cost of common areas and service delivery support areas for assisted living. Subsidy amounts (e.g., HUD vouchers payment standards/fair market rents, operational subsidies, etc.) available to assisted living projects should be adjusted to reflect these additional costs.

Implementation

Guideline for Federal Policy

Rationale

Assisted living programs provide long-term supportive services to frail and cognitively impaired individuals in a residential environment. In order to provide these services (including socialization for isolated persons) in a safe, effective, and economical way, assisted living projects require certain common areas, support spaces, and security systems that exceed those required in independent living projects. Often these requirements are state mandated. These additional requirements may include an activity room(s), dining room, commercial kitchen, bathing room, medication storage room, clinics, staff offices, housekeeping room, interior circulation, resident wandering prevention systems, added life safety systems and standards, etc.

All of these additional elements add to the cost of construction and operations. However, federal housing assistance programs currently available to assisted living residents are designed primarily for independent housing and are not structured to factor in these additional costs. The lack of specific housing programs, or specific rates within housing programs, designed to meet assisted living's cost structure often makes affordable assisted living projects infeasible to develop or operate. Federal housing subsidy rates should be adjusted for assisted living in order to make affordable assisted living a readily available option for persons needing residentially based long-term care.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association for Regulatory Administration, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Center for Medicare Advocacy

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Organizations Abstaining From the Vote on This Recommendation

National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Supplemental Positions for A.16

None Submitted

Affordability

A.17 HUD Assisted Living Conversion Program**Recommendation**

Continue HUD assisted living conversion program (ALCP). Continue to provide federal funding to pay for structural conversion costs within the HUD budget. However, provide a line item for conversion costs separate from the 202 budget line item to eliminate confusion regarding increases/decreases in 202 construction funding.

Implementation

Guideline for Federal Policy

Rationale

The HUD ALCP program offers tremendous promise to bring needed services and physical amenities to existing projects where residents have aged-in-place and are in jeopardy of having to move to institutional care. It has gotten off to a slow start because of the complexity of combining services and housing programs, but it is now building momentum. The program should be continued at current funding levels to provide it a full opportunity to demonstrate its value.

The funding for the program should, however, be provided in a separate line item from the HUD Section 202 budget line item in order to avoid confusion about the relative increases or decreases in the Section 202 construction funding budget.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Committee to Preserve Social Security and Medicare, National Adult Family Care Organization, National Conference of Gerontological Nurse Practitioners, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.17
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Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Affordability**

1) We dissent. The HUD assisted living conversion program should not be continued in the absence of meaningful and enforceable standards for assisted living residences that HUD conversions would support. Federal money should be restricted to residences that meet specific standards that address, at a minimum, staffing ratios and qualifications, participation by health care professionals, and life safety code. Federal money should also be limited to private units, as described in the defeated recommendation A.27 (private units, including, at a minimum, a private toilet with lavatory and shower or tub, and a kitchenette with sink).

The majority's recommendations inadequately describe standards of care for assisted living residences. They do little more than identify areas where guidance for regulatory standards is important; they frequently fail to provide any specific guidance. The result is many recommendations that are meaningless and content-free (e.g., O.02 (National Fire Protection Association Requirements), O.06 (Food and Nutrition), M.07 (Medication Assistive Personnel job description), D.07 (Hospice Care)).

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long-Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Affordability

A.18 Assisted Living Conversion Program for Public Housing**Recommendation**

Congress should enact a comprehensive program for funding the conversion of public housing projects for older persons to assisted living. Such a program should include: a) capital funds for construction, modernization, and modifications; b) service coordinators and other management and maintenance personnel; and c) enhanced congregate housing funds for services in public and federally assisted housing not usually funded under Medicaid and other services programs.

Implementation

Guideline for Federal Policy

Rationale

Public housing provides shelter to more older persons than any other federal project-based housing program. In addition, many public housing projects for the elderly also house large numbers of younger persons with disabilities. The residents in public housing projects tend to have lower incomes than other housing programs. Many of the buildings have large numbers of efficiency units that have been difficult to rent as regular apartments. Such projects can be good candidates for conversion to assisted living, either in whole or in part.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, National Adult Family Care Organization, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare

Supplemental Positions for A.18

Note Deleted

Affordability

A.19 Affordable Assisted Living Demonstrations in Subsidized Housing**Recommendation**

Create affordable assisted living demonstrations in subsidized housing for residents who can no longer reside safely in their current living environment, meet Medicaid financial eligibility standards, but do not meet Medicaid nursing home level of care criteria.

Implementation

Guideline for Federal and State Policy

Rationale

Many people living in subsidized housing have aged-in-place. Often these residents are just barely hanging onto their independence through a combination of self-denial, formal, and informal care. The subsidized housing communities are often ideal candidates for full or partial conversion to affordable assisted living due to their populations' care and economic needs, the concentration of need, and the adaptable environments they offer.

While many or most of the residents meet Medicaid financial eligibility standards, some do not meet the state's Medicaid nursing home level of care criteria. For disabled residents, both those who do and do not meet Medicaid care eligibility standards, the lack of an assisted living program often means displacement. An assisted living demonstration would collect valuable information to inform the discussion regarding what programs are required to avoid displacement, the individual and community benefits of preventing displacement, and the costs and cost savings associated with preventing displacement for both Medicaid eligible and service needy, but ineligible, residents.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, National Adult Family Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

National Network of Career Nursing Assistants

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Affordability****Supplemental Positions for A.19**

1) We dissent. Many programs already bring additional services to tenants of subsidized housing. In the absence of a meaningful definition of assisted living, it is not clear what "assisted living" services are contemplated by this recommendation that are not already and otherwise available.

As stated earlier in our dissent to A.01, we, of course, support development and implementation of a national long-term care policy that gives individuals (with various needs) a variety of choices about where and how to receive long-term care services that meet defined standards of care commensurate with assessed level of need.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Affordability

A.20 HUD Housing Choice Voucher Rules in Assisted Living**Recommendation**

HUD shall modify existing program requirements of Section 8 Housing Choice Vouchers in order for them to become more compatible for use in assisted living residences. Specifically, HUD needs to:

- a. **HAP Contract and Services:** Amend the HAP contract to allow assisted living providers to require service participation and service payment (as required for other residents in the ALR), outside of the rent contract, as a condition of tenancy by modifying Part C Section 6b.
- b. **Maximum Resident Contribution:** For residents receiving Medicaid waiver funding, immediately amend the Section 8 rule that limits a resident's payment for rent from a maximum of 40% to 65% of his/her income.
- c. **Resident Contribution Study:** Conduct a study within the next two years to determine what the appropriate maximum resident contribution for rent should be in assisted living and adjust the Section 8 rules as appropriate when that percentage of income is determined. Residents who use Section 8 to rent an assisted living unit under the temporary 65% rule may continue to pay the percentage of their income established under that temporary rule as long as they continue to reside in the unit or program where they lived at the time of a new maximum contribution rule was established by HUD.
- d. **Third Party Contributions:** For purposes of facilitating use of vouchers in assisted living settings, HUD should issue a formal position and/or policy clarification stating that financial contributions toward Assisted Living services from family members and other third parties are not considered as income.
- e. **Section 8 Assisted Living Designation:** States and local housing authorities should be encouraged to designate a portion of Housing Choice Vouchers specifically to assisted living, including project based vouchers and/or a set aside for emergency use.

Implementation

Guideline for Federal Policy

Rationale**HAP Contract and Services**

The Housing Choice Voucher Program (formerly known as Section 8 Tenant Based Rental Assistance) provides eligible low-income American with a method of obtaining affordable housing. It helps families lease privately owned rental units from participating landlords. The vouchers are generally administered by the local public housing authority or other public entity.

The Housing Assistance Payments (HAP) Contract is a mandatory agreement between the public housing agency and the owner of a unit occupied by an assisted family when the Housing Choice Voucher is utilized. Part C, the Tenancy Addendum to the HAP Contract,

Affordability

contains language that has caused some assisted living homes to decline to participate in the Housing Choice Voucher program. Part C, Section 6b reads as follows: "The owner may not require the tenant or family members to pay charges for any meals or supportive services or furniture which may be provided by the owner. Nonpayment of any such charges is not grounds for termination of tenancy." Similar language is included in a HUD Notice issued in 2000 to address the use of Housing Choice vouchers in assisted living. This policy may have arisen to discourage mandatory meal programs in independent senior housing, a common practice in the 1980's.

Some assisted living home administrators fear that if they accept somebody using a Housing Choice Voucher, the person could refuse to pay for their meals or services, which may be required by state statutes and/or regulations or required to maintain the viability of an assisted living service program. This could potentially create a financial and regulatory challenge for the administrator.

Vouchers are not yet widely used in assisted living, however it is a worthy part of the puzzle for providers attempting to cobble together assisted living programs affordable to very low- income persons. Voucher holders are required to spend a portion of their income on rent; services and meals cannot be paid for using Section 8 funds.

Maximum Resident Contribution

The HUD Housing Choice Voucher (Section 8) currently requires eligible recipients to contribute thirty percent of their income to their rent payment, with the HUD Housing Choice Voucher (Section 8) paying the difference between their contribution and HUD's established Fair Market Rent (FMR) for their unit type and location. If the FMR payment rate is insufficient to pay for a unit, the resident may currently supplement the voucher payment with up to an additional ten percent of his/her income. To maximize a resident's choice in selecting an assisted living residence in the next two years, HUD should temporarily raise the Section 8 forty percent rule for assisted living residents to sixty-five percent. This is the percentage of income that is allowed for rent (and any services included in the rent) under the Senator Dodd's proposed assisted living tax credit bill S1886.

Resident Contribution Study

During the two year temporary increase, HUD shall study how much income a resident in assisted living needs to maintain for other needs and establish a revised maximum rent contribution for residents in assisted living as necessary. In order to allow residents and providers to make informed decisions during the temporary 65% rule, any new cap implemented by HUD shall grandfather the 65% Section 8 voucher rules for those residents and providers enrolled during the temporary contribution period.

Family Contributions

Assisted living services are required to support the needs of many low-income residents eligible for Section 8. Some of these eligible residents will receive family support to pay for assisted living services as allowed by Medicaid or when they cannot access or utilize Medicaid funding. Family contributions together with the Section 8 subsidy often allow a resident to piece together enough resources to cover the room, board, and services charges

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in assisted living. If the family contribution for services counts as income, the resident's income available for service and food payments will be reduced, and in the worst case, their Section 8 subsidy will be revoked. This works against the public's and the resident's interests by making assisted living more difficult to afford, potentially eliminating a residential alternative to institutional care for these residents.

Section 8 Assisted Living Designation

Due to governmental subsidy structures, persons with low-incomes may require a Section 8 voucher to afford the rental component of assisted living charges. To prevent persons from going without needed services or from being placed in a nursing home unnecessarily, Section 8 certificates shall be available when the person's need arises. Because this need often develops from an unpredictable crisis, Section 8 vouchers shall be available without a waiting list. To accomplish this, a Section 8 set aside should be established for individuals who need assisted living services.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Adult Family Care Organization, National Association of Social Workers

Supplemental Positions for A.20
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1) We dissent. This recommendation dismantles protections that HUD has had in place for tenants for many years, particularly in its discussion of the Maximum Rental Contribution (#b and #c). The recommendation immediately increases the amount of income that a tenant could be required to pay for a housing subsidy from 40% of his/her income to 65%. The recommendation then calls for a study to determine the appropriate percentage of income to be contributed to rent but says that if the study finds that a percentage lower than 65% is found to be appropriate, tenants admitted under the 65% rule would nevertheless be required to continue paying the 65%. We object to (1) raising the percentage ceiling from 40% to 65% before conducting a study; and (2) continuing the 65% contribution rate for tenants admitted under the 65% rule if the HUD study determines that a lower

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percentage would be appropriate.

We also strongly object to the family contributions (#d) authorized by this recommendation. The recommendation calls for modification of the HAP contract to permit housing providers to require service participation as a condition of tenancy. Residents without sufficient income to pay for services, and ineligible for Medicaid or unable to use Medicaid, would have no choice but to use family contributions. The recommendation recognizes residents' need to rely on family supplementation and provides that family contributions would not count as income to the resident. We support having public payment be sufficient to pay for assisted living. We do not support government subsidies to programs and entities that rely on family supplementation.

By way of contrast to this recommendation, the Medicaid program requires health care providers to accept the Medicaid rate as payment in full for covered services and prohibits facilities from requesting or accepting additional payments (i.e., supplementation) from family members or other third parties. Individuals choosing assisted living should not have to give up financial protections for residents and their families that the Medicaid program provides for residents of other residential long term care settings such as nursing homes.

While we do not oppose some revisions to the HAP Contract and Services, the recommendation (#a) includes no limitations on what level of participation and payment a HUD provider could demand with respect to services. Although we understand the majority to argue that a hallmark of assisted living is residents' ability to pick and choose the services they want and will purchase, the language of the recommendation appears to give unlimited control to the assisted living residence.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

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A.21 LIHTC QAP & Set Aside for Affordable Assisted Living**Recommendation**

State agencies administering the current 9% low-income housing tax credit program (LIHTC) should review their qualified allocation plan and eliminate any barriers it contains that will prevent AL from achieving a competitive score. To promote the development of affordable assisted living serving the lowest-income, state agencies should create a set-aside for affordable assisted living programs serving Medicaid eligible residents. The amount of the tax credit set-aside should be designed to meet the identified needs for affordable assisted living. Non-profit assisted living projects that do not receive funding under the assisted living set aside should be allowed to compete in the general non-profit set-aside.

Implementation

Guideline for State Policy

Rationale

LIHTCs are a primary resource in creating affordable assisted living, providing substantial and difficult to obtain capital investment. LIHTCs allow a project to reduce or eliminate project debt, providing a project subsidy that reduces rent to a level affordable to persons with low-incomes. Without access to LIHTC, it is very difficult to develop a project to serve persons with income at or near SSI payments.

Assisted Living programs often have difficulty competing for LIHTC due to state qualified allocation plan (QAP) scoring systems. States revise their QAPs each year and may choose to recalibrate the scoring system. The QAP in each state should be reviewed and modified to allow assisted living to score in a competitive range with all other projects. More over, to encourage the development of assisted living that serves residents with the lowest incomes, state agencies should provide a LIHTC set-aside for assisted living. A set-aside establishes a pool of tax credits that may only be awarded to a project meeting the set aside guidelines. Set-asides encourage people to submit applications for projects conforming to the guidelines because competition is reduced and is limited to like projects, eliminating scoring advantages of particular project types. Set-aside funds that are not utilized are returned to the general LIHTC pool.

In at least one state that created an assisted living set-aside, the QAP provided that assisted living projects (non-profit and for-profit) would compete against each other in for the set-aside and those not chosen would automatically compete in the more competitive for-profit category. This effectively limited assisted living tax credit funding for non-profits to one project per year. Because of the great need for assisted living that is affordable to those with the lowest-incomes, non-profits should be allowed to compete in the less competitive assisted living and non-profit set-asides.

Organizations Supporting This Recommendation

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AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, National Adult Family Care Organization, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare

Supplemental Positions for A.21

None Submitted

Affordability

A.22 Assisted Living Tax Credit**Recommendation**

Create a special low-income housing tax credit (LIHTC) for assisted living. Incorporate the following provisions:

- Create program guidelines that specifically acknowledge and allow for the health care and service component of assisted living.
- Create a higher credit amount for assisted living (providing a higher tax credit calculated on the qualified basis).
- Provide for a shorter-term compliance period for investors to mitigate the long-term Medicaid and market risks.

Allocate tax credits outside of the current caps in order to avoid competition with other housing options and provide sufficient credits to develop the volume of affordable assisted living required to serve the demand. New tax credit allocations could be set based on projected budget savings from nursing home diversions.

Implementation

Guideline for Federal Policy

Rationale

The current LIHTC program does not fit assisted living well. Investors and underwriters are uncertain about program compliance due to health care services provided. They are also concerned about the stability of Medicaid funding source and the long-term business risks Medicaid funding creates. Both of these issues raise the risk of a project default, potentially resulting in severe financial consequences for investors. For the LIHTC program to attract investors to assisted living credits, a new program needs to be structured to account for the qualities and risks of assisted living. These changes are required in order to attract investors to assisted living and deliver adequate subsidy to the project after investors discount the credits for assisted living's operational risk.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform.

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National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center
Organizations Abstaining From the Vote on This Recommendation
 None

Supplemental Positions for A.22
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1) We dissent. This recommendation is focused on making affordable assisted living as risk-free and financially advantageous for developers as possible. While we recognize that affordable assisted living will not be built unless developers are willing to build it, we cannot support a recommendation that focuses exclusively on developers' desire to avoid financial risk and that puts developers' interests in safe profits over Medicaid beneficiaries' need for housing and health care.

This recommendation creates an enhanced tax credit for developers of assisted living (second bullet) and shortens the time period for developers' obligation to provide housing to poor people (third bullet). Specifically, this recommendation would allow developers of assisted living to get more financial benefit, while providing less service, than developers of other types of low-income housing. Consequently, the enhanced tax credits supported by this recommendation would not result in the development of a meaningful amount of affordable assisted living. Assisted living developers would essentially be receiving higher tax credits for providing less service.

In addition, there would be no quality control over the assisted living built with this enhanced tax credit. The majority's general recommendations for quality standards for assisted living residences are weak and minimal. This recommendation includes no additional or more specific quality standards that assisted living residences would be required to meet in order to qualify for enhanced low-income housing tax credits. As a result, this recommendation would encourage the development of assisted living residences of dubious quality.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Long-Term Care Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

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A.23 Advisory Boards for Government Initiative in Affordable Assisted Living

Recommendation

State or Federal Agencies should place priority on designing affordable assisted living initiatives. Governments shall have an inclusive advisory board (e.g., consumers, advocates, providers, and related professionals) working with the agency throughout the process. Affordable assisted living initiatives include, but are not limited to, regulations, waiver programs, and state plan services.

Implementation

Guideline for Federal and State Policy

Rationale

State and federal programs impacting or providing assisted living are often constructed without consumer, provider, and advocate input throughout the process. The programs often meet with significant opposition when released for public comment due to the lack of public input during the design period. The late stage modifications brought about during the public comment period often lead to awkward compromises, providing convoluted or imperfect remedies to a program's structural deficits. State and federal programs would benefit from consumer, provider, and advocates input from the start of program design in order to craft rational systems meeting all stakeholders' needs.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Association for Regulatory Administration, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.23

None Submitted

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Affordability

A.24 Aging Network Funding for Training**Recommendation**

Provide federal and state funding to develop and support ongoing training for staff of the Aging Network who provide information and assistance to consumers about choices and decisions regarding assisted living and other long-term care options. At a minimum, training should include: information about what housing and services options are available, eligibility requirements for programs available to assist with the costs of assisted living, the assistance available to pay for services, and other referral resources available in the community that can assist with decision-making.

Implementation

Guideline for Federal and State Policy

Rationale

Assisted Living is an important component of the long-term care system and may become an option or necessity for many consumers during their lifetime. It is imperative, therefore, that potential consumers seeking information about long-term care including assisted living, obtain it from persons or entities that are knowledgeable about what options are available to consumers, the basic eligibility requirements of the programs that are in existence to offer assistance with the costs of assisted living, and the possible avenues a consumer may explore when considering assisted living.

Staff who receive training and regular updates on this information will be a valuable resource to both consumers and their representatives as well as to the network of assisted living programs and services in the state or community in which they are located. Trained staff can help prevent misconceptions about what programs are available and the eligibility requirements of those programs and can also assure that programs and services are represented accurately to consumers and their families.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

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Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Adult Family Care Organization,

Supplemental Positions for A.24

None Submitted

Affordability

A.25 Paper Work Burden of Governmental Programs in Assisted Living**Recommendation**

Governmental agencies providing support to affordable assisted living projects should develop unified reporting documents and procedures where appropriate to reduce the paperwork burden on projects.

Implementation

Guideline for Federal and State Policy

Rationale

Governmental programs, whether state or federal, providing financial assistance to assisted living facilities and for services provided, frequently require separate and often duplicative paperwork and reporting requirements. Because of the burden of completing multiple reports and multiple monitoring requirements, assisted living projects are often reluctant to participate in programs that promote affordable assisted living.

All programs should work together to develop and require uniform and streamlined reporting and monitoring processes so as to eliminate duplication and promote information sharing to the extent permissible.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Gerontological Society, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Association for Regulatory Administration, National Association of Home Care, Association of Health Facility Survey Agencies

Supplemental Positions for A.25
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Affordability

A.26 Food Stamps Usage in Assisted Living**Recommendation**

USDA should provide clarification and guidance to their field offices stating that food stamps may be used by income eligible households residing in assisted living to purchase meals prepared by the assisted living residence and served in a communal area. If a change in the Food Stamp Act is required to provide this guidance, Congress should amend the Act as required.

Implementation

Guideline for Federal Policy

Rationale

Assisted living is housing with services. Low-income residents in assisted living often do not have sufficient income to pay the operator for rent and prepared meals, yet they need the prepared meals to maintain their health and functioning. Food stamps can and do play a critical role in subsidizing meals for low-income assisted living residents in some states. Unfortunately, USDA field office interpretations vary on whether income eligible assisted living residents are eligible "households" and if they are, whether they may use food stamps to purchase meals prepared by the residence. USDA should clarify at the national level that income eligible assisted living residents qualify to receive food stamps and that the food stamps may be used to purchase meal prepared by the ALR and served in a communal setting. If USDA feels that a change in the Act is required to allow food stamps to be used by income qualified assisted living residents, USDA should seek the required changes to the Act.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

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Affordability

Supplemental Positions for A.26

1) We oppose this recommendation. In general, people who live in nursing homes and similar facilities where meals are provided by the facility are not eligible to participate in the food stamp program. 7 C.F.R. §273.1(b)(6). We do not support creating an exception in federal law for assisted living, particularly given the nebulous definition and weak recommendations set forth in the report.

We do support assisted living residents being able to use Food Stamps to purchase food that they cook and consume in their private units. However, assisted living residences should not deny residents congregate meals or discourage residents from eating congregate meals or pressure residents into using Food Stamps and preparing their own food when they can no longer do so.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long-Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The undersigned strongly support Affordability Recommendation A.06 as written for the following reasons:

- Many states have programs that will pay for assisted living services. However, the state subsidies generally do not cover raw food costs or rent (e.g., Medicaid waiver programs).
- Rent and food costs for low-income people must generally be covered out of a resident's SSI payment. SSI payments are almost always insufficient to pay rent costs alone unless a project has received very substantial development subsidies, subsidies that are available to very few projects.
- Even with very substantial development subsidies, rent charges necessary to support the project's debt and on-going costs (e.g., utilities, maintenance) often leave the residents with less income than is required to pay for the raw food costs.
- Food stamps can play an important role in subsidizing the raw food costs for residents without sufficient income to meet rent and food costs.
- Clarification is needed for the current USDA interpretation of assisted living as an "institutional" setting (residents of institutions are not eligible for food stamps) and whether certain categorical eligibility provisions for food stamp recipients override the institutional prohibition.

USDA clarification of current assisted living residents' eligibility for food stamps and, as required, rule or legislative changes to allow assisted living residents to qualify for food stamp assistance would provide much needed assistance to low-income residents and put assisted living on the same footing as other residential options for older persons.

AARP, Consumer Consortium on Assisted Living, NCB Development Corporation, National Center for Assisted Living, National Multiple Sclerosis Society

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority***

Affordability

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not show a voting record were unable to reach two-thirds majority during the development process.

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Affordability

A.27 Federal Development Subsidies and Private Units 2/3 Maj. Not Reached**Recommendation**

Federal programs subsidizing assisted living new construction or conversion should require private units, including, at a minimum, a private toilet with lavatory and shower or tub, and a kitchenette with sink. Subsidy amounts should be sufficient to pay for the private unit requirement.

Implementation

Guideline for Federal Policy

Rationale

Federal housing programs serving older persons require the provision of full private apartments with private toilets, bathing capacity, and kitchen or kitchenettes with cooking capacity. Older persons should not have to forego those basic amenities simply because they have a disability.

At the same time, the Assisted Living Workgroup recognizes that subsidized housing that is built as assisted living or converted to that purpose will have to make accommodations and adaptations to serve persons with disabilities. For example, more common space may be required to offer services. A kitchenette should include, at a minimum, a sink, a food preparation and storage area, a small refrigerator, and a microwave oven. For residents who cannot operate such appliances safely, the housing provider should have a policy and procedure for disconnecting them.

Similarly, individual units may have to be adapted to allow for different living arrangements. While individuals should not be forced to share rooms with a stranger, some may prefer to share an apartment for various reasons—for example, sharing with a spouse, a friend, a domestic partner, or a caregiver. When requested by the resident, sharing accommodations should be permitted and facilitated.

Organizations Supporting This Recommendation

No Vote Recorded

Organizations Opposing This Recommendation**Organizations Abstaining From the Vote on This Recommendation**

Supplemental Positions for A.27
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1) We support this failed recommendation as written.

AARP, American College of Health Care Administrators, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social

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Security and Medicare, National Network of Career Nursing Assistants, National Association of Social Workers, National Senior Citizens Law Center

2) The substance of this recommendation is dealt with in Recommendation A.15, "Federal Housing Subsidy Programs and Assisted Living." The occupancy standard in federal housing programs is that units are shared only by choice. Most units of subsidized housing occupied by older persons are single person occupancy. The organizations listed below believe these occupancy standards should not be waived when assisted living services are offered in subsidized housing. A person should not be forced to share a housing unit with a stranger simply because they have a disability.

AARP, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

Affordability

A.28 Affordable Assisted Living Liability Insurance **2/3 Maj. Not Reached****Recommendation**

State and federal governments in conjunction with relevant stakeholders shall research the causes for the increased cost of liability insurance in AL to determine appropriate solutions to ensure that assisted living is affordable and appropriate insurance is accessible.

Implementation

Further research followed by state and federal policy change.

Rationale

The increased cost of general and professional liability insurance is directly impacting the availability of affordable assisted living services. Possible areas to investigate for solutions include but should not be limited to the following:

1. Develop an experience-based rating for ALRs. That is, rates should be reflective of both ALR vs. nursing home experience and rates should be experience-based by ALR. In other words, those ALRs with good claim histories would pay a lower premium than ALRs with poor claim histories.
2. States and insurance commissioners should work creatively with providers and insurers to develop alternate models of general and professional liability insurance.
3. Developing and implementing comprehensive quality improvement and risk management protocols.

The cost of general and professional liability insurance for assisted living residences has increased dramatically during the past several years. These increases have two direct impacts on assisted living:

1. In private pay assisted living residences, the increased costs are passed to the residents. This may have the effect of making previously moderately priced assisted living too costly for some individuals.
2. In assisted living residences (ALR) that participate in the Medicaid-waiver program, reimbursement has not increased to reflect increased costs related to liability insurance. The provider shall absorb those costs and the net effect may be that the ALR will choose to cease providing services under the Medicaid waiver program. An additional factor is the availability of insurance. In one state the highest licensure level was required of ALRs who chose to participate in the Medicaid waiver program. Providers with that highest license level (which had increased requirements and also allowed for increased services to be offered) have been either unable to obtain liability insurance or the cost is prohibitive. That state has been forced to lower the licensure level for Medicaid waiver providers to ensure access for Medicaid waiver residents.

This recommendation is not intended to take a position on tort reform.

Organizations Supporting This Recommendation

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Affordability

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for A.28
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1) We oppose this failed recommendation. We oppose this recommendation because of the highly politicized discussion at the present time as to the causes of the increased costs of premiums for liability insurance. Although we appreciate the final sentence of the rationale – that the recommendation "is not intended to take a position on tort reform" – we cannot support a recommendation that singles out the high costs of insurance as a threat to affordable assisted living. This recommendation is beyond the scope of expertise of the Assisted Living Workgroup.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsman Programs, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Affordability

A.29 Unit Hold

2/3 Maj. Not Reached

Recommendation

Resident's units in an ALRs are their home. As such, their unit shall be held for them during temporary absences as long as the ALR fees continue to be paid. To make this possible for residents whose room, board, or services are paid by a government entity, the following government payment policies shall be integrated into reimbursement programs.

Housing and board fees: The resident and any government entity that subsidizes the resident's rental payment, continue to pay his/her full share. The ALR may initiate discharge proceedings in instances of nonpayment.

Health or personal care fees: Because the ALR cannot reduce its staffing and operating costs when a resident is absent from the ALR for short terms, the government entity subsidizing the care costs needs to provide funding during the absence to provide for a viable program. For medically necessary absences, the government entity will continue to pay 100% of the rate (less any resident share of cost payment made to the ALR during the absence) for up to 24 consecutive days per medical episode. For a non-medical absences, the government entity will continue to pay 100% of the rate (less any resident share of cost payment made to the ALR during the absence) for up to 14 days per year to allow the resident the opportunity to leave the ALR for personal reasons. If a resident's absence exceeds the government funding period in either instance, the resident or his/her family shall either pay the fees privately to retain the unit or relinquish the unit to the provider, unless at the provider's discretion, the provider is willing to reserve the unit at reduced or no cost for the remainder of the resident's absence. The ALR may initiate discharge proceedings in instances of nonpayment. (Please note: The ALW believes that in the case of non-medical absences, an allowance of 14 cumulative days should be the minimum allowed under government programs. Providing larger allowances for non-medical absences further benefits the residents' options.)

Decisions about terminating residency in the ALR: If the resident decides not to return to the ALR, he/she shall notify the ALR in a manner consistent with law. (The admissions contract shall disclose to residents what these requirements are.) If the ALR claims that under relevant law it is entitled, based on an increase in the resident's care needs, to have the resident transfer or move out, the ALR shall provide the resident (and any designated representative) with a discharge notice. The resident has the right to appeal the discharge in the state administrative process.

Implementation

Federal and State Policy

Rationale

Assisted living residents who are temporarily absent from their ALR want to be able to return to their homes following their temporary absence. The rule shall assure the resident's right to return. In addition, there need to be provisions that address payment during the resident's absence and terminating the residency. Payments during a temporary absence shall be equal to the payments during occupancy because a provider

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Affordability

may not be able to modify operations (e.g., staff down, forego debt payments, reduce utility costs, modify food orders) during a temporary absence.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Association for Regulatory Administration

Organizations Abstaining From the Vote on This Recommendation

American Assisted Living Nurses Association, American College of Health Care Administrators, American Seniors Housing Association, Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for A.29
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1) The undersigned strongly support Affordability Recommendation A.29 as written for the following reasons:

- Without unit hold provisions and continued state service payments during absences, residents risk losing their home if they go into the hospital or leave to visit family.
- ALR's providing affordable assisted living services under governmental programs cannot typically afford to forgo service payment during a resident's absences because they do not have the operational flexibility to scale back staff and fixed expenses on a fractional basis.
- If states do not compensate ALRs for services during a resident's absence, mission-driven providers may be unable to afford to participate in state programs and good quality for-profit providers will likely avoid taking state-reimbursed residents due to their absences' negative impact on the ALR's effective reimbursement rate.

Without the unit hold and reimbursement policies described in A.29, residents may face two unacceptable possibilities: 1) that an absences for medical reasons or to visit family (e.g., funeral, baptism, celebration, vacation) will cause them to forfeit their unit or 2) residents will be pressured by providers not to leave the ALR.

AARP, Consumer Consortium on Assisted Living, NCB Development Corporation, National Center for Assisted Living, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We oppose this failed recommendation. We support R.13, a residents' rights recommendation that addresses unit hold.

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We oppose A.29 because it focuses on assisted living residences' interest in 100% funding during residents' temporary absences rather than on assuring residents' ability to retain their homes during temporary absences.

We also oppose A.29 because it makes no provision for prorating residents' fees for services that residents do not use while they are absent from the assisted living residence. For example, residents who are away on vacation or in the hospital will not eat meals or use housekeeping services. Assisted living residences should be required to give credit for unused services, prorated on a daily basis.

Center for Medicare Advocacy, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

Topic Group Recommendations
Adopted by Two-Thirds Majority of the ALW
Direct Care Services

Purpose

The Direct Care Services Topic Group focused its efforts on the wellness and healthcare needs of ALR residents.

Issues

The main focus of the topic group was in the areas of assessment, resident move-in and transfers, end-of-life and palliative care, dementia care, and wellness.

Participants

The topic group was co-chaired by Doug Pace of the American Association of Homes and Services for the Aging and Jonathan Musher of the American Medical Directors Association.

Topic group participants included Linda Aufderhaar, National Association of Professional Geriatric Care Managers; Fred Cowell, Paralyzed Veterans of America; Marianna Grachek, Joint Commission on Accreditation of Health Care Organizations; Marsha Greenfield, American Association of Homes and Services for the Aging; Meg LaPorte, American Medical Directors Association; Karen Love, Consumers Consortium on Assisted Living; Katie Maslow, Alzheimer's Association; Cherry Meier, National Hospice and Palliative Care Organization; Constance Rowe, National Association of Home Care Physicians; Shelley Sabo, National Center on Assisted Living; Beth Singley, Assisted Living Federation of America; Bradley Schurman, American Assoc. of Homes and Services for the Aging; Ed Sheehy, Assisted Living Federation of America; Lisa Yagoda, National Association of Social Workers

Direct Care

D.01 Pre-Move In Screening Process**Recommendation****Elements of the Pre-Move In Screening Process**

This is to be completed by appropriately qualified and trained individuals with active participation of the prospective resident*.

1. Information and discussion of assisted living residence contract including resident and family expectations and resident rights, responsibilities and move in/move out criteria.
2. Information and discussion regarding the assisted living residence rate structure with full disclosure of rate charges and changes and third party payer information (e.g., Medicaid, LTC Insurance, and other Subsidies).
3. Written information regarding Advance Directives (e.g. Living Will, Durable Power of Attorney, and/or DNR).
4. History and Physical (including diagnoses, a list of current medications, and a TB screen). [These elements should be completed by the prospective resident's primary licensed healthcare provider (M.D., D.O., P.A., N.P.) who has seen the individual within the last 60 days prior to move in. The assisted living residence should obtain a signed release form from the resident to authorize the ALR to access the medical records of the prospective resident.]
5. Evaluation of the prospective resident's ability to self-administer medications or need for medication reminders, or medication administration.
6. Evaluation of ADL's, IADL's, and risk factors (e.g. - falls, weight loss, elopement, self-neglect, abuse, exploitation).
7. Assessment of cognitive abilities and behavioral issues unless included in the prospective residents medical history. When indicated, a structured evaluation should be conducted (e.g. Folstein mini-mental health exam).

Implementation**Guideline for State Regulation****Rationale**

To best assure that an assisted living residence can meet a prospective resident's needs and expectations, the residence will initiate a pre-move in screening. This process is initiated once a prospective resident requests admission into an assisted living residence and is concluded prior to admission.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of

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Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Adult Family Care Organization, National Center for Assisted Living, National Hospice and Palliative Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

National Network of Career Nursing Assistants

Supplemental Positions for D.01
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1) We dissent. Pre-admission screenings are extremely important in determining whether an individual's needs can be met in an assisted living residence. Unfortunately, however, this recommendation has little content. Although the recommendation lists topic areas to be addressed, it does not specify how those areas are to be addressed, and contains no indication as to when a facility employee would be considered "appropriately qualified and trained" to conduct the screening.

Existing state laws do more to assure that screenings are meaningful. Virginia, for example, requires use of a Uniform Assessment Instrument to determine the appropriate level of care, based on the state's two-tier licensing system. The Uniform Assessment Instrument must be completed by a physician, a case manager, or a facility employee "with documented training in the completion of the UAI and appropriate application of level of care criteria." (Virginia Administrative Code, Title 22, §§ 40-71-10, 40-71-170(A)(1))

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We support this recommendation. States should retain the flexibility to decide how to meet the intent of an appropriate recommendation in equally effective alternative ways.

We note the following points:

- Prescreening of a potential is generally not the point at which to conduct what amounts to a full assessment. What should be monitored is whether accurate, complete, and easy to understand information has been given to the prospective resident for the purpose of making an informed decision.
- No reference in the recommendation is made to obtaining any information about the prospective resident's lifestyle, preferences or desires, or even inquiring as to the reason(s) prompting the

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decision to move into the ALR.

· The pre-move in screening process is triggered when a resident requests admission into an ALR. There is nothing intrinsic to a resident's request to move-in that would necessitate an immediate discussion of advance directives or DNR orders. Indeed, some residents may find the timing of such a discussion as insensitive when all parties are working to ensure the consumer's transition into the ALR setting is a positive and welcoming experience.

· No rationale is offered as to why states must require assessments to be completed within 14 days of admission as opposed to another interval already specified in state regulation.

· No rationale is offered as to why states must require the pre-move-in screening process and initial assessment to be conducted as a two-step process.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.02 Initial Assessment**Recommendation****Elements of the Initial Assessment**

When applicable, information from the Pre-Move In Screening Process may be used to complete the Initial Assessment. Initial Assessment should be completed by appropriately qualified and trained individuals with active participation of the prospective resident*.

1. Physical history/exam (to be completed by a M.D., D.O., P.A., N.P.)
2. A Mental Health assessment, if appropriate (to be completed by a qualified, licensed, and/or certified professional based on observation, history and physical, or upon request)
3. Functionality: a) Assessment of ADLs; b) Assessment of IADLs; c) Assessment of risk factors (e.g. - falls, weight loss, elopement, self-neglect, abuse, exploitation).
4. Social Environment Factors (may be completed by a licensed and/or certified social worker or a trained staff member): a) Identify social interaction network (e.g.- cultural, spiritual, activities); b) Identify support resources (family, friends, etc.) and special needs; c) Identify lifestyle preferences.
5. Obtain Advance Directives from resident if applicable.

Time Frame for Assessment to be Completed

Assessing medication requirements and information regarding advance directives and risk factors shall be completed immediately upon admission. All other components of the initial assessment shall be completed within 14 days of admission.

Implementation**Guideline for State Regulation****Rationale**

The process of understanding, defining and measuring a resident's needs to ensure capable, comprehensive services is an on-going process in assisted living. After the pre-move in screening process, a more complete assessment process takes place upon admission. The purpose is to identify the resident's current needs and areas where support services may be needed as the Assisted Living Residence develops the resident's service plan.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care

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Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This RecommendationNone

Supplemental Positions for D.02

1) We support this recommendation. Although the recommendation gives an adequate description of the medical, functional and social components of an assessment, it does not adequately discuss that the focus of the assessment should be on using or identifying triggers or indicators to pursue additional information from the resident or as a cue to provide the resident with more information in a certain area.

American College of Health Care Administrators, Assisted Living Federation of America, National Association for Home Care, National Association for Regulatory Administration, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.03 Service Plan**Recommendation**

1. The assisted living residence shall develop a service plan for each resident. The service plan shall be customized to the needs and preferences of the resident (including flexibility in scheduling, delivery method, social activities, etc.) The resident shall actively participate in the creation of the service plan if they are able to do so.
2. The service plan shall be developed by appropriately trained and qualified staff, with input of direct care staff, in partnership with the resident*. When appropriate, the resident's physician and outside healthcare and service providers shall assist in the development of the service plan. The resident's family will be invited to participate at the request of the resident.
3. The service plan shall be developed using information from the pre-move in screening process, initial assessment, and ongoing assessments.
4. The initial service plan shall be completed within 30 days of admission and signed by the assisted living residence and the resident*. The ALR shall review the service plan 30-60 days after the completion of the initial service plan. The resident* shall receive a copy of the initial and all subsequent service plans upon completion.
5. The service plan shall include both the services provided by or contracted by the assisted living residence and identify services contracted by the resident from outside agencies and health care providers.
6. When services are provided, a service plan should include the following: scope of services; the frequency of services; monitoring of the services being delivered; a review of the resident's goals/outcomes; and who is responsible for the delivery of service, including coordination responsibility between on-site and 3rd party service providers.
7. The service plan shall be reviewed semi-annually, and/or on significant change, and/or revised as the resident's needs or desires change. There shall be a system in place to identify significant change. The service plan is available to, discussed with, and implemented by the appropriate ALR staff.
8. With respect to services provided by third parties, who are contracted by the ALR, the assisted living residence shall have written policies and procedures addressing their charges, notification procedures, provider and/or resident selection and the monitoring of the services provided. The assisted living residence shall coordinate and monitor the services provided by all third parties contracted by the assisted living residence.

Implementation

Guideline for State Regulation

Rationale

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Direct Care

Resident assessments and service plans are two of the cornerstones of assisted living that help assure quality service and care. The preparation of an accurate resident assessment and individualized service plan is the first step in providing quality care in an ALR.

Ongoing assessment of each resident's service and care needs, along with updating each resident's service plan when service and care needs/preferences change, is essential to providing continuous care.

A service plan is a document developed that identifies the needs and preferences of the resident and outlines how they will be achieved. The plan is developed through an organized collaboration between the ALR and the resident*. The goal of the service plan is to promote positive outcomes.

Staff providing resident personal care is assigned primary responsibility for carrying out the service plan and performs the majority of the tasks outlined.

Because the resident's needs and wishes may change, the service plan is monitored on an ongoing basis to ensure that the services being provided as specified in the plan and the plan is adequate to meet the resident's needs.

ALR staff is responsible for observing and reporting changes in the resident's condition, with significant changes reported immediately.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Gerontological Society, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Conference of Gerontological Nurse Practitioners, National Network of Career Nursing Assistants, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

National Center for Assisted Living

Supplemental Positions for D.03
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1) We support this recommendation, although we note that states retain the flexibility to decide how

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it will meet the intent of an appropriate recommendation.

*Assisted Living Federation of America, National Association for Home Care, Joint
Commission on Accreditation of Health Care Organizations,*

Direct Care

D.04 Reasons for Resident Transfer or Move-out from an Assisted Living Residence**Recommendation**

The following reasons may be given for transfer or move-out by the resident or ALR:

1. The resident desires to move.
2. Following a documented assessment, ALR is no longer able to care for the resident due to his/her physical, or mental/cognitive status or behavioral issues based on the scope of services offered or coordinated by the ALR as disclosed to the resident upon move-in and as required by, state licensing requirements; and, wherever practical and except in an emergency, the ALR has attempted to work with the resident* so that move-out or transfer would be unnecessary and this attempt has been unsuccessful.
3. The resident fails to pay or arrange payments for services rendered or other material breaches of contract, after reasonable and appropriate notice to the resident* by the ALR of the nonpayment or material breach.
4. The resident's behavior or conditions presents a direct and serious threat to the well-being or safety of the resident or other residents or staff.
5. The ALR has the right to make a temporary emergency transfer of a resident in the event of imminent and serious danger to the life or safety of the resident or to other residents. In the event of an emergency, the ALR may conduct such transfer without advance notification, although the ALR should make a good faith effort to contact the family or responsible party at the earliest opportunity.
6. The ALR ceases to operate.

Implementation

Guideline for State Regulation

Rationale

When the Assisted Living Residence cannot meet the resident's needs, limitations of its scope of services, or according to law and regulation, the resident may need to move to another setting or a different level of care.

In all such cases, every effort is made to minimize the trauma associated with the move or transfer. The transfer or move-out should be conducted in a manner that is safe and dignified for the resident.

Move-out due to nonpayment should be reserved for instances when rent and/or fees have been unpaid for 30 days or more beyond the due date. The ALR should provide information on government or private subsidies that may be available to help the resident with costs.

The Assisted Living Workgroup recognizes that a resident has certain rights and protections under federal statutes, including the Americans with Disability Act, the Fair Housing Amendments Act, and the Rehabilitation Act of 1973. The applicable provisions of these statutes generally prohibit discrimination against individuals in protected categories and require reasonable accommodation and program accessibility.

In some instances, the ALR may not be required to make an accommodation if the

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modification would impose an undue financial or administrative burden or would require the ALR to fundamentally alter the nature of its program.

A full and complete examination of the circumstances under which these statutes may apply to a specific case involving an involuntary transfer or move-out is beyond the scope of this discussion. However, state agencies and providers should consider how these rights and protections apply to involuntary transfer or move-out requirements, as the federal statutes may take precedence over state regulations permitting an involuntary transfer or move-out.

In some states, involuntary transfer or move-out from an ALR is governed by the state's landlord-tenant laws. In these states, the state agency generally cannot force the resident to move and the resident will have the opportunity to raise any claims regarding the statutes cited above in a Housing Court proceeding.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for D.04
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1) We dissent. This recommendation, in combination with other recommendations, gives an assisted living residence excessive authority to evict a resident when the resident's needs increase, rather than requiring a reasonable effort to accommodate those needs. The recommendation's reference to the scope of services "required by state licensing requirements" is disingenuous, because the recommendations themselves (including all of the "guidelines for state regulation") do not require assisted living residences to provide any particular level of service. Whenever this issue was raised in the Workgroup, provider representatives refused to adopt any required level of service, maintaining that assisted living residences had to retain the "flexibility" to evict residents.

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We recommend that states adopt levels of care within assisted living – for example, Idaho's three-level system of Level I - Minimal Assistance, Level II - Moderate Assistance, and Level III - Extensive Assistance. (Idaho Administrative Code § 16.03.22.010) This type of system lets a resident know what needs can be met.

The majority's recommendation admittedly obligates an assisted living residence to provide the services disclosed at admission. This disclosure is not an adequate safeguard, given that these disclosures can be written in a vague way and, at the time of admission, a resident choosing among assisted living residences has little ability to understand disclosures relating to services.

The rationale references a facility's obligations under federal anti-discrimination law, but a resident should not have to file a federal lawsuit in order to obtain needed services. A level-of-care system would address this problem so that it could be remedied within a state's regulatory system, in response to a resident's complaint.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. Although we support this recommendation in principle, it goes beyond the mandate to the ALW to specifically address the issue of adequate notice upon discharge.

Assisted Living Federation of America, National Association of Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

**D.05 Protocols for Resident Transfer or Move-out from
an Assisted Living Residence****Recommendation**

After the criteria to initiate a move-out of a resident have been met, subject to any appeal rights held by the resident the ALR transfers or moves a resident only after providing the resident with:

1. A meeting will be coordinated with the resident and ALR staff to review the conditions for transfer or move-out. The ALR will assist the resident* in identifying other appropriate alternative settings.
2. Except in an emergency, advance written notice that includes the reason for the transfer or move-out and the approximate date when the transfer or move-out will occur. A simple and expeditious appeals process should be available to allow the resident and family the opportunity to dispute the transfer/move-out, but does not unduly prolong or exacerbate the situation that led to the ALR's or State's decision;
3. Information on the availability of assistance and support services to help the resident make the transfer or move-out to a setting which is adequate and appropriate for the resident.
4. The ALR shall prepare a move-out summary which includes pertinent information regarding the resident's physical and mental and cognitive status and a list of current medications.
5. A copy of all pertinent resident records, including when an emergency transfer occurs

Implementation

Guideline for State Regulation

Rationale

The protocols listed in this recommendation are triggered when the ALR initiates the process to transfer or move-out or at the resident* request.

The protocols are intended to minimize the trauma to a resident as a result of a transfer or move out and to ensure the process is conducted in a manner that is safe and dignified for the resident, balanced with scope of services of the ALR and considers the needs and safety of the other residents and staff.

The Assisted Living Workgroup recognizes that a resident has certain rights and protections under federal statutes, including the Americans with Disability Act, the Fair Housing Amendments Act, and the Rehabilitation Act of 1973. The applicable provisions of these statutes generally prohibit discrimination against individuals in protected categories and require reasonable accommodation and program accessibility.

In some instances, the ALR may not be required to make an accommodation if the modification would impose an undue financial or administrative burden far exceeding what could have been reasonably anticipated upon admission or would require the ALR to fundamentally alter the nature of its program.

A full and complete examination of the circumstances under which these statutes may

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apply to a specific case involving an involuntary transfer or move-out is beyond the scope of this discussion. However, state agencies and providers should consider how these rights and protections apply to involuntary transfer or move-out requirements, as the federal statutes may take precedence over state regulations requiring an involuntary transfer or move-out.

In those states where transfer/move-out is governed by landlord-tenant or other applicable state law, the resident and family may have the opportunity to appeal the ALR's decision. The court or appropriate state agency may require, and the ALR should provide service and discharge planning and information on the availability of services as described above.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for D.05
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1) We dissent. Although we support this recommendation in principle, in our view, it goes beyond the mandate to the Assisted Living Workgroup to provide guidance to the states on matters that will improve quality in assisted living.

Assisted Living Federation of America, National Association of Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.06 Palliative Care**Recommendation**

1. An ALR will provide, within its scope of services offered, care and support for each resident so that he/she may live as fully and as comfortably as possible within the context of the resident's values and symptoms. These outcomes are accomplished when:

--The resident* is provided with accurate and timely information to make treatment decisions.

--The service plan supports the resident's choices that are consistent with the resident's advance directives, values, spiritual preferences, and life-long living patterns, even though these decisions may involve increased risk or personal harm to the resident.

2. Procedures are in place to assure that the resident receives timely attention to palliative care needs.

3. ALR staff report observations of discomfort, adverse reaction/behaviors to an ALR supervisor or qualified health care professional.

4. ALR staff assists the resident in maximizing independence as the resident's functional capacity changes.

Implementation

Guideline for Operations

Rationale

Palliative care includes any comfort measure that will prevent, relieve, reduce, or soothe the symptoms of disease or disorder without affecting a cure. As such, palliative care can be provided throughout an individual's life, although it is usually associated with the end-of-life or hospice.

Comfort care can become a controversial issue when a resident makes a decision to forego treatment that others judge to be of benefit. For example, a resident decides to stop further chemotherapy, refuses surgery, or decides to terminate dialysis. Quality of life can only be defined by the resident*. The responsibility of the ALR staff is to direct the resident to resources regarding palliative care. Treatment decisions are driven by the values and preferences of the resident*. Advance directives, if executed, are a primary source of information.

Studies conducted on end-of-life issues have found that individuals prefer to die at home, surrounded by their loved ones, without pain. The ALR is home and residents may not want to be taken to the hospital or transferred to a nursing facility when they are bedbound or near death. ALR staff may be uncomfortable with death in the facility and feel that they are not capable of meeting the resident's needs. These issues can only be resolved with open communication among the resident, family, and ALR staff. At this point, it may be necessary to consider additional services from outside providers, such as a home health agency or hospice.

Organizations Supporting This Recommendation

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Direct Care

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America

<p>Supplemental Positions for D.06</p>

1) We dissent. Although we support this recommendation in principle, in our view, it goes beyond the mandate to the Assisted Living Workgroup to provide guidance to the states on matters that will improve quality in assisted living.

Further, it preempts state and ALR flexibility to decide how to will meet the intent of an appropriate recommendation to improve quality in equally effective ways.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.07 Hospice Care**Recommendation**

1. If the ALR is able to provide or arrange for the provision of hospice care, the ALR should inform terminally ill residents* of the availability to receive hospice care at the ALR. The ALR should identify and make available to residents* information about hospice services and the names and addresses of providers in the geographic vicinity.
2. When a terminally ill resident is receiving hospice care, transfer from the ALR may not be required, if the needs are being met.
3. The ALR and hospice communicate, establish, and agree upon a coordinated service plan that reflects the hospice philosophy and is consistent with regulatory requirements.
4. The service plan identifies the provider/caregiver/family member that is to be held responsible for implementing the service plan.
5. The ALR and hospice determine a process by which information from the hospice interdisciplinary team and the ALR interdisciplinary team will be exchanged when developing, and evaluating outcomes of care and updating the service plan.

Implementation**Guideline for Operations****Rationale**

A person becomes eligible for Hospice Care when a physician certifies that they have a terminal illness. Individuals living over six months are not discharged from the program unless it is determined, by a physician, that the prognosis is greater than six months. The Hospice Benefit is covered under Medicare and Medicaid (in all but a few states). When an individual elects the Hospice Medicare/Medicaid benefit, they elect to receive palliative care. They may still receive curative care if it is unrelated to their terminal illness. At any time, an individual may revoke the Hospice Benefit and return to treatment under Medicare Part A/ Medicaid. The ALR should be aware of the hospice providers in the community and explore potential opportunities to collaborate.

The Conditions of Participation as a hospice provider stipulate that when a Medicare/Medicaid beneficiary elects to receive hospice care, the hospice assumes professional management and financial responsibility for care related to the terminal illness. This care extends across settings from the person's home, personal care home, assisted living residence, nursing facility, or hospital. For this care, the hospice is reimbursed a per diem rate that is all-inclusive of care, without any additional expense to the individual/family. Services included in the hospice benefit are:

- professional care from the interdisciplinary team;
- supplies;
- medications related to the terminal illness;
- durable medical equipment.

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Hospice providers are required to have contracts with hospitals so that if an individual requires more intense care, it can be provided. Hospice providers may also have available staff to provide continuous care at the person's bedside. The intensity and level of care is based on the needs of the individual/family and adjusted as necessary.

Hospice programs provide state-of-the art palliative care and supportive services to individuals at the end of their lives, their family members and significant others. On-call support is available 24 hours a day, seven days a week, in both the home and facility based settings. Physical, social, spiritual, and emotional care is provided by a clinically-directed interdisciplinary team consisting of physicians, nurses, aides, social workers, clergy, and volunteers. The hospice physician provides guidance to the team and is available for consultation with the primary physician, or is in some cases may assume the role as primary physician.

Hospice provides support and care for persons in the last phase of a terminal condition so that they may live as fully and as comfortably as possible. Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life. Hospice affirms life and neither hastens nor postpones death.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Adult Family Care Organization, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association of Local Long Term Care Ombudsmen, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for D.07
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1) We dissent. There are no standards in this recommendation. Care for terminally-ill residents is possible "[i]f the ALR is able to provide or arrange for the provision of hospice care."

The recommendation suggests wrongly that the presence of a hospice agency is sufficient, regardless of the staffing and expertise of the assisted living residence. In fact, hospice care is supplemental

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care (generally funded by Medicare) for terminally ill persons. Hospice agency employees are visitors that generally see a patient for only a few hours each day.

This weak recommendation is a step backwards. In many states, an assisted living residence can accommodate a hospice care program only if the facility meets certain statutory or regulatory requirements. In California, for example, an assisted living residence can house terminally ill residents only after the facility has demonstrated its competence to the California Department of Social Services, received the appropriate approval from the Department, and then entered into an agreement with a hospice agency. (California Health & Safety Code § 1569.73)

Terminally-ill individuals often present significant health care problems, and need consistent emotional support. Visitation by a hospice agency is not a panacea and, in any case, a hospice agency may fail to carry out its responsibilities. By failing to even take into account the capabilities and responsibilities of an assisted living residence, this recommendation would jeopardize the quality of care provided to terminally ill residents.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.08 Advance Directives**Recommendation**

Assisted Living providers shall complete the following tasks related to advance directives upon admission and when appropriate.

1. Inquire whether the resident has an advance directive and, if so, request a copy of the advance directive for the ALR's records. If a copy is not provided, the residence shall document whether the resident* indicates he or she has an advance directive and, if a health care proxy has been appointed, the name and contact information of the proxy. The ALR shall update this information at least annually, again seeking to include a copy of the current directive in the facility's records.
2. Provide the resident* with an explanation of one's rights under state law to make decisions about medical care, including the right to accept or refuse medical and surgical treatment, and the right to formulate advance medical directives, such as a living will or durable power of attorney for health care, or comfort care only order (DNR order). The explanation approved for hospitals, nursing facilities, hospices and home health agencies by the state's medical assistance program under the federal Patient Self-Determination Act may be used for this purpose.
3. Provide the resident* with an explanation of ALR's policies regarding the delivery of end-of-life care in the residence, including the delivery of hospice and palliative care (pain management), and the use of comfort care only orders (i.e., do-not-resuscitate orders).
4. Take reasonable steps to ensure transfer of the resident's advance directive, or information regarding its existence, to the hospital or other facility.

Implementation

Guideline for Operations

Rationale

As part of the ALR's pre-move in screening process, the ALR is obtaining information from the resident* concerning advance directives. In some instances, the resident* may not have advance directives, nor understand the benefit/risks of having them. It would be beneficial for the residence to have copies of forms accepted by state law and be able to provide information to the resident* to make an informed decision.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Academy of Elder Law Attorneys, National Hospice and Palliative Care Organization, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, National Network of Career Nursing Assistants, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

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Assisted Living Federation of America, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies,

Supplemental Positions for D.08

1) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Direct Care

D.09 Do Not Resuscitate Orders (DNR)**Recommendation**

ALRs should clarify a resident's resuscitation status on admission and with subsequent changes in condition. If the State has regulations regarding out-of-hospital DNR, the ALR should provide the resident* with information to help assure that their treatment decisions are followed. The ALR should contact the physician to obtain appropriate orders.

Implementation

Guideline for Operations

Rationale

To provide portability to a DNR order, some states have regulations regarding resuscitation outside the hospital setting. These regulations were developed to assist Emergency Medical Technicians, Emergency Room personnel, and anyone else responding to a code situation, that the individual does not want resuscitation. Some states have designated devices such as a necklace or bracelet; however, this varies among states. This allows the individual to carry on their normal routine without fear of receiving resuscitation.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Adult Family Care Organization, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for D.09
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1) We dissent. This recommendation evades the central issue – can an assisted living residence honor a DNR order or, more specifically, what does an assisted living residence do when a resident with a DNR order needs resuscitation in order to live?

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Direct Care

Currently many assisted living residences do not have licensed health care professionals on staff. As a result, depending on state law, it often is unclear whether these facilities are allowed to honor DNR orders. In many instances, when a resident suffers a heart attack or similar event in a facility, CPR is initiated and/or the paramedics are called, even if the resident and the resident's physician specifically have requested a DNR order.

We recommend that a level of care system be adopted within assisted living, that the highest level require nurse staffing, and that assisted living residences licensed at the highest level be required to honor DNR honors. Such a system would allow residents' health care desires to be honored, and would guarantee that decisions to withhold CPR would be made by qualified health care professionals.

As is noted in other of our dissents, the majority consistently was unwilling to develop levels of care, or to draw distinctions based on a facility's capacity to provide health care services. As a result, this majority recommendation (particularly the rationale) leaves largely to paramedics the job of deciding whether and to what extent to honor a resident's DNR order. We dissent because we believe that residents deserves an assisted living residence that is qualified to do more than just call 9-1-1.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.10 Identification of Cognitive Impairment/Dementia**Recommendation**

The assisted living residence shall have in place procedures to 1) increase staff awareness of signs and symptoms of cognitive impairment/dementia in a resident, 2) evaluate or obtain an evaluation of the resident's cognitive status as it relates to the resident's ability to manage his/her own affairs and direct his/her own care, and 3) adapt the resident's service plan to meet his/her needs, given the resident's cognitive status.

These procedures should include:

1. Training for all staff members shall include information about the signs and symptoms of cognitive impairment/dementia.
2. When cognitive impairment is identified, staff should strongly encourage the resident and his/her family to obtain a diagnostic assessment by an appropriately trained and qualified professional in order to determine the cause of the cognitive impairment.
3. When cognitive impairment is identified, whether or not the resident has received a formal diagnosis of Alzheimer's disease, another dementing disease or condition, or another condition that causes cognitive impairment, staff shall evaluate the impact of the cognitive impairment on the resident's ability to manage his/her own affairs and direct his/her own care; issues of physical safety, ability to manage medications, and need for a surrogate decisionmaker shall be addressed in this evaluation; the resident and his/her family should be included in this evaluation as much as possible.
4. The resident's service plan should be revised to incorporate any changes needed because of his/her cognitive impairment. Since many diseases and conditions that cause cognitive impairment in elderly people are progressive, the resident's service plan should include a timetable for reevaluation.

Implementation

Guideline for State Regulation

Rationale

Available data indicate that 27-64% of assisted living residents have cognitive impairment but the condition often is not recognized and may not be considered important by assisted living staff. Hawes and Phillip, in their study of assisted living residences, found that 88 percent of staff members who provided or supervised direct resident care believed that memory loss and confusion are part of normal aging. Even in the case of sudden onset of these conditions, 9 percent of staff members believed nothing should be done because the conditions are part of normal aging. These beliefs jeopardize resident safety, interfere with timely identification of serious medical conditions that can cause sudden onset of cognitive impairment, and deprive staff of information they need to provide appropriate care.

In the case of sudden onset of cognitive impairment, diagnosis of the condition causing the change is critical. In the case of more gradual onset and progression, diagnosis is also

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important; however, a diagnosis of Alzheimer's disease or another dementing disease or condition does not establish the level of cognitive impairment or the person's self-care capacity; in this case, for the purposes of assisted living providers, diagnosis of the cause of cognitive impairment/dementia is less important than the evaluation of its impact on the person's self-care capacity and ability to manage their own affairs.

Some people will be admitted to the assisted living facility with cognitive impairment. Others will become cognitively impaired as time passes. Assisted living staff members can be trained to recognize common signs and symptoms of cognitive impairment in residents. All staff should receive this training, even if the assisted living facility has a special dementia care unit, since some residents who are not in that unit are very likely to have or to develop cognitive impairment over time.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Association for Regulatory Administration, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, American Seniors Housing Association

Supplemental Positions for D.10
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1) We respect the fact that many states have set additional requirements for ALRs that seek a special designation to serve people with cognitive impairments. However, we do not attempt to prescribe the specific procedures that a state must regulate.

Residents with mild to moderate dementia can still participate in care decisions and express life long values and wishes regarding the care they are currently receiving. Therefore, our recommended guidance to the states and ALRs is to consider a quality monitoring component that focuses on the perspective of the resident and other responsible parties to look beyond the procedures, and to see if the resident and other affected parties feel that their choices are being respected, their needs are being met, and their opinion is sought as to the quality of the services provided.

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Examples of suggested areas for quality monitoring could include:

- Does the resident acknowledge having opportunities to exercise lifestyle preferences (dining, receiving visitors, activities, directing provision of services)
- Does the resident acknowledge being consulted as to his/her satisfaction with the quality of care and services provided;
- Does the staff have the willingness and the ability to communicate with, and respond to, resident's preferences;
- Does the surrogate decision-maker acknowledge that he/she is encouraged to be involved in the development and implementation of the resident's service plan.
- Do family members report having opportunities for involvement in resident's care.
- Does the resident acknowledge being able to make decisions regarding services to be provided to the extent possible and involvement of his or her family as appropriate.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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D.11 Care for People with Cognitive Impairment/Dementia and Dementia Special Care Units and Facilities
Recommendation
Part 1: Care for People with Cognitive Impairment/Dementia

ALRs shall have in place procedures and services that 1) meet the needs of residents with cognitive impairment/dementia, 2) accommodate and balance concerns about safety and autonomy, 3) recognize and build on strengths, capacities, choices, and values of the resident, and 4) reflect the likelihood that the cognitive status of many of these people will change and deteriorate over time. Such procedures and services include:

1. Staff training about cognitive impairment, dementia, and dementia care;
2. Procedures for assessing and reassessing the resident's cognitive status, abilities, and related care needs;
3. Procedures, including supervision, to help direct care staff understand and respond effectively to residents' behavioral symptoms;
4. Specialized activities that are appropriate for residents with cognitive impairment/dementia;
5. Procedures for working with the resident and the resident's family to define and clarify responsibilities of the resident, the family, and the facility;
6. Procedures for designating and working with a surrogate decision maker, if the resident is not capable of making decisions for him/herself;
7. Policies and procedures to protect residents who wander and/or are at risk of physical harm;
8. Regular monitoring to assure resident safety and health care status, consistent with impairment; and
9. Policies and procedures for involving and supporting family members.

Resident needs related to cognitive impairment/dementia differ depending on the severity of the cognitive impairment. An ALR should have in place procedures and services that are appropriate for the severity of cognitive impairment of its residents.

Part 2: Dementia Special Care Units and Facilities

ALRs that choose to serve only individuals with cognitive impairment/dementia or to establish a special dementia unit or units(s) should define precisely the purpose of the unit(s) and develop admission and discharge criteria, staff training activity programs, and physical design features that are consistent with that purpose.

Implementation

Guideline for State Regulation; Operations

Rationale
Part 1: Care for People with Cognitive Impairment/Dementia

Diseases and conditions that cause cognitive impairment/dementia result in problems with memory, judgment, reasoning, communication, orientation, awareness, and other cognitive abilities. Assisted living residents with cognitive impairment/dementia generally need the same services and help as those who are cognitively intact and some additional services

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that are directly related to these problems. The list of needed services and procedures above is intended to include only those additional services.

Residents with cognitive impairment/dementia are likely to need help with decision making because of condition-related problems with memory, judgment, and reasoning. Some residents with cognitive impairment/dementia have a court-appointed guardian who can make decisions for them, but many do not. For those residents, state laws designate certain relatives and others who can function as surrogate decision makers for people who are not capable their own decisions. ALRs should be aware of the relevant state laws. At the same time, it is important to note that many individuals with cognitive impairment/dementia are capable to make some or all of their own decisions.

Part 2: Dementia Special Care Units and Facilities

Available data show that 27-64 percent of assisted living residents have cognitive impairment/dementia. Some assisted living residences serve only individuals with cognitive impairment/dementia; some have one or more physically separate, dementia special care units; and many do not have dementia special care units. In a 1997/98 study of 2,078 residents of a stratified random sample of 233 assisted living residences in four states, Zimmerman et al. found that 8 percent of small facilities (4-16 beds), 8 percent of large, traditional model facilities (16+ beds), and 25 percent of large, new model facilities (16+ beds and built after 1987) had physically separate care areas for residents with cognitive impairment/dementia. Of all residents with moderate or severe cognitive impairment/dementia in the 233 facilities, 11-32 percent were in these physically separate areas; thus 68-89 percent of residents with moderate or severe cognitive impairment/dementia were not in physically separate areas.¹

Since it is likely that most assisted living residents with cognitive impairment/dementia will not be in a dementia special care unit or an ALR that serves only individuals with cognitive impairment/dementia, the existence of these units and facilities does not eliminate the need for appropriate procedures and services, as describe in Part 1 above, for residents with cognitive impairment/dementia in other units and facilities. State regulations for dementia special care units and facilities generally do not apply to the care of residents with cognitive impairment/dementia who are not in dementia special care units and facilities.

ALRs that choose to serve only residents with cognitive impairment/dementia or to establish one or more dementia special care units should define precisely their policies, procedures, and services in the following areas:

1. Purpose of the unit(s): the ALR could, for example, establish a special care unit that provides special supervision or monitoring, a secured unit to deter elopement, or a unit intended to serve residents with particular behavioral symptoms;
2. Admission criteria: the ALR could, for example, create criteria that admit individuals in a particular stage or stages of a dementing illness, or anyone with a diagnosis of a dementing illness, or individuals with particular behavioral symptoms.
3. Discharge criteria: the ARL could, for example, create criteria that discharge individuals who reach a particular stage of their dementing illness, or individuals whose behavioral symptoms have mitigated sufficiently that they can return to a regular unit.

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4. Staffing ratios and staff training requirements: the ARL could, for example, provide more staff on all shifts or certain shifts in the special care unit; the ARL could also create training requirements that go beyond the dementia care training provided for all direct care staff or that focus on particular behavior management approaches.
5. Activities: the ARL could, for example, provide specialized group activity programs or special dining arrangements in the special care unit.
6. Physical design or environmental features: the ARL could, for example, create a special care unit with physical design features that assist residents to find their way and identify their own room and other rooms (such as the bathroom), and/or a protected area for wandering.

This recommendation applies to activities of the ALR that shall occur before disclosure. Once an ALR has defined the purpose of its special care unit and created policies and procedures that fit the purpose, then it should disclose the relevant information to prospective residents*.

1. Sloane, P.D. Zimmerman, S, and Ory, M.G., "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).

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants Center for Medicare Advocacy, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

National Citizens' Coalition on Nursing Home Reform, National Academy of Elder Law Attorneys

Supplemental Positions for D.11
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- 1) We dissent. The gist of the recommendation is that a facility is required to develop policies related to dementia care, and those policies must address certain areas. We dissent because there is

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no specificity as to what those policies might be. What type of staff training is appropriate for assisted living residences caring for residents with dementia? To what extent is the participation of a physician or nurse required? The recommendation takes no position on these and many other important questions.

Part 2 of the recommendation, pertaining to "Dementia Special Care Units and Facilities," is particularly without content. For example, according to the rationale, a unit could be considered "special care" if it had criteria that allowed for discharge of residents whose dementia reached a specific level. This anything-goes definition of "special care" is wholly unfair to consumers, who would assume reasonably -- but mistakenly -- that "special care" would be some indication of quality or expertise.

Existing state law has done a better job of establishing meaningful standards for the care of residents with dementia. In Alabama, for example, a "Specialty Care Assisted Living Facility" provides specialized care for residents with dementia. A physician must act as a medical director, and a registered nurse must perform assessments. Regulatory minimums are set for staff training, staff levels, and other important matters. (Alabama Administrative Code r. 420-5-20-.04, 420-5-20-.06, 420-5-20-.08)

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Committee to Preserve
Social Security and Medicare, National Network of Career Nursing Assistants,
National Senior Citizens Law Center*

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident's values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

*Assisted Living Federation of America, National Association for Home Care, Joint
Commission on Accreditation of Health Care Organizations*

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D.12 Senior Wellness Programs in ALRs**Recommendation**

The assisted living residence may design and provide a senior wellness program that fits the overall needs of its residents. If components of a senior wellness program are unable to be offered on-site, the assisted living residence may make available community contacts for residents who desire services.

Components of a Senior Wellness Program, beyond what is required under state regulations, may include:

- Mental Health/Psychosocial Programs and Screenings
- Health Screenings (e.g., blood pressure; cholesterol)
- Nutritional counseling
- Physical exercise programs (e.g., walking programs, weight training for seniors)
- Recreational/activity programs
- Spiritual Enrichment
- Health educational seminars
- Holistic Therapies (e.g., aromatherapy; massage therapy; music therapy)

Implementation

Guideline for Operations

Rationale

Wellness programs have the ability to improve the quality of life for ALR residents from a holistic approach. Providing residents with wellness programs that include educational resources, physical activity programs and community referral sources may result in greater understanding of certain conditions associated with aging and prevent issues and illnesses from occurring.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Association for Regulatory Administration, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

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Center for Medicare Advocacy

Supplemental Positions for D.12

1) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident's values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

We believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation. Further, the recommendation would likely have a disproportionate impact on small providers who lack the resources to put into place all of the recommended components beyond what is already required under existing state regulations.

Joint Commission on Accreditation of Health Care Organizations, Assisted Living Federation of America, National Association for Home Care

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority***

Direct Care Services

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not show a voting record were unable to reach two-thirds majority during the development process.

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D.13 Shared Responsibility Agreement**2/3 Maj. Not Reached****Recommendation**

Shared Responsibility Agreements are a tool for communications. They may be exercised when the resident* is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR. As an extension of the Service Plan, the ALR and the resident* may enter into a Shared Responsibility Agreement. The Shared Responsibility Agreements should cover the exception not the rule.

Shared responsibility shall not be a waiver of liability. A shared responsibility agreement is simply a written agreement between both parties--the Assisted Living Residence and the resident*--which memorializes the parties' discussions and agreements regarding the resident's preferences and how they will be accommodated in the community.

Shared Responsibility Agreements may be used when any or all of the following are true:

- There is a deviance from an accepted standard.
- There is a lack of consensus on a course of action.
- The risk of an adverse outcome is high.

The goals of the Shared Responsibility Agreement are:

- Empower the resident to exercise choice regarding service delivery (within established boundaries).
- Identify resident preferences
- Perform a realistic assessment of potential harm due to resident preferences.
- Identify potential outcomes
- Seek consensus around decision.
- Document process of negotiation and decision.
- Provide acknowledgement of the discussion

A Shared Responsibility Agreement should:

- Identify the cause for concern.
- Identify the probable consequences of the resident's choice.
- Make clear what the resident wants.
- Describe possible alternatives.
- Set forth the final agreement.
- Decide what staff will be notified of the agreement and how often follow-up is necessary.
- Agreement is signed by the ALR and the resident*.

Implementation**Guideline for Operations****Rationale**

The agreement itself is an extension of the service plan and the end product of a process in which the Assisted Living Residence, or the ALR and the resident together, identify a resident preference (e.g., to engage in or avoid certain activities or behaviors) which the ALR normally would not recommend or allow, or would remove, because they involve unacceptable risk to the health and safety of the resident or others in the ALR.

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Ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident.

Recognition of the need for a shared responsibility agreement normally arises in one of three ways. In some cases, a resident will verbally express to ALR staff a desire to engage in certain activities or behaviors that normally would be prohibited. In other cases, ALR staff may raise the issue where a resident repeatedly engages in behaviors which normally would not be allowed for that resident. Occasionally, third parties such as family members, or ombudsman or other resident advocates may suggest a shared responsibility agreement to resolve complaints or concerns raised by a resident or family.

Organizations Supporting This Recommendation

No Vote Recorded

Organizations Opposing This Recommendation

Organizations Abstaining From the Vote on This Recommendation

Supplemental Positions for D.13
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1) Many states are requiring shared responsibility or negotiated risk agreements as a part of the management of services in assisted living residences. Recommendation D.4 does an excellent job of describing the legitimate uses of such agreements, they are "a tool for communication" between residents and providers where residents are empowered to exercise choices in activities and expect services according to their preferences.

The recommendation also makes it very clear what are not legitimate uses of such agreements: "Shared responsibility shall not be a waiver of liability." While providers may reasonably use such agreements as part of their risk management policy, nothing in such agreements absolves providers from responsibility for negligent actions.

Perhaps the most useful part of the recommendation is its detailed outline of a process for negotiating such agreements. Many states require negotiated risk or shared responsibility agreements without providing guidance on how they should and should not be developed. The process recognizes that the provider has a responsibility to identify the consumer's preferences as well as potential risks that may be associated with certain behaviors. The process also recognizes that not all courses of action are possible or reasonable, but that resident preferences should be honored even when the provider does not believe them to be in the resident's best interest.

The undersigned organizations believe that this recommendation strikes the right balance between the resident's preferences and the provider's responsibility to provide services within a safe environment. It provides much needed guidance to states as they move into this relatively uncharted area of the law.

AARP, American Association of Homes and Services for the Aging, American Seniors Housing Association, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, NCB Development Corporation, Association of

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Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We oppose this failed recommendation. This recommendation is confusing and unnecessary, and seems to reduce a resident's right to make choices.

It is unclear what type of real-world fact pattern would require the use of a "shared responsibility agreement," particularly given the availability and general acceptance of the care planning process. Although "shared responsibility agreements" purportedly are designed to advance resident choice, they actually diminish resident choice, as shown by the fact that they are to be employed when the resident "is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR," or there is "a deviance from an accepted standard" or "a lack of consensus on a course of action."

The rationale emphasizes that the "shared responsibility" process is to be employed when the assisted living residence disagrees with decisions made by the resident, even if the only person affected is the resident himself or herself. This raises the inference, confirmed by the debate within the Workgroup, that shared responsibility agreements are designed almost exclusively to protect the facility from regulatory requirements and legal action.

There is no need for this confusing and self-contradictory recommendation. Resident/facility disputes are currently being addressed through care planning in assisted living residences around the country.

American Geriatrics Society, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Network of Career Nursing Assistants, National Senior Citizens Law Center

3) We support the recommendation. Negotiated risk agreements are becoming recognized as one of the primary tools through which assisted living providers can operationalize and preserve the values of independence, autonomy, and choice upon which the assisted living model rests so directly. Statutory and/or regulatory mandates in virtually every state direct both regulators and providers to further and nourish resident independence and autonomy in assisted living communities. The negotiated risk process focuses the attentions of resident, community staff, resident families, resident advocates, and regulators via a systematized process on one central issue – what are the wishes and preferences of the resident as balanced against the resident's health and safety needs. By so doing, the negotiated risk process responds to the legislative and regulatory directive to foster and promote these resident values and helps deliver the promise of assisted living.

The negotiated risk process is an individualized planning process designed to maximize a resident's ability to make his or her own decisions by facilitating discussions and analysis of a resident's stated choices where those choices create a normally unacceptable level of risk for the resident.

Negotiated risk is not a waiver of liability on the part of the provider of its obligations under governing regulations.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.14 Access to ALR's for Individuals with Personal Healthcare Needs 2/3 Maj. Not Reached

Recommendation

The personal healthcare needs of individuals should not be a barrier to admission or an automatic trigger for discharge by providers or in state regulation for Assisted Living Residences when the resident* or ALR chooses to provide or arrange care for the condition.

When a person with healthcare care needs wishes to or currently resides in an ALR, and care for the healthcare need is provided by the resident, caregiver (family or contracted), or appropriately qualified and trained staff (if the ALR chooses to make those services available), the existence of the healthcare needs should not be a barrier to admission or a trigger for discharge. This recommendation does not permit ALRs to reduce services below those required by regulation, nor does it require that they provide additional services.

Examples of personal healthcare needs may include but are not limited to:

- Catheter use
- Oxygen
- Medical ostomy, i.e. colostomy, ileostomy, urostomy
- Temporary medical conditions that require bed rest, i.e. severe colds, grade I & II pressure ulcers
- Mobility impairments that require use of a wheelchair, walker, cane or scooter.

Implementation

Guideline for State Regulation

Rationale

Many individuals with personal healthcare needs are capable to manage their care. Others have the ability to self-direct their care with occasional assistance from qualified caregivers or trained staff. These conditions can be easily managed in a home environment, and therefore are manageable in an ALR. It would be discriminatory to exclude individuals with personal healthcare needs from living in an ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Hospice and Palliative Care Organization, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

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Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Bar Association

Supplemental Positions for D.14

1) The failure of Recommendation D-14, by one vote, on March 4, 2003 represents a major setback for people with disabilities and other older Americans who may develop personal healthcare needs and wish to choose assisted living as an alternative to nursing home care.

Current state assisted living regulations prohibit many individuals with disabilities and other aging individuals who may acquire conditions later in life from admission to assisted living because these individuals require the use of a catheter, require oxygen, or have some form of medical ostomy. Additionally, current state assisted living regulations can also require a person with a disability to leave their assisted living home when they develop a temporary medical condition that requires bed rest, i.e., severe colds or Grade I or II pressure ulcers.

People with disabilities who have personal healthcare needs have been living independent lives in their own homes for years and are capable to self-manage or self-direct the personal care they need through a spouse, caregiver, or paid personal assistant. Therefore, these personal care needs should not be a barrier to admission or a trigger for discharge from an assisted living residence.

Assisted living providers may choose to provide these services or not, but must allow an individual resident to choose the most appropriate assistant for her or his personal healthcare needs. Assisted living residents should have the option to select between provider services, when available, or choose the private caregiver of their choice to assist with their personal healthcare needs.

The failure of D-14 only serves to reinforce existing negative stereotypes regarding the abilities of individuals with disabilities and forces these individuals or the organizations that represent them to consider taking expensive legal action to protect their civil rights. Recommendation D-14 was consistent with the U.S. Supreme Court's Olmstead decision and President Bush's New Freedom Initiative which are both designed to provide services in the "most integrated setting" according to the Americans with Disabilities Act.

Recommendation D-17's intent was to correct state assisted living regulations that discriminate against people with disabilities and other aging Americans by unjustly forcing them into severely restricted institutional care environments.

AARP, Alzheimer's Association, Consumer Consortium on Assisted Living, American Assisted Living Nurses Association, American Society of Consultant Pharmacists, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

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2) We oppose this failed recommendation. This recommendation would jeopardize residents' health and safety, because there is no assurance that assisted living residences would be capable of providing care for the residents with healthcare needs. The state licensing agency would be powerless to prevent an assisted living residence from admitting or retaining a resident, even if that assisted living residence was not capable of meeting the resident's needs.

As discussed in other dissents, the majority's recommendations require little health care expertise among assisted living residences. This recommendation establishes no quality of care standards whatsoever. Regardless, this recommendation defines "personal healthcare needs" to include colostomies, ileostomies, and urostomies. Also, the listed personal healthcare needs are just examples, so there is no real limit on the healthcare needs that could be cited by assisted living residences under this recommendation.

Also, this recommendation is completely one-sided. Although the state would be prohibited from citing a "personal healthcare need" as disqualification for assisted living, an assisted living residence could refuse admission or force discharge simply by refusing to provide necessary services.

As an alternative to this recommendation, we recommend a system that would establish levels of care within assisted living -- for example, the Florida system that licenses assisted living residences for either Limited Nursing Services or the more-extensive Extended Congregate Services. (Florida Administrative Code Ann. r. 58A-5.030- 5.031) Such a system would help assure that an assisted living residence would be prepared to meet the needs of a resident with a significant health care condition.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudaman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

3) We believe there should be agreement between the resident and the facility about the care being provided to a resident who wants to move into an ALR or who currently resides in the facility. To make a blanket statement that healthcare needs should not be a barrier or trigger encourages the provision of higher levels of care that may exceed the ALRs care capabilities. States must have the flexibility to determine what is best for their individual state with regard to admission and discharge criteria in ALRs.

American College of Health Care Administrators, National Center for Assisted Living, American Seniors Housing Association

4) We dissent. The recommendation states that it would be discriminatory to exclude individuals with specified personal health care needs from living in an ALR.

This statement is in conflict with the ALW's recommendation for Transfer and Discharge which states that while residents enjoy certain rights and protections regarding reasonable accommodation under federal statutes including the ADA, FHAA, and the Rehabilitation Act of 1973, there may also be instances where the ALR may not be required to make an accommodation, if the modification would impose an undue financial or administrative burden or would require the ALR to fundamentally alter the nature of its program.

Absent a full set of facts regarding a specific case under which a resident was involuntarily

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discharged, the ALW has no basis on which to declare when a discharge for specified health care conditions would categorically violate the ADA, FHAA or the Rehabilitation Act of 1973 and therefore constitute discrimination.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Direct Care

D.15 External Professional Consultant**2/3 Maj. Not Reached****Recommendation****Consultant Role and Responsibility**

To adequately provide for the needs of residents, each ALR should assess whether an agreement with certain consultants, including, but not limited to, physicians, consultant pharmacists, social workers, and registered dietitians with geriatric experience and an understanding of ALR philosophy to assist the ALR with their particular healthcare and wellness services. The consultants would have the following responsibilities based on the specific needs of the residents* and the ALR, including:

- Assist the ALR in ensuring the provision and monitoring of those specific services;
- Assist the ALR in developing policies and procedures related to those specific services;
- Assist the ALR in developing performance expectations;
- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of care, and other health-related services and provide appropriate feedback;
- Participate in the ALR's quality improvement process; and
- Assist the ALR in developing healthcare and wellness information and communication systems with staff, residents, families and others.

Implementation**Guideline for Operations****Rationale**

The types of individuals moving into assisted living are changing. Residents of ALR on average are older and frailer and have more healthcare and cognitive problems. The needs of these individuals span the spectrum from medical/ healthcare to nutritional and psychosocial services.

Because of these needs it is important to consider having an agreement with consultants who have specific knowledge of the healthcare/wellness issues that face this population and the training to help the ALR set up the systems needed to meet the needs of the residents.

A. Physician Consultant Role**Physician Coverage and Performance**

- Assist the ALR in ensuring that residents have appropriate physician coverage and ensure the provision of physician and health care practitioner services;
- Assist the ALR in developing a process for reviewing physician and health care practitioner credentials;
- Provide specific guidance for physician and health care practitioner performance expectations;
- Assist the ALR in ensuring that a system is in place for monitoring the performance of health care practitioners;
- Facilitate feedback to physicians and other health care practitioners on performance and practices.

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- Assist ALR with resident assessment and development of the clinical component of the service plan, when necessary

Clinical Care

- Participate in administrative decision-making and the development of policies and procedures related to resident care and medication management;
- Participate in administrative decision-making on staffing levels, coverage, licensing and training requirements for resident-care staff.
- Assist in developing, approving, and implementing specific clinical practices for the ALR to incorporate into its care-related policies and procedures, including areas required by laws and regulations;
- Review, respond to and participate in federal, state, local and other external inspections; and
- Assist in reviewing policies and procedures regarding the adequate protection of residents' rights, advance care planning, and other ethical issues.

Quality of Care

- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of clinical care, medication management and other health-related services and provide appropriate feedback;
- Participate in the ALR's quality improvement process;
- Advise on infection control issues and approve specific infection control policies to be incorporated into ALR policies and procedures;
- Assist the facility in providing a safe and caring environment with optimal levels of family and community involvement;
- Assist in the promotion of employee health and safety; and
- Assist in the development and implementation of employee health policies and programs.

Education, Information, and Communication

- Promote a learning culture within the facility by educating, informing, and communicating;
- Assist the ALR in developing medical information and communication systems with staff, residents, families and others
- Assist in establishing appropriate relationships with other healthcare professionals.

B. Social Work Consultant Role**Access to Professional Social Work Services**

- Assist the ALR staff in ensuring that residents have access to appropriate social work services and ensure the provision of social work and mental health practitioner services;
- Assist the ALR in developing social work staff qualifications and guidelines for practice;
- Assist the ALR in developing a process for reviewing social work practitioner credentials;
- Assist the ALR in developing a system for monitoring performance of social work practitioners;
- Assist the ALR with resident biopsychosocial assessment and development of the clinical component of the service plan, when appropriate.

Clinical Care

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Direct Care

- Provide direct services to residents, families, and other involved in a resident's care;
- Assist residents, families and others in receiving the maximum benefit of the ALW and community-based social resources throughout the stay of each resident from preadmission to discharge;
- Assist in discharge planning, advocacy, and serve as a community liaison;
- Participate in administrative decision making and the development of policies related to resident biopsychosocial functioning and well being;
- Provide clinical supervision to staff or consulting social workers hired by the ALR as needed;
- Participate in administrative decision making and the development of policies related to resident access to community resources as necessary;
- Participate in administrative decision making on social work staffing levels, coverage, licensing and training requirements;
- Assist in developing, approving, and implementing clinical social work practices for the ALR to incorporate into its care plan related policies and procedures, including areas required by laws and regulations;
- Review, respond to and participate in federal, state, local and other external inspections;
- Assist in reviewing policies and procedures regarding resident's rights, advance care planning and other ethical issues.

Quality of Care

- Assist the ALR in establishing systems and protocols for revising the quality and appropriateness of social work services, both inside and outside of the ALR;
- Participate in the ALR's quality improvement process;
- Advise the ALR in providing a caring environment and promote the highest level of family and community involvement as possible;
- Assist with establishing employee assistance programs to reduce employee stress and promote employee retention and well being.

Education, Information and Referral, Interdisciplinary Communication

- Assist the ALR to achieve and maintain a therapeutic environment essential to the optimal quality of life and independent functioning of each resident.
- Assist the ALR in developing information about community resources and entitlements programs for residents, families and others involved with the resident's care;
- Assist in establishing appropriate relationships with other care providers, public and private community agencies, and other services as appropriate;
- Promote ALR-community interaction through encouraging community involvement in the ALR and resident and staff involvement in the community;
- Assist in developing linkages with a wide range of community resources;
- Strengthen and promote communications between residents, their families, and others, and the program or facility staff.

For more information contact:

The National Association of Social Workers, 750 First Street, NE Suite 700, Washington, DC 20002; (202) 408-8600

C. Assisted Living Dietitian Consultant

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Consultant Role and Responsibility

- Assist the ALR in assessing the kitchen and food service personnel by reviewing and providing consultation in the following areas.
- Safe food handling procedures
- HACCP guidelines
- Sanitation and safety standards/policies throughout the kitchen
- Disaster preparedness per local regulations, that food, water, disposable items and utensils are stocked appropriately.
- Proper techniques for equipment use. (i.e. slicers, ovens, etc.)
- Nutritional care of residents
- Assist the ALR in developing policies and procedures related to food service and nutritional care.
- Review and approve all menus for nutritional adequacy and variety
- Assist with developing policies and procedures that will be implemented to achieve safe food handling that food is received, stored, prepared, transported and served in a safe and sanitary manner.
- Assist the ALR with meeting State regulations in kitchen, dining rooms and meal service areas.
- Review, participate in, and respond to federal, state, local and other external inspections.
- Assist FSD with any budgetary needs (i.e. food cost control, recommending products appropriate for special resident populations, etc.)
- Monitor compliance of special diet orders.
- Monitor resident weights quarterly for weight trends
- Assist the ALR in developing performance expectations
- Assist the ALR in hiring FSD or other kitchen personnel
- Assist in training FSD if needed
- Assist in providing inservice training to FSD and staff at least monthly or as needed
- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of care, and other health-related services and provide appropriate feedback
- Assist ALR with developing a process for screening residents regarding nutritional status.
- Assist ALR with resident assessment and development of the nutritional clinical component of the service plan.
- Assess any person with nutritional risk and make recommendations to PMD and other health care practitioners on areas of nutritional care.
- Assist the ALR in establishing criteria for requiring additional dietitian services for high risk nutritional needs.
- Assist the FSD and ALR in providing "food council committee."

D. Assisted Living Activity Consultant

- Assist the ALR in recruiting, interviewing, checking references and hiring of activity staff
- Assist in developing and explaining models of operations, staffing, programming, documentation and volunteers
- Assist the ALR in writing mission and philosophy statements, goals, objectives, policies and procedures
- Assist in developing forms and systems for documentation
- Assist in scheduling staff, participants, programs and resources

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- Assist the ALR in developing, implementing and evaluating budgets
- Assist in purchasing supplies, equipment, furniture, outdoor furniture and equipment
- Assist the ALR in adapting activities, supplies and equipment to meet residents functional needs and interests
- Monitor staff and participants in action and provide feedback
- Assist in developing and implementation of quality assurance programs
- Assist the ALR with resident assessments and development of an activity service plan
- Assist in developing community resources
- Develop and provide activity in services for all staff
- Assist the ALR with meeting local/state/federal regulations
- Coordinate transportation services

For More Information contact:

National Association of Activity Professionals (NAAP), P.O. Box 5530, Sevierville, TN 37864-5530; (865) 429-0717

National Certification Council of Activity Professionals (NCCAP), P.O. Box 62589, Virginia Beach, VA. 23466-2589; (757) 552-0653

The book, *The Professional Activity Manager and Consultant* was developed and supported by both the National Association of Activity Professionals (NAAP) and the National Certification Council of Activity Professionals (NCCAP). In 1996 it was copyrighted by the National Association of Activity Professionals and Idyll Arbor Inc. For more information contact Idyll Arbor Inc., P.O. Box 720, Ravensdale, WA., 98051. ISBN 882883-24-1

The agreement itself is an extension of the service plan and the end product of a process in which the Assisted Living Residence, or the ALR and the resident together, identify a resident preference (e.g., to engage in or avoid certain activities or behaviors) which the ALR normally would not recommend or allow, or would remove, because they involve unacceptable risk to the health and safety of the resident or others in the ALR.

Ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident.

Recognition of the need for a shared responsibility agreement normally arises in one of three ways. In some cases, a resident will verbally express to ALR staff a desire to engage in certain activities or behaviors that normally would be prohibited. In other cases, ALR staff may raise the issue where a resident repeatedly engages in behaviors which normally would not be allowed for that resident. Occasionally, third parties such as family members, or ombudsman or other resident advocates may suggest a shared responsibility agreement to resolve complaints or concerns raised by a resident or family.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic

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Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Hospice and Palliative Care Organization, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Seniors Housing Association, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for D.15
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1) Statement in support of the recommendation with modifications. As stated in the rationale section of the recommendation, the types of individuals moving into assisted living are changing. Residents of ALRs on average are older and frailer and have more healthcare and cognitive problems. The needs of these individuals span the spectrum from medical/healthcare to nutritional and psychosocial services.

Because of these needs, it is important for ALRs to consider having an agreement with certain consultants, including but not limited to, physicians, consultant pharmacists, social workers, registered dietitians, and activity consultants with geriatric experience and an understanding of ALR philosophy to assist the ALR with their particular healthcare and wellness services.

The External Professional Consultant recommendation is intended to assist ALRs in providing the highest quality service to its residents and to clarify and define the role of clinician consultants in assisted living.

We suggest that Recommendation D.15 should be a guideline for state regulation rather than an operational model but feel that the decision to contract with professional consultants such as a physician consultant be left up to the individual facilities and not mandated across the board to all ALFs.

As reported in the National Academy for State Health Policy State Assisted Living Policy: 2002, "the trend over that past five to ten years has been for states to offer flexibility [in their ALR requirements] in order to accommodate aging-in-place, which allows people with higher levels of impairment to remain in assisted living and allowing health related services to be provided."

American Academy of Home Care Physicians, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Association of Professional Geriatric Care Managers, National Association of Activity Professionals,

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*National Association of Social Workers, National Multiple Sclerosis Society,
Paralyzed Veterans of America*

2) We oppose this failed recommendation because it does not go far enough. The recommendation does no more than require an assisted living residence to "assess" whether it would be appropriate to consult with a physician, pharmacist, social worker, dietician, or other professional. By contrast, we believe that under certain circumstances an assisted living residence should be required to employ or consult with an appropriate professional.

Existing state law already recognizes that it is sometimes appropriate to require that an assisted living residence employ or consult with a professional. For example, Alabama requires that a physician act as medical director in an assisted living residence providing dementia special care. (Alabama Administrative Code r. 420-5-20-.04, 420-5-20-.06, 420-5-20-.08) Arkansas and Oklahoma require under certain circumstances that an assisted living residence contract with and use a consultant pharmacist. (Code Arkansas Rules 016 06 002, § 702.2.1 (Level II assisted living facilities); Oklahoma Administrative Code § 310:663-9-2(a))

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Association of Local
Long Term Care Ombudsmen, National Association of State Ombudsman Programs,
National Citizens Coalition for Nursing Home Reform, National Committee to
Preserve Social Security and Medicare, National Network of Career Nursing
Assistants, National Senior Citizens Law Center*

3) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident's values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

We believe this recommendation gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation. Further, the recommendation would likely have a disproportionate impact on small providers who lack the resources to have all of the specified consultant relationships.

*Assisted Living Federation of America, National Association for Home Care, Joint
Commission on Accreditation of Health Care Organizations*

4) We are opposed to this recommendation due to its potential cost implications for residents. Many assisted living residents are on limited incomes. Assisted living providers are capable of

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determining when outside consultants are needed and for what issues.

National Center for Assisted Living, American Seniors Housing Association

Topic Group Recommendations ***Adopted by Two-Thirds Majority of the ALW***

Medication Management

Purpose

Medication management is an important issue and challenge facing the assisted living industry. Consumer understanding of the services provided, and safe and effective management of the resident's medication regimen are major concerns.

Issues

In its work on developing recommendations for the assisted living residence, the Medication Management topic group focused on the following areas:

- Development of policies and procedures regarding medication management
- Disclosure of ALR policies and procedures
- Role of licensed and unlicensed assistive personnel in medication management
- Resident assessment and service planning, with regard to medication management
- Medication orders, storage and documentation
- Quality improvement

Participants

The topic group was co-chaired by Josh Allen, RN, American Assisted Living Nurses Association and Ed Sheehy, Assisted Living Federation of America.

Topic group participants included Jan Brickley, American Society of Consultant Pharmacists; Tom Clark, American Society of Consultant Pharmacists; Diane Crutchfield, American Society of Consultant Pharmacists; Peggy Daley, RN, Consumer Consortium on Assisted Living; Sandi Flores, RN, American Assisted Living Nurses Association; Kathleen Frampton, RN, American Medication Directors Association; Genevieve Gipson, RN, National Network of Career Nursing Assistants; Brian Lindberg, National Association of State Ombudsman Programs; Willie Long, Sunrise Assisted Living; Jane Mayfield, RN, Senior Residential Care Advisors; Ethel Mitty, EdD, RN, National Committee to Preserve Social Security and Medicare; Martha Mohler, RN, National Committee to Preserve Social Security and Medicare; Jonathan Musher, MD, American Medical Directors Association; Mary Ann Outwater, Massachusetts Quality Committee; Doug Pace, American Association of Homes and Services for the Aging; Barbara Reznick, PhD, CRNP, American Geriatrics Society; Karen Kauffman, PhD, National Conference of Geriatric Nurse Practitioners; Carol Robinson, RN, American College of Healthcare Administrators; Shelley Sabo, National Center for Assisted Living; Bradley Schurman, American Association of Homes and Services for the Aging; Bill West, RN, Morningside Management

Medication Management

M.01 Policies and Procedures

Recommendation

The assisted living residence will have and implement policies and procedures for the safe and effective distribution, storage, access, security, and use of medications and related equipment and services of the residence by trained and supervised staff.

Policies and procedures of the residence should address the following issues:

1. Medication orders, including telephone orders
2. Pharmacy services
3. Medication packaging
4. Medication ordering and receipt
5. Medication storage
6. Disposal of medications and medication-related equipment
7. Medication self-administration by the resident
8. Medication reminders by the residence
9. Medication administration by the residence
10. Medication administration – specific procedures
11. Documentation of medication administration
12. Medication error detection and reporting
13. Quality improvement system, including medication error prevention and reduction
14. Medication monitoring and reporting of adverse drug effects to the prescriber
15. Review of medications (e.g. duplicate drug therapy, drug interactions, monitoring for adverse drug interactions)
16. Storage and accountability of controlled drugs
17. Training, qualifications, and supervision of staff involved in medication management

Implementation

Guideline for State Regulation

Rationale

Many assisted living residents need some level of assistance with medications. Unless the resident is totally independent with regard to medication management, the residence assumes responsibility for the medication management services needed by that resident. Different residents may have differing levels of need for assistance, and the same resident may have differing needs at different times during the stay. The establishment of policies and procedures is a minimum standard that shall be met by any organization that expects to provide effective and accurate medication management services.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Commission of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social

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Medication Management

Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.01
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1) We dissent. This majority recommendation follows the majority's principal flawed assumption -- that the development of standards can be delegated to each individual assisted living residence. On the contrary, some basic standards must be set by the state, so that residents are adequately protected, and consumers can understand what an assisted living residence can do and must do. Development of facility policies is important -- but certainly not sufficient.

The majority's recommendation merely requires an assisted living residence to establish and implement policies and procedures related to medication. The recommendation (which is written as a proposed regulation) does not specify in any way what these policies and procedures might be, even though many of the 17 specified areas involve procedures that may require some significant level of health care expertise -- for example, "[d]isposal of medications and medication-related equipment," "[m]edication monitoring and reporting of adverse drug effects to the prescriber," "[s]torage and accountability of controlled drugs," and [t]raining, qualifications, and supervision of staff involved in medication management." The majority's recommendation is inadequate guidance, particularly given that the majority's recommendations contemplate that an assisted living residence will care for individuals who have significant health care needs.

In sharp contrast to the imprecise recommendation of the majority, some existing state laws establish meaningful substantive standards. Maine assisted living regulations, for example, establish required procedures for the destruction of medication, the administration of controlled substances, and the recording of medication errors.

(Code of Maine Rules 10-144-113, §§ 5080, 5090, 5120.3)

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Association of Local
Long Term Care Ombudsmen, National Association of State Ombudsman Programs,
National Citizens Coalition for Nursing Home Reform, National Committee to
Preserve Social Security and Medicare, National Network of Career Nursing
Assistants, National Senior Citizens Law Center*

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Medication Management**

should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

State governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care. Further, the totality of the recommendations related to medication management would have a disproportionate impact on small providers. The vast majority of assisted living facilities in this country are less than 50 beds. In fact, the average facility size is less than 16 beds.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

Medication Management

M.02 Policies and Procedures**Recommendation**

Prior to signing the residency agreement, the assisted living residence will disclose and explain in easily understood language policies, procedures, and service capacity relevant to the medication management needs of the residents and associated costs, including the disposition of medications.

Implementation

Guideline for State Regulation

Rationale

Medications are an important part of the therapeutic regimen for residents. The resident's ability to manage his/her medications may change over time. The ALR shall disclose to the resident* the policies and limitations of the assisted living residence with regard to medication management. The disposition of medications that are no longer needed is governed by federal and state laws and regulations. Prior to admission, the ALR shall disclose to the prospective resident* policies of the assisted living residence pertaining to medication disposal.

Organizations Supporting This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, American Seniors Housing Association, Catholic Health Association of the United States, National Center on Assisted Living, AARP, Alzheimer's Association, Consumers Consortium on Assisted Living, National Senior Citizens Law Center, American Assisted Living Nurses Association, American Medical Directors Association, American Society of Consultant Pharmacists, National Association of Social Workers, National Hospice and Palliative Care Organization, NCB Coming Home Program, National Association of Professional Care Managers, Association of Health Facility Survey Agencies, Pioneer Network, National Association of Activity Professionals

Organizations Opposing This Recommendation

National Association of Local Long Term Care Ombudsmen, Center for Medicare Advocacy

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.02
--

1) We dissent. This recommendation is redundant with several recommendations. The recommendation on Contracts and Agreements which says in part that contracts should provide a comprehensive description of all services provided for a basic fee. Recommendations concerning Pre-Screening and Initial Assessment, and Service Plan also deal with assessing and implementing a care plan related to the resident's need for assistance with medication assistance which would necessitate disclosure of service capacity.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.03 Resident Assessment and Management of Medication

Recommendation

Residents who desire to manage and self-administer their own medications shall be assessed by a qualified licensed health professional regarding the ability of the resident to self-administer or the need for medication reminders or medication administration.

The resident's individual service plan should reflect the findings of the most recent resident assessment. The extent of the resident's ability to self-administer or manage medications will be mutually determined by the resident; assisted living residence; and the qualified licensed health professional; and will be included in the resident's individual service plan.

The resident will be re-assessed at least annually, and upon a significant change in physical, cognitive, functional status, or resident choice, to evaluate the resident's continued ability to self-administer or manage medications.

The service plan will be updated to reflect significant changes in the resident's ability to self-administer or need for medication reminders or medication administration.

Implementation

Guideline for State Regulation

Rationale

Mistakes made with medications can have serious consequences. While the resident may perceive his/her ability to self-administer to be adequate, these perceptions may not be accurate, especially if some degree of cognitive impairment is present. A qualified licensed health professional will conduct an assessment of the resident's ability to safely self-administer.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

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Medication Management

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.03

1) We dissent. This recommendation is redundant with several recommendations. Recommendations concerning Pre-Screening and Initial Assessment, and Service Plan also deal with assessing and implementing a care plan related to the resident's need for assistance with medication assistance, reporting a change in condition, periodic reassessments, etc

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Medication Management

M.04 Resident Assessment and Management of Medication

Recommendation

It is the responsibility of the resident who is self-administering medications his/her medication to provide the ALR with a written list of all prescribed and over-the-counter medication use and changes. When the resident is reassessed for continued ability to self-administer or manage medications, the list of current medications will be updated.

Implementation

Guideline for State Regulation

Rationale

The ALR needs to know the resident's medications so that this information may be conveyed to the appropriate health professionals in the event of an emergency situation.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Senior Citizens Law Center, National Adult Family Care Organization

Supplemental Positions for M.04
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1) We dissent. This recommendation is redundant with recommendations concerning Pre-Screening and Initial Assessment, and Service Plan which also deal with assessing and implementing a care plan related to the resident's need for assistance with medication assistance, reporting a change in condition, periodic reassessments, etc. The rights of residents to confidentiality of their medical affairs (refer to Recommendation on Residents Rights) would have to be discussed before assigning a responsibility to a resident to report medication usage to the ALR.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Medication Management

M.05 Resident Assessment and Management of Medication

Recommendation

For residents whom the ALR administers medication, an authorized prescriber(s) shall prescribe all medication, including over-the-counter medications. Such orders are kept current for all medications. The facility shall develop a process to ensure that the primary care physician be kept aware of all medications taken by the resident.

Implementation

Guideline for State Regulation

Rationale

This guideline is for the protection of the resident and the residence. Facility staff may not have the expertise to evaluate possible interactions between prescription drugs and over-the-counter medications or herbal supplements.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

American Seniors Housing Association, Assisted Living Federation of America, Joint Commission on Accreditation of Health Care Organizations, National Center on Assisted Living

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.05
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1) We dissent. The general thrust of this recommendation is that a person who prescribes medications must be authorized under existing laws. As such, this recommendation provides no new guidance to the states as to how improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

2) The organizations below agree with the concept of the recommendation passed as recommendation M.05 --Resident Assessment and Management of Medication--with one slight difference of opinion. We believe that the sentence that states that the "ALR must develop a process to ensure that the primary care physician be kept aware of all medications taken by the resident" places a burden on the ALR that is not achievable. Indeed, it is the ALR that must be kept aware by the primary care physician of the medications for which their residents have been prescribed for whom they provide medication management.

American Seniors Housing Association, National Center for Assisted Living

Medication Management

M.06 Medication Administration by Medication Assistive Personnel

Recommendation

Medication assistive personnel (MAP) may administer medications after successfully completing a state approved training course that includes a written and performance-based competency examination. To qualify for training as a MAP, the individual shall be a high school graduate (or equivalent) and have English language proficiency.

Implementation

Guideline for State Regulation

Rationale

When used incorrectly, medications may fail to achieve their intended purpose of controlling chronic diseases, and improving functional status and quality of life. Medication errors can also result in severe adverse effects, including loss of life. Because the consequences of inappropriate medication use are potentially severe, safeguards are needed to prevent harm to residents.

While it may not always be possible or feasible to have a licensed nurse to administer or supervise all medications for residents who need assistance in the assisted living setting, the personnel who provide this support need adequate training and supervision to safely fulfill these responsibilities. When the assisted living residence assumes responsibility for medication administration for one or more residents, the MAP who provides these duties shall have the training, supervision and evaluation needed for effective performance.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

AARP, Assisted Living Federation of America, National Association of Home Care, Center for Medicare Advocacy, National Association of State Ombudsman Programs, National Senior Citizens Law Center, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, Joint Commission on Accreditation of Health Care Organizations, National Association of Social Workers

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

Medication Management

Supplemental Positions for M.06

1) To meet the demands of safe and effective care, the performance of MAP medication administration should be under the supervision of a registered nurse (who may delegate this supervision to an LPN). States should allow the MAP to perform their duties through either or both approaches:

- 1) The state supports/creates a category of trained and certified medication assistive personnel who administer medication under the supervision of a registered nurse;
- 2) A registered nurse may delegate medication administration to MAP.

The RN may delegate supervision of the MAP to a Licensed Practical/Vocational Nurse. When the licensed nurse is not supervising onsite, he/she will be accessible by other means (e.g. telephone, pager, etc.).

The ALR administrator (or manager) and nurse supervisor are responsible for medication administration. MAP are accountable to the state, the facility administrator, and nurse supervisor for safe, efficient, and effective performance of their duties.

Appropriate qualified licensed health professionals should work with the ALR to develop policies and procedures related to:

- a) Medication management
- b) Receipt of medications and medication orders
- c) PRN medication administration
- d) Complex or high-risk drug regimens
- e) Supervision of the MAP, including determining when more frequent visits by the nurse are necessary
- f) Appropriate measures to address inadequate performance by the MAP
- g) Communication between MAP and supervising nurse
- h) Definition and documentation of medication errors and adverse medication events

The resident should be informed, in writing and prior to admission, of the ALR policies regarding medication administration by the MAP

Personnel who administer medications must be trained to practice under prevailing standards of medication administration as taught in accredited schools of nursing, and supervise to safely fulfill these responsibilities.

AARP, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Healthcare Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We dissent. This dissent is based on opposition to the broad authorization by medication management recommendations for "Medication Assistive Personnel" to administer medication. Although we recognize that there may be a need in an assisted living setting for administration of medication by non-nurses, the majority's recommendations give broad authority to MAPs, but require little training or oversight.

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Medication Management

Specifically, the majority's recommendations would allow any virtually any type of medication to be administered by a person with a high school equivalency degree, and some unspecified modicum of particularized training. This would be true in any assisted living residence, even if a nurse was almost never present, or if (for example) the residence claimed a specialization in the care of complex medical conditions.

It should be noted that existing state law offers much more specificity about training requirements. In Indiana, for example, a "qualified medication aide" must complete at least 100 hours of training – at least 60 hours of classroom instruction, plus at least 40 hours of supervised practicum. The practicum supervision must be conducted by a nurse. (Indiana Administrative Code, Title 412, §§ 2-1-3, 2-1-5)

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

3) We dissent. Recommendation requires states to adopt a state-approved training course for MAPs. Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the use of MAPs depends on the scope and interpretation of statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.07 Medication Assistive Personnel Job Description

Recommendation

The MAP shall have a job description that identifies the nature and scope of medication-related responsibilities. These duties shall not exceed the scope of the training and competency examination.

Implementation

Guideline for State Regulation

Rationale

The greater the expectations and duties of the MAP, the more training will be needed to meet the expectations. The job description should not include duties for which the MAP is not trained and evaluated.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association of Home Care, National Association of State Ombudsman Programs, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Senior Citizens Law Center, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for M.07

1) We dissent. There is no real content to this recommendation, particularly because this recommendation purportedly is a guideline for state regulation. The substance of the job description is left entirely to the assisted living residence, subject to other weak recommendations pertaining to medication assistive personnel.

The rationale acknowledges: "The greater the expectations and duties of the MAP, the more training will be needed to meet the expectations." Nonetheless, none of the recommendations pertaining to medication assistive personnel (with the sole exception of M.18, for insulin injections) makes any

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accommodation for the complex medical conditions presented by some assisted living residents.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. This recommendation for state regulation attempts to micromanage routine administrative paperwork and is beyond the mandate of the ALW.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.08 Curriculum for MAP Training Program

Recommendation

The learning and performance objectives for the MAP training program shall include:

- a. Satisfactorily demonstrate the six rights of medication administration (right resident, right drug, right dose, right route, right time, right documentation)
- b. Measure pulse, temperature, blood pressure, and respirations
- c. Measure pain using (an) appropriate scale(s)
- d. Describe the purpose of the various routes of medication administration
- e. Demonstrate appropriate storage of medications
- f. Follow appropriate infection control measures
- g. Understand anatomy as it relates to routes of medication administration
- h. Administer medications via the following routes: oral; topical, including topical patches; rectal; vaginal; stomal; eye, ear and nasal drops; inhalers; nebulizers; sublingual
- i. Documentation associated with the administration of medications
- j. Identification and reporting of common medications and their side effects
- k. Use resources/references related to medications
- l. Understand regulatory requirements related to medications

Implementation

Guideline for State Regulation

Rationale

The training program for the MAP within each state should be standardized to ensure that minimum standards are achieved. The items included on this list are considered to be important in any training program for MAPs involved in assisted living.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

American Seniors Housing Association, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Association of Home Care, National Committee to Preserve Social Security and Medicare, Center for Medicare Advocacy, National Association for Regulatory Administration, National Senior Citizens Law Center, National Academy of Elder Law Attorneys, National Citizens' Coalition for Nursing Home Reform, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations, Association for Social Workers

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1) We dissent. In general, the recommendations for medication assistive personnel do not recognize that some assisted living facilities care for residents with significant health care conditions. The very general standards set forth in this recommendation are inadequate to meet the needs of these vulnerable residents. The standards are set improperly at the lowest common denominator. This is particularly troubling given that a MAP has authority in the recommendations to administer medication through the rectum, the vagina, or a stoma.

These standards need more detail, and trainers should be required to meet certain minimum standards. Curriculum and trainers should be approved by the state health department or board of nursing.

Some existing state laws contain the type of detail that recommendation M.08 lacks. In Indiana, for example, training for "qualified medication aides" must include fundamentals of pharmacology, fundamentals of each of nine systems within the body, psychotherapeutic medications, infection, nutritional deficiencies, positioning of the patient, use of an oximeter, hemocult testing, applying a dressing to a healed gastrostomy tube site, and 21 other topics related to the administration of medication. The classroom training must be conducted by a registered nurse who has completed a state health instructor course. (Indiana Administrative Code, Title 412, § 2-1-3(2))

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. This recommendation sets forth the requirements that a state must include in a training program and infringes upon state authority. This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living. There is also an absence of any data to support what is considered to be the optimal training curriculum for assistive personnel.

American Seniors Housing Association, Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.09 Ongoing MAP Training

Recommendation

After successful qualification, MAP will receive relevant, regularly scheduled and as needed inservice or continuing education by a qualified licensed health professional that will enhance the MAP's ability to perform with confidence and competency, proficiency, safe practice, and meeting residents needs.

Implementation

Guideline for State Regulation

Rationale

New medications are continually being introduced in the market, and the residence may periodically change procedures as part of continuous quality improvement. It is important for MAP to keep informed of changes that impact the safe oversight or administration of medications.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Adult Family Care Organization, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association of Home Care, Center for Medicare Advocacy, National Association of State Ombudsmen Programs, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center, National Association for Regulatory Administration, National Academy of Elder Law Attorneys, National Citizens' Coalition for Nursing Home Reform, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations, National Association of Social Workers

Supplemental Positions for M.09

1) We dissent. This recommendation – which is being recommended as a guideline for state regulation – could never be enforced. Who is to say what is "relevant, regularly scheduled and as needed inservice or continuing education"? This recommendation, like many others, is so general that it provides no meaningful guidance for state regulation.

Existing state laws provide the content that this recommendation lacks. For example Kansas, which

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limits its nurse aides to oral administration and external application, requires ten hours of continuing education every two years. The continuing education must be provided by a registered nurse approved as an instructor by the state. (Kansas Administrative Regulations § 28-39-170(a), (b)(1)) Oklahoma requires at least eight hours of continuing education annually. (Oklahoma Administrative Code § 310:677-13-1(b))

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the use of MAPs and training requirements depends on the scope and interpretation of statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.10 MAP Activities Related to Medication Administration

Recommendation

MAP may perform the following activities related to medication administration, according to the needs of the individual resident:

- a. Receive medication and store it in an appropriate and secured location
- b. Identify the correct resident
- c. When indicated by the prescriber's orders, measure vital signs and administer medications accordingly
- d. Take the medication from the original container
- e. Crush or split the medication as necessary and ordered by the prescriber
- f. Place the medication in a medication cup or other appropriate container
- g. Bring and hand the medication to the resident
- h. Place the medication in the resident's mouth (or other route as indicated)
- i. Observe the resident taking their medication
- j. Complete documentation associated with medication administration.

MAPs may administer medication by the following routes: Oral; Topical, including topical patches; Rectal; Vaginal; Stomal; Eye, ear and nasal drops; Inhalers; Nebulizers; Sublingual

Implementation

Guideline for State Regulation

Rationale

At least 17 definitions of "medication administration" or "assistance with self-administration" have been developed in various states. There is no practical difference between these concepts, as confirmed by the wide variation in attempts to distinguish them.

The key issue in assisted living is whether the resident is able to independently manage medications without assistance. If the resident needs assistance at any level, the residence has accepted responsibility for managing the medications. The staff of the organization should then be expected to provide the needed assistance.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

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Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations, National Association of Social Workers

Supplemental Positions for M.10

1) We dissent. This recommendation puts residents' health at risk. The recommendation contemplates that medication assistive personnel could administer medication through the rectum, the vagina, or a stoma, and could administer any type of medication. This would be done even though the "supervising" nurse would infrequently or never be at the assisted living residence.

As explained above, in a dissent to recommendation M.09, the majority's training requirements for MAPs are very sketchy. Many existing state laws are much more careful in authorizing unlicensed staff members to handle medication. In Ohio, for example, staff members must be trained by a nurse, and are limited to assistance with a resident's self-administration of medication - reminding a resident to take medication, helping a resident to read and open a medication bottle, or assisting "a physically impaired but mentally alert resident" in the necessary physical tasks. (Ohio Administrative Code §§ 3701-17-55(E)(2)(a), 3701-17-59(F)) In Kansas a medication aide can administer medication only if the medication is for oral administration or external application. (Kansas Administrative Regulations § 28-39-170 (b)(1))

Administration of medication by unlicensed personnel might be an appropriate option in some circumstances, but such a program would need stricter limitations on the medication to be administered, and/or higher standards for training and supervision.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the use of MAPs and the scope of practice depend on the specification and interpretation of statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint

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Medication Management

M.11 Medication Packaging**Recommendation**

Each assisted living residence should adopt a consistent style of medication packaging for all residents for whom the residence provides medication administration. To the extent possible and consistent with meeting the needs of providing affordable care, medications for ALR residents should be provided in specialized packaging systems.

Implementation

Guideline for State Regulation

Rationale

Reducing process variation is a standard principle of continuous quality improvement. The consistent use of a specialized medication packaging system, such as unit dose or "bingo cards" throughout the facility provides a means of positive medication identification and reduces the risk of medication errors. Some systems may allow return and reuse of medications, which provides a cost savings to the resident.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Adult Family Care Organization, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.11

1) We dissent. The specialized packaging systems referenced in this recommendation are extremely important. In general, these specialized packaging systems hold one dosage of medication in a separate plastic bubble. Use of these packaging systems, instead of pouring out pills from a bottle, makes it much more likely that a resident will get a correct dosage – particularly if medication is to be administered by unlicensed "medication assistive personnel."

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Medication Management

Unfortunately, the majority's recommendation contains no requirement that these specialized packaging systems actually be used. The recommendation suggests that medications "should be" provided in specialized packaging systems, but only "[t]o the extent possible and consistent with meeting the needs of providing affordable care." If adopted as a regulation (as suggested by the majority), this recommendation would be meaningless, because an assisted living residence could be exempted merely by claiming that the appropriate packaging system was too expensive. By contrast, a meaningful regulation would require use of these specialized packaging systems.

Existing state laws are more appropriately prescriptive. For example, Alabama currently requires that assisted living facilities use these specialized packaging systems. (Alabama Administrative Code r. 420-5-4-.06(4)(j) (requiring "unit dose packaging"))

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. It is not known whether the process for timely adjustment of medications (when medications are added or deleted) is feasible with multi-dose packaging, especially in ALRs that receive medication from several pharmacies. The issue is when a medication is added or discontinued from a multi-dose pack, only the pharmacist may break into the pack and make the change – this is a logistical problem when a pack is already dispensed with multiple doses and either the pharmacy has to issue a new multi-dose pack (and the old one is discarded and wasted) or the pharmacist has to come to the ALR to remove/add the medication to the pack.

There are issues related to limiting consumer choice as well— requiring the resident to use a designated packaging system from a single pharmacy eliminates the resident's right to choose their own pharmacy; and the practice may result in increased medication costs if the resident was able to receive a better deal for their routine medications via mail order or another pharmacy provider.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Medication Management

M.12 Medication Packaging**Recommendation**

Congress and states should require all publicly funded pharmacy benefit programs to provide payment for specialized packaging for medications for older adults, including those who reside in assisted living. These pharmacy benefit programs include those affecting the Veterans Administration; retired federal employees; retired military personnel; medicare outpatient pharmacy benefit, if implemented; Medicaid.

Implementation

Guideline for Federal and State Policy

Rationale

To promote safe, accurate, and efficient medication administration to residents, the assisted living residence needs to adopt a consistent style of specialized medication packaging throughout the residence. Pharmacy benefit programs for older adults shall consider the special needs of those older adults who reside in assisted living or nursing facilities, or need specialized packaging to promote safe medication management practices.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.12

1) We dissent. No estimate is given of the cost of this recommendation or how it would be funded. Beyond the mandate of the ALW to make recommendations for new federal spending.

Assisted Living Federation of America, National Association of Home Care, Joint

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

Medication Management

Commission on Accreditation of Health Care Organizations

Medication Management

M.13 Storage**Recommendation**

Medications shall be stored safely, securely, and properly, following manufacturer's recommendations or those of the supplier, and in accordance with federal and state laws and regulations. Medications stored inside of a resident's unit shall be secured and accessible only to the resident, authorized persons, or both. Medications stored by the assisted living residence shall be stored in a designated area, which is secure, locked, and accessible only to authorized personnel.

Implementation

Guideline for State Regulation

Rationale

When stored at inappropriate temperatures, some medications are subject to rapid deterioration. Other medications, such as morphine and related products, are desirable targets for theft or diversion, and shall be stored securely. Residents with cognitive impairment and mental confusion may attempt to take medications that are not intended for them, if conditions permit. The residence has a responsibility to ensure that medications are stored appropriately.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Adult Family Care Organization, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.13
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- 1) We dissent. The thrust of this recommendation is that ALR must comply with existing federal
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Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

Medication Management

and state laws and regulations regarding storage of medications. As such, this recommendation provides no new guidance to the states as to how to improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.14 Medication Records

Recommendation

(1) The ALR shall maintain and periodically update the following medical information on every resident:

- (a) Emergency contacts (family/guardian)
- (b) Primary physician
- (c) Pharmacy provider
- (d) Current medical conditions and diagnoses
- (e) Allergies

(2) The ALR shall maintain a record on each resident to whom the residence administers medications. The record should include:

- (a) Resident's name;
- (b) Room number;
- (c) Allergies;
- (d) Diagnoses;
- (e) Prescriber's name;
- (f) Current record of all prescription and non-prescription medication;
- (g) Medication name, strength, dosage form, dose, route of administration, and any special precautions;
- (h) Frequency of administration and administration times;
- (i) Duration of therapy;
- (j) Date ordered, date changed, date discontinued;
- (k) Indication for use of as needed (PRN) medications;
- (l) Date and time of medication administration;
- (m) Name and initials of the person administering the medication; and
- (n) Location of where resident's medications are stored

Implementation

Guideline for State Regulation

Rationale

Assisted living residents are usually frequent users of the health care system. The assisted living residence should maintain basic information about each resident so that critical information can be available to the health professionals who care for the resident, especially in emergency situations.

When the residence accepts responsibility for medication management, basic information about the resident, medications, and conditions being treated shall be maintained. This information may be critical in later evaluations of the resident's drug therapy, including effectiveness and safety of the medications in use.

Organizations Supporting This Recommendation

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging
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AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.14
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1) We dissent. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority***
Medication Management

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not show a voting record were unable to reach two-thirds majority during the development process.

Medication Management

M.15 Definitions**2/3 Maj. Not Reached****Recommendation**

a. **Significant Change:** A new or markedly different physical, functional, cognitive or psychosocial condition in a resident that impacts the service delivery of the resident's individual service plan, to include:

- Deterioration or improvement in an individual's health status or ability to perform activities of daily living;
- A deterioration or improvement in an individual's behavioral or mood status.

b. **Authorized Prescriber** – A licensed health professional that meets the federal and state requirements for prescribing medications and treatments.

c. **Medication Assistive Personnel (MAP)** are caregivers who are not licensed health professionals but have successfully completed training and a state-approved competency examination, that permits the person to administer medications to a resident.

d. **Medication Management** is the structures and processes established by the assisted living residence to establish accountability and safe use of medications. Elements of medication management include:

- Acquisition of medications
- Storage of medications
- Receipt and verification of medications
- Administration of medications
- Medication reminders
- Disposition of medications
- Resident assessment and monitoring
- Record keeping
- Medication review
- Quality improvement
- Resident identification system (e.g. photographs)

e. **Medication Administration** is the process of providing medications to residents or assisting residents with taking their medications. Medication administration may include the following elements, which can only be performed by medication assistive personnel or qualified licensed health professionals:

- Observe the resident taking their medication, to verify consumption of the medication
- Take the medication from the original container
- Correctly identify the resident
- Place the medication in a medication cup or other appropriate container
- Crush or split the medication as necessary and ordered by the prescriber
- Bring and hand the medication to the resident
- Place the medication in the resident's mouth (or other route as indicated)
- Document that the medication was administered to the resident, or refused by the resident
- Assisting the resident with self-administration

Medication Management

f. Medication Reminder – Verbal or written= cuing to alert the resident to take scheduled medication, including documentation that the resident was reminded.

g. Qualified licensed health professional is a physician, physician's assistant, pharmacist, nurse practitioner, or registered nurse acting within their scope of practice.

h. Self-Administration – Independent management and administration of medication by the resident without assistance or oversight from the assisted living residence. This could include the use of electronic cuing devices.

Implementation

Guideline for State Regulation

Rationale

In summary, three levels are recognized with regard to residents and medications:

- Resident self-administration (no involvement by residence staff)
- Medication reminders (can be done by staff who are not trained as MAPs)
- Medication administration, which can be done by appropriate health professionals or unlicensed assistive personnel (MAPs)

Balancing the goals of the assisted living workgroup was a driving force in developing these recommendations. Consumers, providers, regulators, and health professionals have valid concerns related to medication management in the assisted living residence. These sometimes-differing goals include:

- Resident autonomy in decision-making
- Resident safety and protection from medication errors and medication-related problems
- Flexibility for the assisted living residence
- Managing costs for the resident and the assisted living residence
- Responsibility of the nurse and other licensed health professionals for the role of the medication assistive personnel
- Reciprocity between states of qualifications and certifications for medication assistive personnel

State laws and regulations governing the administration and use of medications in assisted living vary considerably. In some states, the term "assistance with self-administration" is used in place of "administration" to describe the same process. This is due to legal restrictions that permit the use of the term "administration" only in the context of licensed health professionals. The Assisted Living Workgroup recommends that the term "assistance with self-administration" NOT be used because of the confusion that results from use of the term.

The assisted living workgroup recommends that the term "administration" be used to describe the activities associated with administering or assisting residents with medications, whether these activities are conducted by a health professional or by unlicensed assistive personnel (with appropriate training and competency testing).

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging
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Medication Management

It is recognized that some states will need to change laws or regulations to adopt the medication management model presented here. Because of the wide variability in state laws and regulations on this subject, this would be true no matter what model or recommendations are made. This model was designed to provide a medication management system that meets the needs of the residents and the residence.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for M.15
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1) Statement in support of the recommendation. It is necessary to clarify the ambiguity that exists in many state regulations regarding the terms medication management, medication administration, and assistance with medications. It is additionally necessary to clarify the role of unlicensed staff persons in medication management and administration. This position is intended to show strong support for the definitions and medication management model as described in the above recommendation.

To clarify this, text from the rationale is restated:

State laws and regulations governing the administration and use of medications in assisted living vary considerably. In some states, the term "assistance with self-administration" is used in place of "administration" to describe the same process. This is due to legal restrictions that permit the use of the term "administration" only in the context of licensed health professionals. The Assisted Living Workgroup recommends that the term "assistance with self-administration" NOT be used because of the confusion that results from use of the term.

It is recommended that the term "administration" be used to describe the activities associated with administering or assisting residents with medications, whether these activities are conducted by a health professional or by unlicensed assistive personnel (with appropriate training and competency testing).

Medication Management

It is recognized that some states will need to change laws or regulations to adopt the medication management model presented here. Because of the wide variability in state laws and regulations on this subject, this would be true no matter what model or recommendations are made. This model was designed to provide a medication management system that meets the needs of the residents and the assisted living residence.

AARP, American Seniors Housing Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, Association of Professional Geriatric Care Managers, American College of Healthcare Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We oppose this failed recommendation. This opposition is based on the recommendation's definition of "Medication Assistive Personnel" or "MAP."

Medication mistakes have been recognized as a serious problem within assisted living. See, e.g., General Accounting Office, *Assisted Living: Quality-of-Care and Consumer Protection in Four States* 27, GAO/HEHS-99-27 (1999) (medication administration the third most common problem in assisted living). This problem could be addressed by requiring all medication administration to be performed by nurses, but other medication management recommendations authorize the use of MAPs for the administration of virtually all types of medication, even though the MAPs may be minimally-trained for the administration of medication, without knowledge of even basic personal care skills, and without meaningful supervision.

Medication administration by unlicensed personnel might be an acceptable strategy for some residents, and for some medication. But the other medication management recommendations make no allowances for the resident's health care conditions, or for the type of medication being administered. Existing state laws are far superior in balancing safety with expense, and in recognizing that some assisted living residents have health care conditions that require nurse expertise.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

3) We agree with much of the recommendation but believe that letter G needs to read as follows: Qualified Licensed Health Professional is a physician, physician's assistant, pharmacist, nurse practitioner, or licensed nurse (in lieu of registered nurse) acting within their scope of practice.

Alzheimer's Association, American Seniors Housing Association, National Center for Assisted Living

4) We dissent. Many of the ALW's recommendations on Medication Management hinge on the use Medication Assistive Personnel (MAPs) administering medications to residents. MAPs would perform their duties under the supervision of a RN.

Some states currently allow aides who have completed and passed a training program to administer

Medication Management

medications, while other states do not. To a large extent, the use of MAPs depends on the scope and interpretation of statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.16 Supervision of Medication Assistive Personnel

2/3 Maj. Not Reached

Recommendation

The performance of MAP medication administration is under the supervision of a registered nurse. States will allow the MAP to perform their duties through either or both approaches:

- 1) The state creates a new category of trained and certified medication assistive personnel who administer medication under the supervision of a registered nurse;
- 2) A registered nurse may delegate medication administration to MAP.

When not supervising onsite, a registered nurse will be accessible by other means (e.g. telephone, pager, etc.). The RN may delegate supervision of the MAP to a Licensed Practical/Vocational Nurse.

A Registered Nurse will verify the MAPs medication administration competencies, including basic knowledge regarding medication issues, at the time of employment by the ALR and/or prior to the MAPs administration of any medication.

The ALR administrator (or manager) and RN supervisor are responsible for medication administration. MAP are accountable to the state and to the facility administrator, and RN supervisor for safe, efficient, and effective performance of their duties.

The RN and appropriate qualified licensed health professionals will work with the ALR to develop policies and procedures related to:

- a) Medication management
- b) Receipt of medications and medication orders
- c) PRN medication administration
- d) Complex or high-risk drug regimens
- e) Supervision of the MAP, including determining when more frequent visits by the ORN are necessary
- f) Appropriate measures to address inadequate performance by the MAP
- g) Communication between MAP and supervising RN; role of LPN/LVN if applicable
- h) Definition and documentation of medication errors

The resident is informed in the admission agreement of the ALR policies regarding medication administration of the MAP and supervision by the RN (and licensed nurse, if applicable).

Implementation

Guideline for State Regulation

Rationale

Personnel who administer medications shall be trained to practice under prevailing standards of medication administration as taught in accredited schools of nursing, and supervise to safely fulfill these responsibilities.

Definitions (from Delegation: Concepts and Decision-Making Process, National Council on

Medication Management

State Boards of Nursing, 1995)

--Accountability: Being responsible and answerable for actions or inactions of self or others in the context of delegation.

--Delegation: Transferring to a competent individual the authority to perform a selected nursing task in a selected situation. The nurse retains accountability for the delegation.

--Supervision: The provision of guidance or direction, evaluation and follow-up by the licensed nurse for accomplishment of a nursing task delegated to unlicensed assistive personnel.

The National Council on State Boards of Nursing (NCSBN) is recommended as a resource for guidelines regarding the principles and practices of appropriate and safe delegation

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Bar Association

Supplemental Positions for M.16

1) We oppose this failed recommendation. Under this recommendation, a nurse might only be at the assisted living residence once or twice a year, or even less frequently. The recommendation in December 2002 stated that "[a] registered nurse will be onsite to directly observe each MAP at least quarterly," but the current recommendation contains no requirement at all that a nurse be present.

The recommendation acknowledges that medication assistive personnel might be involved with "PRN [as-needed] medication administration" and "[c]omplex or high-risk drug regimens." The recommendation, however, contains no assurances that medication assistive personnel would be capable of handling such difficult situations, particularly considering that a nurse almost certainly would not be on-site.

The recommendation also attempts to draw a confusing distinction between supervision and

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delegation. The distinction suggests that delegation to medication assistive personnel could be carried out even if the personnel were neither trained nor certified.

Many state laws require much greater participation by licensed health care professionals. In many states – California, Florida, and Illinois, for example – all medication administration must be performed by a licensed health care professional. (California Code of Regulations, Title 22, §§ 87575,(a)(5), (6), 87582(b); Florida Administrative Code Annotated r. 58A-5.0181(1)(e)(2); 210 Illinois Compiled Statutes Annotated 9/70) Participation by licensed health care professionals is mandated even in those states that authorize administration by unlicensed personnel; in Oklahoma, for example, medications must be reviewed monthly by a registered nurse or pharmacist, and quarterly by a consultant pharmacist. (Oklahoma Administrative Code § 310:663-9-2(a))

American Geriatrics Society, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Conference of Gerontological Nurse Practitioners, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the use of MAPs depends on the scope and interpretation of statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

3) We support the use and training of MAP and medication administration. The performance of MAP medication administration should be under the supervision of a licensed nurse (in lieu of registered nurse) acting within their scope of service.

National Center for Assisted Living, American Seniors Housing Association

Medication Management

M.17 MAP and PRN Medications

2/3 Maj. Not Reached

Recommendation

MAP may administer PRN (as needed) medications when the medication orders meet all of the following specifications:

- a. The PRN medication has been prescribed for the resident by an authorized prescriber.
- b. The minimum time interval for the medication is clearly defined in the prescriber's instructions (e.g. every 4 hours, not every 4-6 hours)
- c. The symptom or conditions for administration of the medication are clear and specific in the prescriber's instructions (e.g. PRN headache or knee pain, not PRN pain).
- d. Instructions for contacting the prescriber are included in the prescriber's instructions (e.g. Acetaminophen 325 mg tablets, two tablets every four hours PRN fever < 101 degrees F, contact prescriber if 101 or above).

When the resident is capable of requesting a dose of PRN medication, the MAP may administer the medication to the resident. When the resident is unable to initiate the request for a PRN medication, the MAP should check for the symptoms or conditions related to the administration of the PRN medication and administer the PRN medication as needed.

Implementation

Guideline for state regulation.

Rationale

Clearly defining criteria for the use of PRN medications, it removes the need for a MAP to make a clinical assessment and judgment as when to administer it.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

American College of Health Care Administrators, American Seniors Housing Association, Assisted Living Federation of America, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association of State Ombudsman Programs, National Association of Home Care, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, Joint Commission on Accreditation of Health Care Organizations, National Association of Social Workers, National Association of Local Long Term Care Ombudsmen

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Medication Management****Supplemental Positions for M.17**

1) Statement in support of the recommendation. PRN medications are commonly prescribed and administered in a variety of settings, including one's own home. In order for the role of the MAP to be complete and to truly meet the needs of the resident, PRN medications must be addressed. The above recommendation (M.17) provides for a system of training and competency verification prior to allowing the MAP to administer the PRN medication. The recommendation also provides for additional safety by ensuring proper documentation both in the prescriber's instructions and on the medication label.

AARP, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Association of Activity Professionals, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America

Medication Management

M.18 MAP and Insulin Injections**2/3 Maj. Not Reached****Recommendation**

MAP may administer insulin injections to residents who have stable diabetes, when all of the following conditions are met:

- a. The MAP has completed a state-approved training program ((with input from the state board of nursing) that includes instruction on diabetes symptoms and complications, and safe and accurate administration of insulin injections, with practical experience in insulin injection technique.
- b. The residence has policies and procedures on administration of insulin injections.
- c. The MAP has been tested and demonstrated competency on administration of insulin injections and use of a blood glucose monitor by a qualified licensed health professional. If the blood glucose value is outside the range established by the resident's physician, the MAP will immediately contact the appropriate qualified licensed health professional, according to the ALR policy.
- d. A qualified licensed health professional observes the MAP's ability to administer insulin injections at least every 90 days. This review will include a review of medication administration records by a qualified licensed health professional.

Implementation

Guideline for State Regulation

Rationale

Because of the risk associated with inappropriate administration or dosing of insulin, special training and competency checks are necessary. Residents with unstable diabetes, such as those receiving insulin according to a sliding scale schedule, require close medical supervision. If unable to manage their insulin without assistance, these residents should be assisted by a licensed nurse.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

Medication Management

Association of Health Facility Survey Agencies, Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for M.18

1) Statement in support of the recommendation. The risk for Type 2 diabetes increases with age. Nearly 20.1% of the United States population or 7.0 million people age 65 and older have diabetes. (American Diabetes Association)

Medical and indirect expenditures attributable to diabetes in 2002 were estimated at \$132 billion, with 51.8% of direct medical expenditures incurred by people over 65 years of age. The report also states that more than \$1 out of every \$4 spent for nursing home, home health, and hospice care is spent to provide services to someone with diabetes. (Economic Costs of Diabetes in the U.S. in 2002. American Diabetes Association. 2003.)

These statistics demonstrate a clear need for a safe, and cost-effective alternative for seniors with diabetes. This recommendation begins to lay the ground-work for this type of solution. To that end, the recommendation includes several important elements that help to ensure the safe administration of insulin injections by MAP:

1. Only recommended for stable diabetics.
2. State-approved training must be completed prior to administering insulin.
3. Ongoing monitoring by a qualified licensed health professional.

AARP, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We oppose this failed recommendation. As set forth in more detail in dissents for recommendations M.06, M.07, M.08, M.09, M.10, and failed recommendation M.16, the recommendations for medication assistive personnel are fundamentally flawed. Although recommendation M.18 attempts to set legitimate standards for insulin injections, it is based untenably on the unsound framework set forth in the other recommendations related to medication assistive personnel.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

3) We believe that residents with diabetes who are insulin dependent should be able to live in assisted living if their needs can be met. Insulin injections should be administered in accordance to the individual state nurse practice act.

American College of Health Care Administrators, National Center for Assisted Living, American Seniors Housing Association

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Medication Management**

4) We dissent. Many ALW's Recommendations on Medication Management hinge on the use Medication Assistive Personnel (MAPs) administering medications to residents. MAPs would perform their duties under the supervision of a RN.

Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the scope of practice of assistive personnel depends on statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association of Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.19 MAP and Enteral Medication Administration**2/3 Maj. Not Reached****Recommendation**

MAP may administer medications through an enteral tube (e.g. NG (nasogastric), gastrostomy, or PEG (percutaneous enteral gastrostomy tube) to residents when the following conditions are met:

- a. The MAP has completed a training program that includes instruction in proper technique for administration of medications through an enteral tube, including checking for proper placement of the enteral tube.
- b. The MAP has been tested on administration of medications via enteral tube by a qualified licensed health professional.
- c. The qualified licensed health professional observes the MAP's ability to administer medications via an enteral tube at least every 90 days. This review will include a review of medication administration records by the qualified licensed health professional.
- d. The residence has policies and procedures on administration of medications via enteral tube, including what to do if the tube gets clogged.
- e. If there is any doubt that the enteral tube is not in proper placement, the resident's physician is immediately contacted. No medications or feedings are administered until receiving further orders from the physician..

Implementation

Guideline for State Regulation

Rationale

Enteral therapy is a special skill that requires additional instruction and competency, due to risks associated with enteral therapy, such as misplacement of the tube or incompatibility of medications.

Organizations Supporting This Recommendation

No Vote Recorded

Organizations Opposing This Recommendation**Organizations Abstaining From the Vote on This Recommendation**

Supplemental Positions for M.19
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1) MAP should be authorized to administer medications through an enteral tube to residents when the following conditions are met:

- a. The MAP has completed a training program that includes instruction in proper technique for administration of medications through an enteral tube, including checking for proper placement of the enteral tube.
- b. The MAP has been tested on administration of medications via enteral tube by a qualified licensed health professional.
- c. The qualified licensed health professional observes the MAP's ability to administer medications via an enteral tube at least every 90 days. This review will include a review of medication

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administration records by the qualified licensed health professional.

d. The residence has policies and procedures on administration of medications via enteral tube, including what to do if the tube gets clogged.

e. If there is any doubt that the enteral tube is not in proper placement, the resident's physician is immediately contacted. No medications or feedings are administered until receiving further orders from the physician.

AARP, American Assisted Living Nurses Association, NCB Coming Home Project

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Medication Management

M.20 Telephone Orders**2/3 Maj. Not Reached****Recommendation**

MAP shall not have the authority to receive medication orders. When a prescriber attempts to issue an order for a medication via telephone to the MAP, the MAP will instruct the prescriber to do one of the following:

1. Fax the order directly to the ALR, or
2. Issue the order via telephone to a licensed nurse who is onsite in the ALR, or
3. Issue the order directly to the pharmacy

Implementation

Guideline for State Regulation.

Rationale

The completeness and accuracy of medication orders are essential to safe and successful medication administration. Because of potential risks and the complexity of medication orders, they are to be submitted to the facility in writing or directly to a qualified licensed health professional.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for M.20
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1) The completeness and accuracy of medication orders are essential to safe and successful medication administration. Because of the potential risks and the complexity of medication orders, the protocol for telephone orders must be addressed by state regulation. The undersigned fully support M.20.

AARP, American Association of Homes and Services for the Aging, American Society

Medication Management

of Consultant Pharmacists, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We dissent. Many ALW's Recommendations on Medication Management, such as this one, hinge on the use Medication Assistive Personnel (MAPs) administering medications to residents. MAPs would perform their duties under the supervision of a RN.

Some states currently allow aides who have completed and passed a training program to administer medications, while other states do not. To a large extent, the scope of practice of assistive personnel depends on statutory or regulatory language related to delegation in each state's Nurse Practice Act (NPA). There may be additional statutes and regulations outside of those governed by state boards of nursing that will impact on delegation.

This recommendation offers no alternative recommendations for those states where existing laws or regulations do not allow MAPs in assisted living nor does it suggest guidance as to how licensing agencies or ALRs should approach reconciling statutory conflicts that lie outside the arena of assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management

M.21 Quality Improvement**2/3 Maj. Not Reached****Recommendation**

Each assisted living residence that administers medications shall adopt or create a quality improvement program to set and implement standards, evaluate performance and implement necessary changes for improvement of medication management. This quality improvement program should address the full range of medication management services provided by the residence.

The quality improvement program includes a system for identifying, collecting, documenting, and reporting medication errors. The QI team reviews results of medication error reports and medication reviews to identify areas where improvements can be made in the medication management system.

The QI team also establishes residence policies and guidelines for medication usage (e.g. psychotropics, pain management, anticoagulants, etc.) and reviews patterns of use of psychotropic medications to ensure appropriate use of these agents. Non-pharmacological approaches should always be considered in the management of various conditions (e.g. pain, behavioral symptoms associated with dementia, etc.).

The quality improvement program is directed and implemented by a team that includes:

- The administrator or manager of the residence
- A consultant pharmacist
- A registered nurse (e.g. staff, consultant, home health or hospice nurse)
- Physician or other authorized prescriber
- A Medication Assistive Personnel (MAP), if employed by the facility

2. An ALR that provides medication reminders shall implement a quality oversight and improvement process that relates to the system of reminding residents.

Implementation**Guideline for State Regulation****Rationale**

Medication management is affected by a variety of factors, which are subject to change over time. A structured quality improvement process is needed to evaluate the effectiveness of the medication management program on a regular basis, so that needed changes can be identified and improvements made as needed.

Quality improvement efforts require participation by all the key stakeholders in the medication management system. The interdisciplinary team should work together to coordinate quality improvement efforts.

Medication errors are usually caused by deficiencies in the medication use system. Reports of errors are collected and analyzed to identify ways to improve the medication use system and build in safeguards to prevent injury to residents. The residence should encourage reporting of medication errors in an environment and culture that focuses on

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Medication Management

improving medication accuracy.

Evaluation of results of medication reviews can help the residence identify high-risk medications or conditions that may require special monitoring or interventions to improve safe use of medications in the residence.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Catholic Health Association of the United States, Center for Medicare Advocacy, Joint Commission on Accreditation of Health Care Organizations, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Association of Health Facility Survey Agencies, National Committee to Preserve Social Security and Medicare

Supplemental Positions for M.21
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1) Medication management is affected by a variety of factors that are subject to change over time. A structured quality improvement process is needed to evaluate the effectiveness of the medication management system on a regular basis so that needed changes can be identified and improvements made. The undersigned fully support M.21.

AARP, American College of Health Care Administrators, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We encourage assisted living residences to develop a process for improving the overall quality of care provided to its residents, not simply medication management. Providers can design these programs to review medication errors, falls, and any other issues the assisted living residence deems important.

Catholic Health Association of the United States, National Center for Assisted Living, American Seniors Housing Association, American Association of Homes and Services for the Aging

3) We dissent. This recommendation for a quality improvement program assumes a multi-disciplinary team akin to a SNF. This is not typically the case in assisted living, nor are the health

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records as complete as a SNF. Given typical staffing models and the current lack of contracted pharmacists and attending physicians, the recommendation is not realistic and could be cost prohibitive for many small providers.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Medication Management**M.22 Consultant Pharmacist Role****2/3 Maj. Not Reached****Recommendation**

Each ALR shall assess whether an agreement is needed with a consultant pharmacist to assist the residence with medication management is necessary. The consultant pharmacist may be contracted for independently or through the ALR's primary pharmacy. The consultant pharmacist is responsible to assist the ALR with medication management issues, including ensuring the security and accountability of controlled substances.

To assist the ALR with medication management, the consultant pharmacist duties, in collaboration with the quality improvement team, shall include:

- a. Assist the residence in setting standards and developing, implementing, and monitoring policies and procedures for the safe and effective distribution, storage, control and use of medications, including controlled substances, and related equipment and services of the residence
- b. Assist with inservice education of ALR staff on medication management issues
- c. Review ALR documentation related to medication orders and administration of medications to residents
- d. Review patterns of use of various medications (e.g. psychotropics, pain management, anticoagulants, etc.) for compliance with ALR policies and guidelines.
- e. Provide a written report of findings and recommendations resulting from the review. The report is provided to the ALR administrator, who shares it with the QI team and discusses it with appropriate ALR personnel, and follow-up actions are recommended as needed.

Implementation

Guideline for State Regulation

Rationale

Medication management is a critical function that provides essential support to most assisted living residents, and serious harm can result to residents when the system fails to function properly. Consultant pharmacists have specialized expertise in developing, monitoring, and improving medication management systems in long-term care settings. Involvement by a consultant pharmacist is a minimum standard to help prevent medication errors and ensure accountability of controlled drugs in the ALR. States should develop criteria to assist ALRs in assessing the need for a consultant pharmacist.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, National Association of Activity Professionals, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

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American Association of Homes and Services for the Aging, American Seniors Housing Association, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Joint Commission on Accreditation of Health Care Organizations, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

NCB Development Corporation, National Association of Professional Geriatric Care Managers

Supplemental Positions for M.22

1) We oppose this failed recommendation. Under this recommendation, an assisted living residence is required only to "assess" whether an agreement with a consultant pharmacist is necessary. This would be a meaningless and unenforceable regulation.

A comparison with existing state law indicates the flimsiness of this recommendation. For example, state laws in Arkansas and Oklahoma contain requirements that assisted living residences contract with and use a consultant pharmacist. (Code Arkansas Rules 016 06 002, § 702.2.1 (Level II assisted living facilities); Oklahoma Administrative Code § 310:663-9-2(a))

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We dissent. Unlike in a SNF, consent by the ALR resident would be needed for review of medication records and could impact on a resident's right to privacy. Refer to the recommendation on Resident Rights and a resident's right to confidentiality of medical records. The financial cost of contracting for a consultant pharmacist could have a disproportionate impact on small providers.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

3) We are opposed to this recommendation due to its cost implications for residents. It is important to keep in mind that many assisted living residents are on limited incomes. In addition, we believe assisted living providers are capable of determining when outside consultants are needed and for what issues.

National Center for Assisted Living, American Seniors Housing Association

Topic Group Recommendations Adopted by Two-Thirds Majority of the ALW Operations

Purpose

The Operations Topic Group of the Assisted Living Workgroup had as its focus both environmental elements and operational processes which foster quality of life, quality of care, and safety for everyone involved in an assisted living residence.

Issues

The topic group made recommendations in the following areas: activities; activities for special care populations; assisted living resident councils; food storage, preparation and transporting; transportation; smoking; environmental management; building codes, fire safety, life safety, evacuation plans, contingency plans, emergency protocols; and security for wandering residents.

Participants

The topic group was co-chaired by Mary Anne Kelley of the Pioneer Network and Ken Preede of the American Seniors Housing Association.

Topic group participants included Lyn Bentley, National Center for Assisted Living; Marianna Grachek, Joint Comm. on the Accreditation of Healthcare Organizations; Rick Harris, Association of Health Facility Survey Agencies; Donna Lenhoff, National Citizens' Coalition for Nursing Home Reform; Toni McMonagle, Consulting Dietitians in Healthcare Facilities; Doug Pace, American Association of Homes and Services for the Aging; Jackie Pinkowitz, Consumer Consortium on Assisted Living; Bonnie Ruechel, National Association of Activity Professionals; Beth Singley, Assisted Living Federation of America; Catherine Zofkie, American Medical Directors Association

Operations

O.01 Building Codes**Recommendation**

Assisted living residences should comply with applicable state and/or local building codes according to the residents they serve. States should regularly update their requirements and adopt the most current national version of building codes to ensure that state of the art perspectives on building safety which have been incorporated into national building codes are incorporated in state requirements.

Implementation

Guideline for State Regulation

Rationale

There are various building codes, Building Occupational Code Authority (BOCA) and International Building Code (IBC) to name two, and the codes have been developed by professionals who are familiar with both necessary construction standards and the provider entity for which the code has been developed. It seems counter-productive for us to attempt to reinvent what is already in existence. Furthermore, states and local jurisdictions often include additional requirements specific to certain conditions in their locale: for example, requirements based on ensuring safe buildings in the event of an earthquake, a tornado or a hurricane.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Multiple Sclerosis Society, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

Center for Medicare Advocacy

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.01

- 1) We dissent. The general thrust of this recommendation is that ALRs must comply with existing

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state and local building codes. As such, this recommendation provides no new guidance to the states to improve quality in assisted living.

*Assisted Living Federation of America, National Association for Home Care,
National Association for Regulatory Administration, Joint Commission on
Accreditation of Health Care Organizations*

2) We support this recommendation as it is written and want to clarify a portion of the Rationale. Since the recommendation was written, the National Fire Protection Association (NFPA) 5000 Building Code was adopted by NFPA. This is the first building code developed through an open, consensus-based process that is accredited by the American National Standards Institute (ANSI), the administrator and coordinator of the United States private sector voluntary standardization system. Requirements in NFPA 5000 are designed to be consistent with the NFPA 101 Life Safety Code.

*Consumer Consortium on Assisted Living, National Center for Assisted Living,
American Seniors Housing Association, American Association of Homes and Services
for the Aging*

Operations

O.02 Life Safety Compliance**Recommendation**

According to services provided and evacuation capacity assisted living residences should comply with the most appropriate chapter, and the most current version of the National Fire Protection Association Life Safety Code (NFPA 101) and/or the International Code Council's (ICC) International Fire Code (IFC), or equivalent standards.

Implementation

Guideline for State Regulation

Rationale

There are two primary Life Safety Codes that have been developed: NFPA 101 and ICC's International Fire Code. These codes have been created by groups of experts in both fire safety and the provider entity for which the code has been developed. These codes are updated on a regular basis to reflect the most current safety standards and measures recognized by fire safety professionals. Many jurisdictions develop their own codes using one of these documents as a template.

Each code is reviewed and updated on a three-year cycle. The codes always include specifications related to "new buildings" and "existing buildings". The requirements for new buildings tend to reflect the most current and up to date life safety standards that are in existence. For "existing buildings" new requirements are imposed when they reflect new, state of the art equipment or design that will clearly provide increased protection for building occupants. For example, when smoke detectors first came on the market, all new facilities had to have them and existing facilities also had to install smoke detectors. Additionally, when "significant renovations" are made to an existing building, that portion of the building shall comply with new life safety code standards for new buildings.

When a state is adopting a particular building classification, it is important to consider the type of residents who will likely be living in an assisted living facility paying particular attention to the level of frailty, cognitive ability, and the degree to which the residents may need assistance in evacuating the building. It is also important for the state to consider the cost to the consumer of the particular building classification and the relative safety that will be created.

When a state is determining to which building code assisted living facilities shall comply, there are several questions that shall be asked and answered:

- What type of evacuation capabilities will be necessary?
- What type of individuals will be living in the building and how quickly will they be likely to evacuate?
- What level of frailty will individuals residing in this building eventually reach (based on move-in and move-out criteria of provider policies and the state regulations)?
- Will many individuals require the use of assistive devices for purposes of mobility, such as walkers and wheelchairs?

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Operations

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Multiple Sclerosis Society, National Adult Family Care Organization, National Center for Assisted Living, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

National Network of Career Nursing Assistants

Supplemental Positions for O.02
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1) We dissent. This recommendation has no content. It fails to set a standard and, instead, merely asks assisted living operators to voluntarily comply with what the operator believes or claims is the appropriate NFPA chapter according to services provided and evacuation capacity. A more appropriate recommendation would require states to adopt specific NFPA or other applicable safety code. We recommend NFPA Life Safety Code: Residential Board and Care Occupancies, Impractical Evacuation Capability, excluding NFPA 101A Alternative Approaches to Life Safety.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) We support this recommendation as it is written and want to clarify a portion of the rationale. The National Fire Protection Association (NFPA) 101 Life Safety Code is the only life safety code that is developed through an open, consensus-based process that is accredited by the American National Standards Institute (ANSI), the administrator and coordinator of the United States private sector voluntary standardization system. Requirements in NFPA 101 are consistent with the NFPA 5000 Building Code.

Consumer Consortium on Assisted Living, National Center for Assisted Living, American Seniors Housing Association, American Association of Homes and Services for the Aging

3) We dissent. The general thrust of this recommendation is that ALRs must comply with existing Life Safety Code standards. As such, this recommendation provides no new guidance to the states or ALRs to improve quality in assisted living.

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Operations

*Assisted Living Federation of America, National Association for Home Care, Joint
Commission on Accreditation of Health Care Organizations*

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Operations

O.03 Communication of Life Safety Standards**Recommendation**

An assisted living facility shall provide information to prospective residents and/or their families about the type of life safety standards that are in place that offer protection for residents. This information shall include such things as: whether the facility is sprinklered; and if the building is designed such that residents who require significant assistance for evacuation will be protected and able to reside in the ALR.

Implementation

Guideline for State Regulation

Rationale**Organizations Supporting This Recommendation**

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Citizens' Coalition on Nursing Home Reform, National Adult Family Care Organization, National Committee to Preserve Social Security and Medicare, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Association of Health Facility Survey Agencies, American Seniors Housing Association, Center for Medicare Advocacy, Joint Commission on Accreditation of Health Care Organizations, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.03
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1) In large measure, the real need for this recommendation derives from the fact that the previous recommendation (O.02), in the form submitted by the majority, fails to ensure that appropriate life safety code standards apply to all facilities. This recommendation, then, is an inadequate attempt to provide protection to residents by ensuring some pro forma disclosure concerning the degree of life safety code protection provided. Such disclosure is no substitute for requiring compliance with specific, enforceable life safety standards. Moreover, it is not at all clear that such disclosure would really give consumers useful information about the fire safety risks in a particular facility. The codes themselves and other aspects of safety features would be difficult for the average consumer to understand, being technical in nature and addressing characteristics of materials, construction, and other building features.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy,

Operations

National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) Communication of life safety information to residents* is very important, particularly when a resident is cognitively impaired and the family seeks assurance that the individual's needs in this regard will be met. We have concern with phrase in the last sentence: "designed such that residents who require significant assistance for evacuation will be protected and able to reside in the ALR." There are no life safety protections in existence that will absolutely provide 100% safety to every individual in any building.

We suggest the recommendation should read:

An ALR should disclose upon request their life safety plan and fire plan. This information should include such things as: whether the facility is sprinklered; and if the building and evacuation plan are designed such that residents who require significant assistance for evacuation will be able to reside in the ALR with as much protection from fire as is reasonably possible.

Association of Homes and Services for the Aging, National Center for Assisted Living, American Seniors Housing Association

3) We dissent. This recommendation requires ALRs to disclose to residents if the building is designed in such a way that residents who require significant assistance for evacuation will be protected and able to reside in the ALR. The wording of the recommendation is unclear as to intent. The wording could be interpreted to mean that an ALR must give assurance a resident will be able to reside in the building if they need significant assistance for evacuation without regard for limitations set by occupancy use standards and/or life safety code standards.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Operations

O.04 Emergency and Disaster Preparedness Plans**Recommendation**

An assisted living residence shall develop a written emergency and disaster preparedness plan for fires and other natural disasters. This plan shall also include emergency protocols to deal with catastrophic events such as chemical spills, biohazardous events and weather-related emergencies. Evacuation routes shall be developed for all parts of the building. The relevant evacuation route should be posted in each common area, by all building exits, by all fire extinguishers and provided to all residents on admission and updated as needed. All staff should be provided a copy of all evacuation routes.

Implementation

Guideline for State Regulations

Rationale

It is essential that providers develop plans to deal with emergencies such as fires or natural disasters. Unless plans are developed before the emergency occurs, it is possible that key elements for providing protection will be overlooked. An evacuation plan is the method by which the facility is prepared to get the residents and staff out of the building (or to a point of safety within the building) in case of an emergency. It is important to note that "evacuation" may be either to the outside of the building to a point of safety, or inside the building to a point of safety. It is also important for the ALR to develop emergency protocols for events that may not require a building evacuation, but do require that the ALR take some sort of action to protect the well-being of its residents and staff (such as chemical spills and/or extreme heat or cold).

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration

Organizations Abstaining From the Vote on This Recommendation

None

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1) We dissent. While we support the intent of the recommendation, it is beyond the scope of most ALRs and particularly small providers to have protocols to deal with catastrophic chemical spills and biohazardous events. Plans to deal with these sort of catastrophic emergencies are the province of civil authorities and homeland security personnel.

*Assisted Living Federation of America, National Association for Home Care,
National Association for Regulatory Administration, Joint Commission on
Accreditation of Health Care Organizations*

2) We recommend the following revision to Recommendation O.4

An assisted living residence must develop a written emergency and disaster preparedness plan for fires and other natural disasters. This plan must also include emergency protocols to deal with catastrophic events such as chemical spills, biohazardous events and weather related emergencies. Evacuation routes must be developed for all parts of the building and posted.

*American Association of Homes and Services for the Aging, American Seniors
Housing Association, National Center for Assisted Living*

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Operations

O.05 Contingency Plan**Recommendation**

An assisted living residence shall have a written contingency plan in place for both short- and long-term evacuations and for when a building system fails and when utilities are interrupted.

Implementation

Guideline for State Regulation

Rationale

A contingency plan is the method by which the facility will be prepared to care for the residents after an evacuation has occurred. In some instances, the building can be immediately reoccupied, but when that is not the case, the contingency plan will prepare the facility for that eventuality. This contingency plan should be discussed with local and/or state authorities.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association for Regulatory Administration, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.05
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1) We dissent. Contingency planning in the event of an evacuation are generally covered by local and state laws. As such, this recommendation provides no new guidance to the states that will improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Operations

O.06 Food Storage, Preparation and Transporting**Recommendation**

Foods handled by the ALR will be stored, prepared, transported, and served in a safe and sanitary manner, and at appropriate temperatures as recommended by the Food and Drug Administration (FDA). The ALR shall have written policies and procedures that it will implement to achieve this recommendation.

Implementation

Guideline for State Regulation and Operations

Rationale

Proper food storage, handling and preparation are essential for ensuring that there are no food-borne illnesses in an ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association of the United States, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, National Association of Home Care, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Academy of Elder Law Attorneys, National Citizens' Coalition for Nursing Home Reform, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Bar Association

Supplemental Positions for O.06
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- 1) We dissent. This recommendation is too vague to provide a meaningful standard. We believe that the only specifics that provide substance to this recommendation - now recorded in the "Operational Models" section - must be moved into the body of the recommendation to make it useful. Further, the current language should be strengthened to require that the "food service supervisor who need not be a registered dietitian" be at least knowledgeable and trained in food safety procedures as evidenced by successful completion of a state-approved course for food-handlers.

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Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Operations

O.07 Food & Nutrition**Recommendation**

The assisted living residence will ensure that food provision corresponds to the recommended number of servings and categories of food on the USDA Food Guide Pyramid.

Meals shall be provided and / or coordinated at least three times a day, seven days per week, and snacks shall be available seven days per week.

Availability of meals should allow for reasonable flexibility in resident schedules.

Menus shall be planned taking into consideration residents' personal, ethnic and religious preferences and with resident input.

Menus shall be accessible to residents when completed and when the menus are prepared by the ALR, this should be at least one week in advance.

A variety of food choices shall be available to accommodate resident preferences, special needs and diets.

Reasonable menu or food substitutions shall be offered.

Resident meals, snacks and nutritional supplements shall be attractive and palatable. Fluids shall be available and appropriately offered to residents and assistance provided, as needed, to promote adequate fluid intake.

Menus shall be reviewed and approved by a registered dietitian for nutritional adequacy and variety.

Implementation

Guideline for State Regulation and Operations

Rationale

Food service is more than meeting nutritional needs; at its best, it is an opportunity for social engagement, enjoyment and meeting nutritional needs. Meals served at consistent and culturally appropriate dining times and for a sufficient length of time to meet resident needs will help to achieve these goals. It is also important for residents to be able to obtain delivery of meals under special circumstances such as illness, injury, or needs delineated in service plans.

Because fluid intake plays a critical role in health and well being, assisted living residences should encourage residents to drink fluids during and between meals and make fluids available to residents throughout the day, both in private areas and areas where residents gather and group activities occur.

Organizations Supporting This Recommendation

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging
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Operations

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsmen Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Association for Regulatory Administration, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Joint Commission on Accreditation of Health Care Organizations, National Association of Home Care

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.07
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1) We agree with much of this recommendation but believe that certain parts should be eliminated. We believe the recommendation should read:

The assisted living residence will ensure that food provision corresponds to the recommended number of servings and categories of food on the USDA Food Guide Pyramid or other generally accepted guidelines.

Meals must be provided and/or coordinated at least three times a day, seven days per week, and snacks must be available seven days per week.

Availability of meals should allow for reasonable flexibility in resident schedules.

Menus must be planned taking into consideration residents' personal, ethnic and religious preferences with resident input.

Menus must be accessible to residents when completed and when the menus are prepared by the ALR, this should be at least one week in advance.

A variety of food choices must be available to accommodate resident preferences, special needs and diets. Reasonable menu or food substitutions must be offered.

Resident meals, snacks and nutritional supplements must be attractive and palatable. Fluids must be available and appropriately offered to residents and assistance provided, as needed, to promote adequate fluid intake.

National Center for Assisted Living, American Seniors Housing Association

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Operations

O.08 Smoking**Recommendation**

The assisted living residence will have a policy regarding smoking and the use of other tobacco products, which will be disclosed to the prospective resident prior to his/her entering into a residency agreement.

Implementation

Guideline for State Regulation

Rationale

Smoking in assisted living residences is a hotly debated issue, with some states more permissive than others in allowing smoking and some states silent on this issue. In assisted living residences where smoking is permitted, this recommendation provides for clearly articulated and communicated smoking guidelines for the well being and safety of residents, staff, families and visitors and the reduction of passive smoking to others.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

Center for Medicare Advocacy

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.08
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1) We dissent. Recommendation micromanages the house rules of an ALR. Beyond the mandate of the ALW.

Assisted Living Federation of America, National Association for Home Care

Operations

O.09 Activities**Recommendation**

Assisted living residences shall provide daily structured and unstructured, and individual and group, activities in accordance with residents needs, interests, choices, beliefs, values, functioning levels and abilities. Activity programs shall be directed by appropriately qualified and trained individuals. Activity plans, identifying resident preferences, shall be part of each resident's ongoing assessment and service plan. Current, understandable and accessible activity calendars shall be conspicuously posted in assisted living residences.

Assisted living residences shall adopt objective methods that include measures of resident satisfaction for evaluating the participation in, and effectiveness of, activities.

Implementation

Guideline for State Regulation

Rationale

Properly designed and delivered activities can maintain and enhance resident life.

To achieve maximum outcomes, activities shall be: resident centered; provide materials, approaches, interactions and environments which enhance resident well-being; and assist in achieving or maintaining resident functional levels and abilities, focusing on resident strengths and not weaknesses. Given the diversity of residents in assisted living, it is important that those responsible for planning activities understand resident characteristics in order to provide a meaningful activity environment, with activities that create a stimulating social culture within the assisted living community.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Medical Directors Association, American Seniors Housing Association, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Association for Regulatory Administration, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Association of Home Care

Organizations Abstaining From the Vote on This Recommendation

American College of Health Care Administrators

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Operations

Supplemental Positions for O.09

None Submitted

Operations

O.10 Activities for Special Care Residents**Recommendation**

ALRs that accommodate special care residents shall provide daily interactions and experiences that are meaningful (based upon residents' interests, feelings, and lifestyle), appropriate (for their abilities and functioning levels), and respectful (of their age, beliefs, cultures, values, and life experiences) of residents, as determined by individual assessments and indicated in their service plans.

Activity programs shall be directed by appropriately qualified and trained individuals who have experience in activities responsibilities and training in special care.

Staff involved in planning and implementing activities for special care residents shall, on an on-going basis, be given training that includes, but is not limited to: basic physiological understanding of dementia and other special conditions of residents being served; behavioral symptoms and consequences; behavioral intervention and management strategies, including redirection techniques; understanding of individual resident's specific needs, appropriate activities and accommodations for meeting special resident needs (e.g. cognitive, language, behavioral, motor, and social skills).

Implementation

Guideline for State Regulation

Rationale

ALRs are encouraged to view activities as every interaction that occurs between the resident and their environment and as the foundation for quality care. The scope of activities therefore includes every encounter and exchange between residents and all members of and visitors to the ALR community. Interactions centered around activities of daily living and scheduled activities should be viewed by staff and family members as significant elements in meeting resident's physical, psycho-social and behavior management needs and enhancing resident's care and quality of life. Education, collaboration and communication among staff and family members is a relevant component in achieving intended outcomes of meeting the residents' needs and fostering quality care and psychological comfort within the ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and

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Operations

Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

American Assisted Living Nurses Association

Supplemental Positions for O.10
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1) We dissent. We respect the fact that many states have set additional requirements for ALRs that seek a special designation to serve people with cognitive impairments. However, we do not attempt to prescribe the specific procedures that a state must regulate.

Residents with mild to moderate dementia can still participate in care decisions and express life long values and wishes regarding the care they are currently receiving. Therefore, our recommended guidance to the states and ALRs is to consider a quality monitoring component that focuses on the perspective of the resident and other responsible parties to look beyond the procedures, and to see if the resident and other affected parties feel that their choices are being respected, their needs are being met, and their opinion is sought as to the quality of the services provided.

Examples of suggested areas for quality monitoring could include:

- Does the resident acknowledge having opportunities to exercise lifestyle preferences (dining, receiving visitors, activities, directing provision of services)
- Does the resident acknowledge being consulted as to his/her satisfaction with the quality of care and services provided;
- Does the staff have the willingness and the ability to communicate with, and respond to, resident's preferences;
- Does the surrogate decision-maker acknowledge that he/she is encouraged to be involved in the development and implementation of the resident's service plan.
- Do family members report having opportunities for involvement in resident's care.
- Does the resident acknowledge being able to make decisions regarding services to be provided to the extent possible and involvement of his or her family as appropriate.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Operations

O.11 Transportation**Recommendation**

All assisted living residences shall provide and/or arrange for both the scheduled and unscheduled transportation needs of its residents. Clear, written information shall be provided to all assisted living residents and prospective residents about which types of transportation are available, at what times those services are available by the ALR and in the community (e.g., regularly scheduled van trips to the shopping mall), and any additional costs associated with transportation services over and above the monthly service fee.

In cases in which the assisted living residence owns or leases the vehicle providing transportation to the residents, all safety and inspection records shall be kept and the vehicle shall meet all local and state safety standards for the class of vehicle.

Staff responsible for the operation of vehicles will receive training on how to operate the vehicles and the equipment inside the vehicle, and how to assist residents who are utilizing the service, including assisting residents with special needs for transportation, such as those with cognitive impairments, dementia or special needs due to physical disabilities. When transporting residents with special needs, the ALR will ensure that adequate staff is provided.

Staff responsible for the operation of vehicles will have current, appropriate licenses and classes of licenses to operate the vehicles.

Implementation

Guidelines for State Regulation

Rationale

According to the most recent research, the proportion of assisted living residents who still own or drive a car is less than 5%. Because the vast majority of assisted living residents no longer drive or own a car, an assisted living residences' transportation services are considered a key component of its service package.

There are several ways that an assisted living residence can meet the transportation needs of its residents: by directly providing the transportation with an assisted living residence-owned or leased vehicle (e.g., a bus or van), and/or by arranging for transportation services through a third party (e.g., a service agreement with a local taxi cab company or utilizing other currently offered transportation programs).

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of

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Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Association of Home Care

Organizations Abstaining From the Vote on This Recommendation

American Seniors Housing Association

Supplemental Positions for O.11

None Submitted

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Operations

O.12 Environmental Management**Recommendation**

The ALR shall maintain safe conditions for residents, staff, and visitors. The facility shall be properly maintained in compliance with applicable federal, state and local laws. Appropriate to the size of the ALR and the scope of services provided, buildings and outdoor areas shall maintain effective utility capacity (electric, plumbing, water, refrigeration, etc), lighting, and accommodate residents' needs and safety. Common areas shall accommodate residents using assistive devices for mobility. The ALR and outdoor areas shall be kept clean and free of potential hazards and hazardous substances.

Implementation

Guideline for State Regulation

Rationale**Organizations Supporting This Recommendation**

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Center for Medicare Advocacy, National Academy of Elder Law Attorneys

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.12
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1) We dissent. The general thrust of this recommendation is that ALRs must comply with existing laws and regulations. As such, this recommendation provides no new guidance to the states as to how improve quality in assisted living.

However, the degree to which a resident feels that his/her assisted living community is a safe and homelike residential environment is of vital importance to a resident's perception of their quality of life. Therefore, our recommended guidance to the states and ALRs is to consider a quality

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monitoring focus from the perspective of the resident to look at how well the residential environment is supporting consumer choice, autonomy, independence, and privacy.

For example:

- Does the resident acknowledge that the AL setting feels homelike.
- Resident acknowledges/denies having opportunities to control private space:
 - food storage/preparation
 - individual temperature control
 - roommate provision consultation
 - use of personal vs. ALR furnishings in unit
 - modifications to unit
 - availability of personal key to unit
- Does the resident acknowledge availability of staff assistance to help resident use inaccessible public areas?
 - Dining rooms, activity room, library, TV room; limitations to areas within/outside setting due to: cognitive limitations; physical barriers (steps, doorways, etc.)
- Does the resident report a lack of access to a private phone/key to a mailbox
- Is the staff able/unable to demonstrate knowledge regarding methods to promote a homelike setting; resident lifestyle preferences; methods to protect resident privacy.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Operations

O.13 Assisted Living Residence Councils**Recommendation**

ALRs shall provide opportunities and space for resident council meetings, schedule regular meetings, and encourage residents to attend those meetings. The Resident Council may be organized by the staff but should be led by the residents. The staff may participate in the Resident Council, as invited by residents.

An ALR may have a Family Council as part of the activity or social service programming, with space made available by the ALR. This council allows families to be aware of, and participate in, residence operations in a welcoming and productive manner.

Implementation

Guideline for State Regulation

Rationale

Community Councils offer meaningful opportunities for enhanced participation and community-building that ultimately benefit the quality of life for all members of the ALR. Resident Councils are formal meetings where resident can learn, interact and come to better understand the various psycho-social activities of the assisted living residence. Because assisted living residents are the guiding force in planning activities, their wishes should always be taken into consideration and Resident Council gives the residents a place to ask questions and express concerns, with the aim of information sharing, building community and resolving potential problems. Residents may also desire to fulfill a needed role through volunteering, which can increase their sense of self-esteem and usefulness, as well as provide opportunities to meaningfully utilize the vast experience they have attained during their lives for the betterment of the ALR and/or extended community. Family Councils can provide opportunities for support and education within a comfortable peer group setting.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

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Assisted Living Federation of America, National Association of Home Care, National Academy of Elder Law Attorneys

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.13
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1) We dissent. Resident input is critical to a well-run community. Yet, there are any number of methods ALR management might employ to assure that input is both solicited and acted upon. Some managers might prefer focus groups. Other might utilize customer satisfaction surveys. Yet others might "manage by walking around" and engaging residents in one-on-one discussions. All can be effective. No one process is likely to be unique in achieving desired results. Yet, this recommendation is reflective of the ALW's focus, not on outcomes, but on the means by which facilities, in the ALW's judgment, must strive to achieve those outcomes.

Rather than specifying that the required process for scheduling and convening a resident council meeting, our Supplemental Position recommends suggested areas for monitoring to determine if the desired result of promoting resident autonomy is being met. For example:

- Do residents report having opportunities to provide input into development and implementation of existing house rules and community decision-making;
- Do residents report that requested changes to rules that have been accepted or acted upon by management.
- Do residents acknowledge receiving an explanation for maintaining current policy upon request for a change;
- Do residents acknowledge management/staff responsiveness to grievances/complaints.
- Do residents acknowledge receiving requested clarification of existing rules
- Do residents acknowledge being informed of community governance events (Resident Council, committee meetings, etc.)

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Operations

O.14 Community Environment & Standards**Recommendation**

Pets may be allowed to live in or to visit the ALR to provide resident companionship and comfort if it is within the policy of the ALR. For live-in pets, it shall be clearly determined who is responsible for feeding, grooming and providing for the general care of the pet, and veterinary records and vaccination records shall be made available to the ALR. Pet policies shall follow applicable state and local health regulations.

Implementation

Guideline for Operations

Rationale

Assisted living residences are based on a home-like model and pets can be a nurturing element within the ALR. Pets can provide companionship, comfort, and stimulation, and enhance positive feelings among all community members.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Association of Home Care

Organizations Abstaining From the Vote on This Recommendation

Center for Medicare Advocacy

Supplemental Positions for O.14
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None Submitted

Operations

O.15 Security for Wandering Residents**Recommendation**

If an ALR accommodates residents who exhibit unsafe wandering behaviors, then the ALR shall have a secure boundary or perimeter to safely accommodate residents. In no event shall locking devices violate life safety codes. Approved locking devices shall not be considered a physical restraint. An ALR with secure perimeters shall conduct frequent staff training on the importance of preventing unsafe wandering and maintaining alarm systems and door locking systems in a functional capacity.

Implementation

Guideline for State Regulation

Rationale

A secure perimeter defines the boundaries within which wandering residents may be safely accommodated. These boundaries may change during the day or during other periods, and may depend on such factors as exterior weather and scheduled, supervised activity periods. For example, an interior courtyard may be included within the secure perimeter during daylight hours on a warm day, but may be outside the secure perimeter at night or on a cold winter day. Exterior building walls and doors, and walled or fenced outdoor areas may be used to form this boundary. Doors forming parts of the outer boundary of a secure perimeter may be secured by electrical or electro-magnetic locking devices with key card or security code keypad access, by physical human intervention (as, for example, when the front door of a building has a reception desk that is staffed by individuals who are trained and prepared to intervene if a resident attempts to exit), with manual locks (if and only if the manually locked door is not part of a required means of egress from the building), or by some combination of these methods.

Assisted living residents who exhibit wandering behavior are likely to be residents with dementia, although other residents may also exhibit this behavior. A 1997/98 study of 2,078 residents age 65+ in 193 assisted living residences in 4 states (FL, MD, NJ, and NC) found that, depending on the size and type of facility, 19% to 26% of residents with dementia in non-specialized facilities and 28% to 44% of residents with dementia in special care units exhibited pacing and aimless wandering behaviors. In contrast, only 4% to 5% of non-demented residents exhibited these behaviors (Sloan, P.D. et al., "Caring for Persons with Dementia." Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly, Baltimore, MD: Johns Hopkins University Press, 2001).

Clearly, not all pacing and wandering behaviors are unsafe, but assisted living staff are rightly concerned about residents who may wander off and get lost. In addition to secure perimeters, many other approaches for managing pacing and wandering have been developed and tested (Rader, J. "A Comprehensive Approach to Problem Wandering," *Gerontologist* 27(6): 756-760, 1987). These other approaches begin with identification of the reason for the behavior. Some residents with dementia may believe they have to go to work or go home to take care of their children; often staff can find ways to distract or otherwise satisfy them. Other residents with dementia may pace and wander because they do not know where they are; environmental cues can help them find their way to their

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room or other familiar spot in the facility. Pacing and wandering can also indicate general restlessness or boredom; individual escorted walking and activity programs may reduce or eliminate these problems. Exercise programs can help not only with pacing and wandering behaviors but also with agitation and sleep problems. Lastly, residents with dementia who exhibit potentially unsafe wandering behaviors should be enrolled in the Alzheimer's Association's Safe Return Program so that they can be quickly located if they do become lost.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Social Workers, National Association of Professional Geriatric Care Managers, National Center for Assisted Living, National Conference of Gerontological Nurse Practitioners, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Seniors Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association of Local Long Term Care Ombudsmen, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for O.15
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1) We dissent. Although some of the material in the rationale is useful, the recommendation itself is too weak to serve as a guideline for state regulation, or even as operational guidance. It does not address or specify such essential areas as:

- Ensuring that secure perimeters are never substituted for an adequate number of well-trained direct care staffs and well-designed programs that respond to the special needs of cognitively impaired residents;
 - Ensuring that any measures to protect residents who are cognitively impaired and/or engage in unsafe wandering behavior are based on sound initial and ongoing assessments and care/service planning, and are designed to protect the resident from harm while maximizing autonomy and quality of life;
 - Assurance that residents have routine access to safe outdoor areas and, as appropriate, to opportunities for planned community excursions; and
 - Assurance that the secured environment is kept free of ordinary substances, objects and furnishings that might be hazardous to seriously cognitively impaired residents
- Also, this recommendation states "[an] Approved locking devices shall not be considered a physical

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restraint." This language is much too general; any types of physical restrictions must be subject to strict scrutiny to ensure they do not constitute inappropriate restraints.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants

2) We dissent. Infringes on state authority and flexibility to decide how it will meet the intent of an appropriate recommendation in equally effective alternative ways.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority
Operations***

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not have a voting record were unable to reach two-thirds majority during the development process.

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O.16 Restraints

2/3 Maj. Not Reached

Recommendation

No form of restraint or seclusion shall be applied to residents of an ALR except in extreme emergency situations when the resident presents a danger of harm to himself or herself or to other residents. In such an event, the ALR shall immediately notify the resident's physician and sponsor, and appropriate treatment, transfer to an appropriate health care facility, or both shall be provided without any avoidable delay.

Implementation

Guideline for State Regulations

Rationale

None

Organizations Supporting This Recommendation

No Vote Recorded

Organizations Opposing This Recommendation**Organizations Abstaining From the Vote on This Recommendation**

Supplemental Positions for O.16
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1) We strongly support this failed recommendation. Restraints are dangerous medical devices that should not be used in the assisted living setting, except in extreme emergency situations pending the arrival of emergency personnel or transport to an appropriate psychiatric facility.

Restraints are so dangerous that hospitals require stringent safety measures and extraordinary physician oversight when restraints are used in emergency situations. It is unlikely that any assisted living residence has the ability to offer similar safety measures, and for good reason. ALR's are not psychiatric treatment facilities for violent patients.

The use of restraints in the long term setting for chronic (non-emergency) conditions has long been discredited among knowledgeable medical professionals. This is because they often result in serious injury or death even when properly applied, and, when improperly applied, as frequently occurs, the risks of serious adverse outcomes become even greater. Restraints result in more serious injuries than the ones they are implemented to prevent. It is often said about restraints that the cure is worse than the disease.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The use of restraints is an important topic to address in assisted living. The undersigned support the following guideline for state regulations regarding restraints.

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Assisted living residents have the right to be free from physical or chemical restraints for the purposes of discipline or convenience or to prevent wandering. Restraints shall only be used when required to treat the resident's medical symptoms. The resident* has the right to accept or refuse restraints. The ALR shall implement a system that emphasizes alternatives to restraints, with the goal of achieving a restraint-free environment.

There are limited circumstances under which the use of a restraint is temporarily justified for an assisted living resident. Under these circumstances, restraints shall be safely and appropriately used. Restraints shall be used only when based on a documented assessment of the resident's needs. Restraints shall be used only after an evaluation of less restrictive alternatives and only if and when these less restrictive measures have been ruled out as ineffective. No form of restraint or involuntary seclusion shall be applied to residents of an ALR except in an emergency and under a physician's order. The physician's order shall last not more than 12 hours. In such an event, the ALW shall immediately notify the resident's physician and sponsor and the local ombudsman without any avoidable delay. Use of a restraint in an emergency situation is to be temporary, while appropriate treatment is sought. When restraints are used, the resident shall be observed and assessed, attention shall be paid to the resident's needs, and the restraints shall be periodically removed or released in accordance with the resident's needs.

States shall enforce standards to eliminate the unnecessary use of physical and chemical restraints. States shall ensure that physicians, ALR staff, and families are educated about the negative effects of restraints and about alternatives to their use.

Definitions

"Chemical restraints" are any drugs that are used for discipline or convenience and not required to treat medical symptoms.

"Emergency" shall be defined as an unanticipated and rarely occurring situation when the resident presents an immediate and serious danger of harm to himself or herself, residents, staff, or other individuals in the ALR.

"Involuntary seclusion" is a means of separation of a resident from other residents or from his or her room against the resident's will.

"Physical restraints" are any manual method or physical or mechanical device, material, or equipment attached or adjacent to the resident's body that the individual cannot remove easily which restrict freedom of movement or normal access to one's body. "Physical restraints" include, but are not limited to, bedrails, leg restrains, arm restrains, hand mitts, soft ties or vests, and wheelchair safety-bars and lap trays. Also included are ALR practices that meet the definition of restraints.

AARP, American Seniors Housing Association, American Assisted Living Nurses Association, NCB Development Corporation, National Association of Social Workers, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

3) There are limited circumstances under which the use of a restraint is temporarily justified for an assisted living resident. No form of restraint or seclusion shall be applied to residents of an ALR except in the extreme emergency situations when the resident presents a danger of harm to himself or herself, to other residents or staff. In such an event, the ALW shall immediately notify the resident's physician and sponsor without any avoidable delay. Use of a restraint in an extreme emergency situation is to be temporary, limited to only a few hours, while appropriate treatment is

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sought.

Consumer Consortium on Assisted Living, American Assisted Living Nurses Association, National Association of Professional Geriatric Care Managers

Topic Group Recommendations Adopted by Two-Thirds Majority of the ALW Resident Rights

Purpose

The Resident Rights Topic Group focused on issues pertaining to disclosure, marketing practices, and the rights of residents.

Issues

The recommendations from this topic group centered on open disclosure of information about various ALR services and fees to residents and prospective residents, consistency of marketing information, discharge policies, appeals systems, contracts and resident rights.

Participants

The topic group was co-chaired by Donna Lenhoff of the National Citizens' Coalition for Nursing Home Reform and David Kylo representing the National Center for Assisted Living.

Topic group participants included Sharon Bridger, National Committee To Preserve Social Security and Medicare; Eric Carlson, National Senior Citizens Law Center; Stephanie Edelstein, American Bar Association Commission on Law and Aging; Marsha Greenfield, American Association of Homes and Services for the Aging; Dan Haimowitz, American Medical Directors Association; Karen Kauffman, National Conference of Gerontological Nurse Practitioners; Cherry Meier, National Hospice and Palliative Care Organization; Mark Miller, National Association of State Units on Aging; Doug Pace, American Association of Homes and Services for the Aging; Mary Parker, Institute for Palliative and Hospice Training, Inc.; Bonnie Ruechel, National Association of Activity Professionals; Ed Sheehy, Assisted Living Federation of America; Beth Singley, Assisted Living Federation of America; Erica Wood, Consumer Consortium on Assisted Living.

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Resident Rights

R.01 Consistency in Contracts and Marketing**Recommendation**

All information conveyed by an assisted living residence (ALR) to prospective residents (e.g. marketing materials, sales presentations, and tours) should be consistent with the contract.

Implementation

Guideline for State Regulation

Rationale

This recommendation is the foundation for an ethical assisted living marketing program and emphasizes the importance of consistency and accuracy of all oral and written communications.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Hospice and Palliative Care Organization, National Association of Local Long Term Care Ombudsmen, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.01
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1) We support the recommendation. The assisted living marketing professional is charged with educating the public about assisted living, but even more importantly, plays a critical role in helping families decide if the assisted living option is the correct choice for them. What is involved in "full disclosure?" Disclosure is not just what is written in a legally binding contract, it's also about what's said in sales conversations and marketing materials. It's about constantly keeping people informed. It's about understanding that families in crisis may remember only a fraction of what they are told, so "disclosure" is an ongoing process. Disclosure has to be part of the ALR's culture.

Resident Rights

During the sales and marketing process, dialog with the potential resident and their family must include information that falls into two key areas: explanation of assisted living and critical information regarding fees, services, and policies that impact on the resident.

Full disclosure is, itself, a process that occurs through ongoing communication and education and culminates the signing of the resident agreement. Approached sensitively, full disclosure is a win-win for the consumer and the ALR:

1. Full disclosure builds a foundation of trust between the consumers and the provider.
2. Full disclosure builds credibility.
3. Full disclosure ensures that customers know what to expect and receive the services they want..
4. Greater customer satisfaction results from giving consumers realistic expectations and then meeting them.

American Assited Living Nurses Association, Assisted Living Federation of America, Consumer Consortium on Assisted Living, National Association for Home Care, National Center for Assisted Living, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.02 Contracts and Agreements: Consistency with Applicable Law

Recommendation

All contract provisions shall be consistent with applicable law. The parties may agree to modify the contract as long as all parties agree to the modification and signify their agreement. Such modification will be consistent with applicable law.

Implementation

Guideline for State Regulation

Rationale

Contracts or similar agreements are the legal documents that disclose the obligations of the resident and ALR to each other. Recommendation R-02 recognizes that each resident is individual and may have a particular want, need or circumstance that would require modifying a standard contract or agreement. It also recognizes that both the ALR and resident shall agree to any modifications.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.02

1) We dissent. The general thrust of this recommendation is that all contract provisions must be consistent with applicable law. As such, this recommendation provides no guidance to states or ALRs that will help to improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.03 Contracts and Agreements: Readability and Pre-Signing Review**Recommendation**

Contracts shall be written in simple language and be understandable. Prior to signature, the prospective resident has the right to review a contract and/or have the contract reviewed by a third party. Prior to the execution of the contract, a representative of the ALR shall offer to read and explain the contract and answer any questions.

Implementation

Guideline for State Regulation

Rationale

None listed

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Adult Family Care Organization, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.03
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None Submitted

Resident Rights

R.04 Contracts and Agreements: Required Elements

Recommendation

Contracts/agreements should include at a minimum the following information:

- a) the term of the contract;
- b) a comprehensive description of the ALR's billing and payment policies and procedures;
- c) a comprehensive description of services provided for a basic fee;
- d) a comprehensive description of and the fee schedule for services provided on an a la carte basis or as part of a tiered pricing system that are not included in a basic fee;
- e) the policy for changing the amount of fees;
- f) how much advance notice the ALR will give before changing the amount of fees (e.g., 30 days, 60 days). Notices should be readable and understandable by the resident;
- g) whether the ALR requires an entrance fee, security deposit, and/or other fee(s) at entry, the amount of those fees and/or deposits and the policies for whether or not fees and deposits are refundable and procedures for refunding those fees and/or deposits;
- h) a description of the circumstances under which residents may receive a refund of any prepaid amount such as monthly rent;
- i) a description of the ALR's policy during a resident's temporary absence;
- j) the process for initial and subsequent assessments and the development of the service plan based on these assessments, including notification that the resident has the right to participate in the development of the service plan;
- k) a description of all requirements for assessments or physical examinations, including the frequency and assignment of financial responsibility for such assessments and/or examinations;
- l) an explanation of the use of third party services (including all health services), how they may be arranged, accessed and monitored (whether by the resident, family or the ALR), whether transportation is available if the services are not provided on-site, any restrictions on third party services, and who is financially responsible for the third party services and transportation costs;
- m) a description of all circumstances and conditions under which the ALR may require the resident to be involuntarily transferred, discharged or evicted, an explanation of the resident's right to notice, the process by which a resident may appeal of the ALR's decision, and a description of the relocation assistance (if available) offered by the ALR;
- n) a description of the ALR's process for resolving complaints or disputes, including any appeal rights, and a list of the appropriate consumer/regulatory agencies (if applicable; e.g. appropriate state/local long-term care ombudsman program, the state regulatory agency, the local legal services program, and other advocacy bodies/agencies);
- o) a description of the procedures the resident or ALR shall follow to terminate the agreement; and,
- p) a list of residents rights as detailed in the statute or regulations governing assisted living residences is incorporated by reference and attached.

Implementation

Guideline for State Regulation

Rationale

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Resident Rights

Recommendation R-04 contains a detailed list of elements to be included in contracts. The topic group recognizes the high level of detail in Recommendation R-04 but believes such detail is necessary because of the importance of contracts and similar agreements to the provider and the resident. This list contains key contract provisions generally disclosed by most assisted living providers today. In addition, the topic group believes it is essential to include such detail in this recommendation to address past concerns raised by the General Accounting Office and Congress with regard to contracting and disclosure practices in assisted living.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Hospice and Palliative Care Organization, National Association for Regulatory Administration, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.04
--

None Submitted

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Resident Rights

R.05 Contracts and Agreements: Prohibition on Waiver of Right to Sue**Recommendation**

The contract should not require the resident to waive the right to sue the ALR under applicable law. The contract may disclose but not require options for alternative dispute resolution available to the resident or ALR.

Implementation

Guideline for State Regulation

Rationale

Recommendation R-05 is a common provision often used in other contracts and agreements.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Network of Career Nursing Assistants, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Joint Commission on Accreditation of Health Care Organizations

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.05
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- 1) We dissent. Recommendation attempts to preempt state law by stating that contracts may not stipulate a provision for alternative dispute resolution.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.06 Posting Contact Information**Recommendation**

Current contact information for the appropriate state/local long-term care ombudsman program, the state regulatory agency, the local legal services program, and other advocacy bodies/agencies mandated by the state should be posted in a size and format that is easily read and placed in a conspicuous public location in the ALR and provided to residents upon request.

Implementation

Guideline for State Regulation

Rationale

While the same contact information is listed under recommendation R-04-n dealing with contracts, Topic Group participants believe that this information also should be made readily available to residents and their families by being posted in the residence and provided to the resident upon request.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.06
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None Submitted

Resident Rights

R.07 Pre-Admission Disclosure for Specialized Programs of Care**Recommendation**

ALRs representing in any way that they provide special care programs for persons with Alzheimer's disease or other dementias, or any other specific health conditions, shall disclose how the program and its services are different from the basic services. At a minimum, the ALR shall disclose the following information to each prospective resident prior to admission:

- The ALR's philosophy of the special care program.
- The process and criteria for placement in, and transfer or discharge from, any specialized unit and/or the ALR.
- The process for assessing residents and establishing individualized service plans.
- Additional services provided and the costs of those services relevant to the special care program.
- Specialized (condition-specific) staff training and continuing education practices relevant to the special care program.
- How the physical environment and design features are appropriate to support the functioning and safety of residents with the specific condition(s).
- The frequency and types of activities offered to residents.
- Options for family involvement and the availability of family support programs.

Implementation

Guideline for State Regulation

Rationale

The most common forms of special care programs found in ALRs/units today are those designed for individuals with Alzheimer's disease and other dementias. On a much smaller scale, some ALRs have been developed to care for individuals with other diseases such as diabetes. This specialization and diversification of assisted living is expected to continue. Such special care programs hold themselves out to be different - something beyond traditional assisted living programs. As such, special attention should be given by the ALR to clearly communicate how the special care program is designed differently from traditional assisted living and how the resident benefits from these differences. In addition, the ALR should disclose any costs or additional fees it charges as part of the specialized program.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Adult Family Care Organization, National Hospice and Palliative Care

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Organization, Pioneer Network

Organizations Opposing This Recommendation

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of State Ombudsman Programs, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Network of Career Nursing Assistants

Supplemental Positions for R.07

1) We dissent because disclosure alone is insufficient. Quality-of-care standards are also necessary, but the majority recommendations include no meaningful quality-of-care standards for dementia care.

This recommendation requires assisted living residences that offer special care or programs for residents with Alzheimer's Disease or other dementias to disclose certain information about those programs and services. While disclosure has great merit as a consumer education tool, disclosure must be accompanied by enforceable standards for the services being disclosed, to ensure that residents needing those services are protected.

In proposing R-07, the topic group anticipated that enforceable standards for specialized services or programs, including dementia care, would be included elsewhere in the report. The majority's recommendation on Dementia Care Services (D-11) as adopted includes no such enforceable standards. D-11 does little more than require an assisted living residence to establish policies regarding certain aspects of care, which renders R-07 inadequate.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

Resident Rights

R.08 Contracts and Agreements: Third Party Responsibility**Recommendation**

The contract shall disclose clearly that a signature by a third party (such as a "responsible party") does not indicate acceptance of any personal financial responsibility for fees, costs or charges incurred by the resident, and does not make the third party a guarantor, unless the third party has signed a separate agreement indicating such.

The separate agreement shall include, at a minimum, the following information:

1. Third party voluntarily agrees to be financially liable for paying the residents' expenses as agreed.
2. Third party has the right to have this agreement reviewed by an attorney or other person.
3. Third party has the right to revoke the separate agreement with 30 days notice.

Implementation

Guideline for State Regulation

Rationale

Contracts are legally binding agreements between the resident and the ALR. Frequently, family members or others with close relationships to the residents may want to help residents pay for ALR expenses. Third party payers may or may not be legal surrogates. These third parties taking financial responsibility shall clearly understand that they are financially obligating themselves to pay for ALR expenses. To avoid confusion, such agreements should be handled separately from the contract with the resident.

Sometimes, residents move into an ALR quickly and under difficult circumstances (such as quick discharge following a short hospital stay). Regardless, third parties accepting financial obligations should have the ability to have their attorneys or others review the agreements and adequate time to weigh their decisions. However, ALRs and third party payers should make every effort to sign the separate agreements well in advance of move-in so that the 48-hour "cooling off" has expired to minimize the potential for unnecessary emotional trauma to individuals on the cusp of moving into the ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, NCB Development Corporation, National Adult Family Care Organization, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Hospice and Palliative

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Care Organization, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

American Seniors Housing Association, Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

National Association of Home Care, Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for R.08

1) We dissent. Recommendation attempts to preempt state law by requiring contracts to have specifically worded provisions regarding third party payors. Beyond the mandate of the ALW.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.09 Pre-Admission Disclosure on Advance Directives**Recommendation**

ALRs shall provide residents* with information about their rights under state law to make decisions about medical care, including their right to accept or refuse health-related services, the right to formulate advance medical directives, such as a living will, a directive to physicians or durable power of attorney for health care.

The ALR information should disclose its philosophy and policies about implementation of advance medical directives, including, but not limited to, implementation of Do Not Resuscitate order (DNRs) and medical directives that require limitations on delivery of medical services, food, or hydration, and situations in which the ALR is required to summon emergency medical services.

Implementation

Guideline for State Regulation

Rationale

The goal of this recommendation is to ensure that prospective residents* can make informed decisions about whether the ALR will meet their needs and follow their care directives. It is important for the resident* and ALR to openly discuss and understand each other's position. The laws surrounding advance medical directives vary from state to state, and who has the authority to honor these directives also may vary. It is not the intent of this recommendation to address these differences but to stress the importance of full disclosure and understanding between a prospective resident* and the ALR about the implementation of this important resident right to health care decision making.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Association for Regulatory Administration, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

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Resident Rights

None

Supplemental Positions for R.09

1) We dissent. Redundant with recommendation dealing with advance directives in conjunction with the pre-move in screening and initial assessment.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.10 Pre-Admission Disclosure on End-of-Life Care**Recommendation**

ALRs shall clearly disclose information to residents* about applicable state laws and about the ALR's philosophy and policies regarding delivery of end-of-life care, including delivery of hospice and palliative care services. Disclosure shall include the circumstances, if any, under which a resident with terminal illness or in the process of dying may be required to leave.

Implementation

Guideline for State Regulation

Rationale

The goal of this recommendation is for full disclosure and a clear understanding of the roles, rights and responsibilities of a prospective resident and of the ALR with regard to end-of-life care needs. This recommendation recognizes the ALR's as a residence for people who may have chronic illness and frail health, and who may expect that as a resident in this supportive living environment they will be able to come to the end of their lives in peace and comfort.

In some states, there may be laws or regulations that affect the provision of end-of-life care within an ALR and these laws vary from state to state. It is not the intent of this recommendation to address these differences in law, but to stress the importance of disclosure and common understanding between a prospective resident* and the ALR about the implementation of this important resident right to exercise choice about end-of-life care, including dying in chosen surroundings with peace and in comfort.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Academy of Elder Law Attorneys, National Adult Family Care Organization, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Conference of Gerontological Nurse Practitioners, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

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Resident Rights

None

Supplemental Positions for R.10

None Submitted

Resident Rights

R.11 Resident Rights and Provider Responsibilities

Recommendation

Within the boundaries set by law, residents have the right to:

- Be shown consideration and respect;
- Be treated with dignity;
- Exercise autonomy;
- Exercise civil and religious rights and liberties;
- Be free from chemical and physical restraints;
- Be free from physical, mental, fiduciary, sexual and verbal abuse, and neglect;
- Have free reciprocal communication with and access to the long term care ombudsmen program;
- Voice concerns and complaints to the ALR orally and in writing without reprisal;
- Review and obtain copies of their own records that the ALR maintains;
- Receive and send mail promptly and unopened;
- Private unrestricted communication with others;
- Privacy for phone calls and right to access a phone;
- Privacy for couples and for visitors;
- Privacy in treatment and caring for personal needs;
- Manage their own financial affairs;
- Confidentiality concerning financial, medical and personal affairs;
- Guide the development and implementation of their service plans;
- Participate in and appeal the discharge (move-out) planning process;
- Involve family members in making decisions about services;
- Arrange for third party services at their own expense*;
- Accept or refuse services;
- Choose their own physicians, dentists, pharmacists and other health professionals;
- Choose to execute advance directives;
- Exercise choice about end of life care;
- Participate or refuse to participate in social, spiritual or community activities;
- Arise and retire at times of their own choosing;
- Form and participate in resident councils;
- Furnish their own rooms and use and retain personal clothing and possessions;
- Right to exercise choice and lifestyle as long as it does not interfere with other residents rights;
- Unrestricted contact with visitors and others as long as that does not infringe on other residents' rights; and,
- Come and go and rights that one would enjoy in their own home.

In addition, residents' family members have the right to form and participate in family councils.

In the context of resident rights, providers have a responsibility to:

- Promote an environment of civility, good manners and mutual consideration by requiring staff, and encouraging residents, to speak to one another in a respectful manner;
- Provide all services for the resident or the resident's family that have been contracted for

Resident Rights

- by the resident and the provider as well as those services that are required by law;
- Obtain accurate information from residents* that is sufficient to make an informed decision regarding admission and the services to be provided;
 - Maintain an environment free of illegal weapons and illegal drugs;
 - Obtain notification from residents of any third party services they are receiving and to establish reasonable policies and procedures related to third party services;
 - Report information regarding resident welfare to state agencies or other authorities as required by law;
 - Establish reasonable house rules in coordination with the resident council.
 - Involve staff and other providers in the development of resident service plans; and,
 - Maintain an environment that is free from physical, mental, fiduciary, sexual and verbal abuse and neglect.

*An ALR may require that providers of third party services ensure that they and their employees have passed criminal background checks, are free from communicable diseases and are qualified to perform the duties they are hired to perform.

Implementation

Guideline for State Regulation

Rationale

These resident rights support resident dignity, privacy and choice and are essential to the mission of assisted living and cornerstones of quality in an ALR. For assisted living to promote individualized care and quality of life, residents shall be treated with respect and their legal rights, individuality and autonomy shall be recognized.

The rights described recognize the importance of a resident's right to make decisions that affect his or her quality of life in assisted living within the boundaries set by law. To avoid duplication, the list includes a general category of civil and religious rights and liberties (e.g., constitutional rights and rights under the Americans with Disabilities Act and the Fair Housing Amendments Act) but does not include issues addressed in other recommendations, e.g., copy of the contract, review of inspection and survey reports, procedural protections upon discharge from the facility. The list of resident rights will be included in the contract as recommended in R.4.

It is also recognized that providers have responsibilities that support their ability to deliver quality services to assisted living residents in a safe, homelike environment. These responsibilities strike a necessary balance between an individual's ability to exercise his or her rights and the ALR's responsibility to establish reasonable rules and guidelines that will ensure the dignity, privacy, comfort and well-being of all residents.

The provider responsibilities (which were originally contained in R.12) contained in this recommendation are intended to establish a framework within which providers and residents may work together to maintain a quality living environment. They are not intended to discourage residents from exercising legal rights or lifestyle choices. However, they do acknowledge the responsibility of the provider to enforce rules commonly recognized as necessary in any group living environment. (For example, the ALR should

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Resident Rights

establish and enforce rules prohibiting the playing of loud music at 2 a.m. when most residents are asleep.)

A list of provider responsibilities should be given to the resident when the ALR gives the resident a copy of the list of resident rights that accompanies the contract.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.11
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1) We dissent. We support the intent of this recommendation, however this recommendation attempts to hold the ALR accountable to a capricious standard for promoting "good manners".

American College of Health Care Administrators, Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.12 Ethics Committee/Consultation

Recommendation

An ALR should have knowledge of how to access an ethics committee or a source of ethics consultation to: (1) advise in development of policies and procedures; (2) educate staff, families, residents and its own members on ethical issues; and (3) provide a forum for case consultation on ethical issues concerning resident care and services.

Implementation

Guideline for Operations

Rationale

Ethics committees or consultation teams offer a forum for thorough and thoughtful examination of difficult ethical concerns, in accordance with pre-established procedures. Ethical questions can arise in dealing with residents and families as care needs change with illness or the aging process. Ethical questions might involve choices about major medical treatment, end of life treatment, or matters of "everyday ethics" that surface from residents living in close proximity with others. Questions might be triggered when the physician seeks guidance on treatment choices, or when there is a difference of interests or perspectives between the ALR and the physician, physician and family/resident, family and resident, or resident and resident. There may be questions in which the resident's decision-making capacity or identification of a surrogate is at issue; in which the safety and best interests of the resident shall be weighed against resident autonomy; or in which individual choice may conflict with the common good.

The committee or consultation team should be objective and sufficiently independent from the ALR. It should be multidisciplinary in composition, and should include long-term or acute care staff (including direct care staff), families, residents/patients, and community representatives, e.g., from religious, medical, legal and consumer advocacy organizations. The ALR may use the services of an ethics committee or consultation team in a hospital, nursing home or other nearby health care organization – or may develop its own committee or consultation team that maintains independence and objectivity from the ALR. The committee or consultation team is an advisory body, not a decision making body, and accordingly cannot limit the decision making rights of the resident or the ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local

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Long Term Care Ombudsmen, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.12

1) We dissent. A focus of the Ethics Committee is to be on the development of policies and procedures. This recommendation, like many others does not, as the Senate Committee asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Resident Rights

R.13 Room/Unit Hold During Resident Absence**Recommendation**

The resident has the right to leave the unit temporarily as long as fees are paid.

Implementation

Guideline for State Regulation

Rationale

The purpose of this recommendation is to ensure the resident's right to hold his/her unit as long as fees are paid.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.13

None Submitted

Resident Rights

R.14 Acceptance of Public Funds: ALR Policy and Information for Residents

Recommendation

The contract/agreement shall include the ALR's policies concerning acceptance of public benefits and continued residency by a resident whose private funds have been exhausted.

When a resident* informs an ALR that personal funds will become exhausted, the ALR shall inform or refer the resident to sources of information about Medicaid and other benefits before initiating discharge procedures.

Implementation

Guideline for State Regulation

Rationale

The goal of this recommendation is to ensure that residents* understand prior to move-in whether the ALR participates in any public or other financing programs that would help pay their expenses should they "spend down" and no longer be able to pay for their care and services. When residents can no longer pay privately, the ALR should inform or refer residents to sources that can help residents with their options under public programs such as Medicaid.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.14

None submitted

Resident Rights

R.15 Fee Increases, Security Deposits and Resident Finances

Recommendation

Fee Increases

The ALR shall give residents a minimum of 30 days notice in writing before changing the amount of the basic fees or other fee schedules as set forth in the contract. This 30-day requirement does not apply to a fee increase specified in the contractual fee schedule, and triggered by a change in the resident's service plan.

Security Deposits

The ALR shall hold security deposits in an interest bearing account and shall return any deposits plus accrued interest as set forth in the contract or as required by state law, minus allowable deductions for unpaid fees or damage to the unit within 30 days of the date the resident leaves the ALR.

Resident Finances

The operator or staff of an ALR shall not serve as a resident's guardian, attorney-in-fact, or representative payee. The ALR may manage the resident's funds only with a written authorization by the resident, witnessed by a person with no affiliation to the ALR management. The ALR has a fiduciary responsibility to the resident in any management of a resident's money.

Implementation

Guideline for State Regulation

Rationale

These three recommendations are designed to ensure residents' funds and deposits are protected and that residents receive adequate notice of fee increases so that they have adequate time to evaluate how or whether the changes will affect their lives and finances.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Association of Local Long Term Care Ombudsmen, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

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American Seniors Housing Association, Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.15
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1) We dissent. Fee increases - redundant with recommendation on terms and conditions of the resident contract. Security Deposits- redundant, says ALR must comply with existing requirements in state law.

American College of Health Care Administrators, Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

2) We agree with this recommendation with the exception of the language stating that the operator/staff serve as the representative payee. Operators/staff do serve this role when residents are beneficiaries in certain government programs. Therefore, we believe the "Resident Finances" section should read:

Resident Finances: The operator or staff of an ALR shall not serve as a resident's guardian or attorney-in-fact. The ALR may act as representative payee for Social Security or SSI payments, but must have written authorization, approval from the Social Security Administration, and annually file accounting reports with the Social Security Administration. The ALR may manage the resident's funds only with a written authorization by the resident, witnessed by a person with no affiliation to the ALR management. The ALR has a fiduciary responsibility to the resident in any management of a resident's money.

American College of Health Care Administrators, National Center for Assisted Living, American Seniors Housing Association, American Association of Homes and Services for the Aging

Resident Rights

R.16 Resident Rights Upon Transfer or Discharge**Recommendation****Transfer or Discharge**

An ALR intending to transfer or discharge a resident involuntarily in a non-emergency situation shall provide written notice of such intent to the resident* at least 30 days prior to transfer or discharge. The notice shall include:

- Effective date of the transfer or discharge.
- Reason(s) for transfer or discharge, including facts and circumstances on which the decision is based.
- Resident's right to appeal the decision.
- Information on where to appeal and timeframe for filing appeal.
- Contact information for the Long Term Care Ombudsman Program.
- Resident's right to represent himself/herself or to be represented by legal counsel, a relative, friend or other spokesperson.

This notice shall be provided in a format that is readable and in language that the resident* can understand.

Emergency Transfer or Discharge

In case of emergency (as defined by Recommendation D-5), no written notice is required prior to the transfer or discharge; however the ALR shall provide verbal notice to family members or other individuals designated by the resident, and such notice should be given as soon as is practical under the circumstances.

Appeal of Transfer or Discharge

Residents* have the right to appeal an involuntary transfer or discharge decision to the state licensing or other appropriate agency as determined by the state. States shall designate an agency or agencies for hearing such appeals, and shall develop processes that are expeditious, impartial, and staffed by qualified personnel. These processes shall provide for an in-person hearing accessible to the resident. The resident and the ALR shall have the right to present evidence and arguments and to refute evidence and arguments presented by other parties. Residents may also appeal the decision to the ALR in accordance with internal procedures developed by the ALR. Residents shall not be required to exhaust internal procedures before appealing the ALR decision to the state.

In states without appeals systems it is recommended that ALRs create an appeal process that utilizes neutral outside mediation. (This recommendation should not be construed as supporting or requiring mandatory arbitration.)

Implementation

Guideline for State Regulation

Rationale

Recommendations D.4 and D.5 address the reasons why ALRs may seek to transfer or discharge residents (D.4) and the internal protocols for implementing such a decision (D.5). Recognizing seriousness of such decisions and its impact on residents, this

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Recommendation supplements D.4 and D.5 by providing residents with procedural rights and protections.

Many ALRs have internal mechanisms for reviewing transfer or discharge decisions but because they are conducted by ALR staff or administrators, these reviews may not be as objective as if they were performed by a third party. A number of states have implemented external systems and identified an agency, frequently the licensing agency, to hear appeals of ALR discharge decisions.

R.16 requires ALRs to provide residents* with adequate notice of a decision to transfer or discharge the resident, reasons for the decision, and the opportunity to appeal it. It also provides ALR residents with a right they would have as residents of traditional rental housing or nursing homes - the right to appeal to an impartial forum, a decision that affects one of the most important areas of their lives.

The recommendation does not remove the authority of ALRs to establish their own review mechanisms, but it does allow residents to appeal to the external forum without waiting for the ALR to make a final decision. Understanding the need for all parties to have timely and effective decisionmaking in this area, the recommendation calls for external processes that are expeditious, objective, and staffed by qualified personnel.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Academy of Elder Law Attorneys, National Association of Local Long Term Care Ombudsmen, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Association of Professional Geriatric Care Managers, National Adult Family Care Organization, National Conference of Gerontological Nurse Practitioners, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America

Supplemental Positions for R.16
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1) We dissent. The general thrust of this recommendation is that an ALR must comply with existing state laws regarding transfer and discharge. Also holds state governments accountable for designating certain agencies for hearing appeals and ensuring that the agency is staffed. Beyond the mandate to the ALW. Infringes on state authority to decide how it will meet the intent of an appropriate recommendation.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging

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R.17 Access to State Survey/Inspection Reports**Recommendation**

The ALR shall at all times have readily available copies of all inspection reports and plans of corrections from the past 12 months or, if they have not had a survey in 12 months, the most recent survey cycle. The ALR shall post notice of the availability of such report in a visible, public location and provide copies upon request to prospective and current residents.

Implementation

Guideline for State Regulation

Rationale

Such reports are public documents and residents*, their families and prospective residents can use to provide a recent history of a state's review of the ALR's performance.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for R.17
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None Submitted

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging
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Resident Rights

R.18 Disclosure of Staffing Levels**Recommendation**

The ALR shall disclose the minimum number of direct-care staff available on each shift.

Implementation

Guideline for State Regulation

Rationale

While a rough guide, minimum staffing levels may be helpful in selecting an ALR.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Social Workers, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Association of Local Long Term Care Ombudsmen, National Adult Family Care Organization, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, Assisted Living Federation of America, Catholic Health Association of the United States, Joint Commission on Accreditation of Health Care Organizations, National Center for Assisted Living

Organizations Abstaining From the Vote on This Recommendation

American College of Health Care Administrators

Supplemental Positions for R.18
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1) We believe the following revised recommendation better meets consumer information needs.

The ALR shall disclose upon request the number of staff available each day.

While a rough guide, disclosing staffing patterns may be helpful to consumers when selecting an ALR. Several different staff positions contribute to the quality of life of residents, not just direct-care staff (as defined by the ALW). For instance, activities staff can significantly contribute to the well being of residents. For some residents, these types of services go further to meet resident needs than services traditionally delivered by direct care staff. In addition, it is worth noting that resident ADL and health needs vary from facility to facility making it difficult for consumers to determine whether the minimum number of direct care staff is adequate in a particular ALR. Finally, it is important to recognize that not all ALRs staff in the traditional day, evening and night shifts.

American Association of Homes and Services for the Aging, Catholic Health

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Association of the United States, National Center for Assisted Living, American Assited Living Nurses Association, American Seniors Housing Association

2) We dissent. The number of direct care staff on each shift can vary from day to day according to resident needs. Unclear as to how and in what manner this disclosure would be expected to be made and in what context it would be presented to describe the care planning and service need assumptions that go into staffing schedules.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority***

Resident Rights

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not have a voting record were unable to reach two-thirds majority during the development process.

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Resident Rights

R.19 Lost and Stolen Property**2/3 Maj. Not Reached****Recommendation**

An ALR shall take reasonable efforts to safeguard the property of residents. If an ALR believes that a resident's property has been stolen, the ALR should contact local police. An ALR shall reimburse residents for lost or stolen property if the ALR has failed to make a reasonable effort to safeguard that property.

Implementation

Guideline for State Regulation

Rationale

The intent of this recommendation is not to make ALR's responsible for every loss of resident property. Rather it is to encourage ALRs to take whatever steps are reasonable under the circumstances to help residents ensure the safety of their possessions.

Organizations Supporting This Recommendation

No Vote Recorded

Organizations Opposing This Recommendation**Organizations Abstaining From the Vote on This Recommendation**

Supplemental Positions for R.19
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1) We support this failed recommendation because it sets a standard of care that assisted living providers must follow in safeguarding resident property, and places responsibility for resulting loss on a provider who fails to meet that standard.

The recommendation recognizes that by caring for residents who need oversight and assistance as a result of physical or mental incapacities, assisted living providers assume responsibility for helping those residents to safeguard their possessions. When providers fail to exercise reasonable care, and resident property is lost or stolen as a result, providers should be liable for that loss.

Proposed substitute recommendation: An assisted living residence shall exercise reasonable care in safeguarding the personal property of residents. If the residents' property is lost or stolen as a result of the assisted living residence's failure to exercise reasonable care, the facility shall reimburse residents for the value of the property. An assisted living residence operator who believes that a resident's property has been stolen should contact, or facilitate the resident's* efforts to contact, appropriate law enforcement agencies.

Implementation: Guideline for state regulation

Rationale: This recommendation recognizes the obligation of assisted living residences to exercise reasonable care in helping residents who are living in their facilities because they need oversight and assistance as a result of physical or mental incapacities, to safeguard their possessions.

*Association of Health Facility Survey Agencies, Center for Medicare Advocacy,
National Association for Regulatory Administration, National Association of Local*

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Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) Loss and theft of personal property does occasionally happen in ALRs. A recommendation is needed to address this possibility. The undersigned support the following language: An ALR shall take reasonable efforts to safeguard the personal property of residents. If an ALR believes that a resident's property has been stolen, the ALR shall contact local police. An ALR shall disclose and provide information in its resident contract that the ALR can not guarantee the safekeeping of personal property. Residents will need to make decisions about what personal property (including jewelry) to bring.

AARP, Consumer Consortium on Assisted Living, National Association of Professional Geriatric Care Managers, NCB Development Corporation, National Center for Assisted Living, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

3) We agree that ALRs should take reasonable efforts to safeguard the property of residents. However, how "reasonable efforts" would be defined was unclear. Because of this, there is strong likelihood of abuse of such a facility policy by some. Further, this recommendation would have held ALRs to a higher level of liability for lost or stolen items than in other settings or businesses in this country.

National Center for Assisted Living, American Seniors Housing Association, American Association for Homes and Services for the Aging

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Resident Rights

R.20 Medicaid Reimbursement**2/3 Maj. Not Reached****Recommendation**

An ALR that has agreed to participate in the Medicaid program should make every effort to accept Medicaid reimbursement for any current resident for whom Medicaid reimbursement is available.

Implementation

Guideline for Operations

Rationale

By definition, a Medicaid-eligible resident has spent down virtually all of his/her savings and has relatively little income. To prevent residents from having to move, Medicaid-certified providers are encouraged to accept Medicaid reimbursement on behalf of Medicaid-eligible individuals.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

Joint Commission on Accreditation of Health Care Organizations

Supplemental Positions for R.20
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1) We oppose this failed recommendation because it requires nothing and, in any case, it has been made merely a non-binding guideline for operations (as opposed to a guideline for state regulation).

This recommendation is a radically watered-down version of the language approved by the Resident Rights Topic Group. As the recommendation now stands, assisted living providers are merely encouraged to retain residents for whom Medicaid reimbursement becomes available, as guideline for operations. There is no requirement that they do so. The original language, a guideline for state regulation, stated: "An ALR that participates in the Medicaid program shall be required to accept

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reimbursement for any current resident for whom Medicaid reimbursement has become available during his/her stay in the facility." This was a reasonable requirement: if an assisted living residence has chosen to be certified for Medicaid reimbursement, and Medicaid reimbursement for a resident is available, the assisted living residence should be required to accept that reimbursement. This is particularly important because, by definition, the resident in question likely has become financially eligible for Medicaid by paying much of his or her life savings to the assisted living residence as payment for care received.

Federal law prohibits Medicaid-certified long-term care providers from discriminating on the basis of payment source. 42 U.S.C. §§ 1395i-3(c)(4), 1396r(c)(4)(A), 42 C.F.R. § 483.12(A)(2)(v). There is no principled reason to make an exception for assisted living. It is unconscionable to allow an assisted living residence to discharge an individual who becomes eligible for Medicaid after impoverishing herself by paying for her care in the residence.

Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

2) We dissent. Goes beyond the mandate to the ALW to stipulate the degree to which an ALR must go to accept Medicaid reimbursement.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Topic Group Recommendations Adopted by Two-Thirds Majority of the ALW

Staffing

Purpose

The staffing topic group of the ALW focused on practices and procedures related to the staffing components of ALRs.

Issues

Recommendations related to staffing were made in the following areas: communication; criminal background checks; abuse registry; job descriptions; staff vaccinations; compliance with federal employment laws; verification of employment history; administrator qualifications; workload; awake staff; acting administrator authorization; management recruitment and retention practices; human resources recruitment and retention practices; direct care training and supervision; orientation; and performance evaluations.

Participants

The topic group was co-chaired by Bernadette Wright of AARP and Karen Love of the Consumer Consortium on Assisted Living.

Topic group participants included Linzi Burns, American College of Health Care Administrators; Steven Evans, American Medical Directors Association; Sandy Flores, American Assisted Living Nurses Association; Iris Freeman; Elinor Fritz, New Jersey LTC Assessment and Survey Division; Genevieve Gipson, National Network of Career Nursing Assistants; Marianna Grachek, Joint Commission on Accreditation of Healthcare Organizations; Marsha Greenfield, American Association of Homes and Services for the Aging; Rick Harris, Association of Health Facility Survey Agencies; Gerald Kasunic, National Association of State Ombudsmen Programs; Karen Kauffman, National Conference of Gerontological Nurse Practitioners; Martha Mohler, National Committee to Preserve Social Security and Medicare; Jonathan Musher, American Medical Directors Association; Doug Pace, American Association of Homes and Services for the Aging; Mary Parker, Institute for Palliative and Hospice Training Inc.; Jackie Pinkowitz, Consumer Consortium on Assisted Living; Brian Rasmussen, United Cerebral Palsy; Barbara Resnick, American Geriatric Society; Shelley Sabo, National Center for Assisted Living; Beth Singley, Assisted Living Federation of America; Mary Tellis-Nayak, American College of Health Care Administrators; Janet Wells, National Citizens' Coalition for Nursing Home Reform; Jacquie Woodruff, National Association of Local LTC Ombudsman Programs.

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Staffing

S.01 Staffing Qualifications: Communication**Recommendation**

In ALRs serving a majority English speaking population, staff who interact with residents in the delivery of services will have the ability to communicate in English with ALR residents and the community at large. Staff shall be able to communicate or have a method or mechanism to communicate with all residents. There shall be at least one person on duty at all times who has the ability to communicate in English.

Implementation

Guideline for State Regulation

Rationale

It is important that service staff have the ability to communicate with residents. For most ALRs, proficiency in English will be necessary to communicate with residents and with the community at large (e.g., residents' families, physicians, outside service providers).

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association for Regulatory Administration, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, National Association of Home Care

Organizations Abstaining From the Vote on This Recommendation

NCB Development Corporation

Supplemental Positions for S.01
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1) We dissent. Although we can support the intent of this recommendation, it goes beyond the mandate of the ALW.

Assisted Living Federation of America, National Association of Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing

S.02 Federal Criminal Background Checks**Recommendation**

The federal government should establish an affordable and timely system that allows ALRs to access the national criminal background check registry. The system should use appropriate technologies to ensure the validity of the information (e.g. fingerprints, retinal scans, etc.).

Implementation

Guideline for Federal Policy

Rationale

State criminal background checks only provide information on an individual's criminal record in that state. If an individual has been convicted of a crime in one state and then applies for a job in another state, a criminal background check in that state would not detect the prior conviction in the other state.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.02

None Submitted

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Staffing

**S.03 Staff Qualifications: Use of Information from
Criminal Background Checks**

Recommendation

Each state should enact legislation or adopt rules requiring health care providers, including assisted living residences, to conduct criminal background checks before hiring staff members. The legislation or rules should also specify the crimes, conviction of which will result in disqualification from employment in the ALR.

Implementation

Guideline for State Regulation

Rationale

The benefits of conducting criminal background checks, as well as other measures to screen those who have access to vulnerable AL residents, are intuitively obvious. Of course, a criminal background check does not, by itself, provide any protection. It merely provides information. The critical factor is how the information gathered by criminal background checks will be used. There is a tremendous potential benefit to residents and to providers in having a uniform set of standards specifying which crimes ought to disqualify an individual from working in the AL setting, as well as how long a particular crime's disqualification should last.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Local Long Term Care Ombudsmen, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Adult Family Care Organization, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.03
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None submitted

Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging**Staffing****S.04 Federal Abuse Registry****Recommendation**

The federal government should establish and fund a national registry of individuals with histories of abuse, to include founded complaints substantiated by state survey agencies. A system of due process should be in place to allow workers to appeal a finding of abuse.

Implementation

Guideline for Federal Policy

Rationale

All 50 states have a nursing home aide abuse registry. This could be expanded to cover assisted living.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.04

None Submitted

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Staffing

S.05 Verification of Employment History**Recommendation**

The ALR should contact prior employers for all potential employees in order to verify employment history. Written documentation should be kept in the employee's confidential file.

Implementation

Guideline for Operations

Rationale

Contacting references can be a useful tool for assessing the fit between the applicant and the job and for screening out applicants who are untruthful about their work history.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America

Supplemental Positions for S.05
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1) We dissent. This recommendation attempts to micromanage routine administrative paperwork by requiring ALRs to keep verification of employment history in a file folder. It provides no guidance to the states or ALRs that would improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

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Staffing

S.06 Compliance with Federal Employment Laws**Recommendation**

Assisted living residences shall comply with all applicable federal employment laws, including, but not limited to the American Disabilities Act (ADA), the Fair Labor Standards Act (FLSA), the Civil Rights Act, and the Occupational Safety and Health Act (OSHA).

Implementation

Guideline for Operations

Rationale

Several federal employment laws apply to ALRs. ALRs should comply with all of these laws.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.06
--

1) We dissent. The thrust of this recommendation is that ALR must comply with existing laws. As such, it is redundant, and provides no new guidance to the states that will improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing

S.07 24-Hour Awake Staff**Recommendation**

The ALR shall ensure that the right number of trained and awake staff are on duty and present at all times, 24 hours a day, 7 days a week, to meet the needs of residents and to carry out all the processes listed in the ALR's written emergency and disaster preparedness plan for fires and other natural disasters.

Implementation

Guideline for State Regulation

Rationale

For the ALR to be able to protect residents in the event of an emergency or disaster, it is essential that the ALR ensure that there are present at all times staff who are trained to implement the ALR's written emergency plans. At a minimum, this will require at least one awake trained staff person at all times. The number of staff needed to respond to emergencies will vary, depending on the size and layout of the ALR and the needs of its residents.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Adult Family Care Organization, National Center for Assisted Living, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Network of Career Nursing Assistants, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Bar Association

Supplemental Positions for S.07
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1) We dissent. A minimum number of trained, alert staff on duty must be specified in state regulation. It should not be left to the ALR alone to determine "the right number." States must also set a standard for augmenting the number of staff above the required minimum, in proportion to the number of dependent residents. At the very least there should be two staff members on duty on each residential floor or unit of more than five residents, thus allowing at least one to attend to an urgent

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situation and one to call for help and meet on-going needs of residents. Beyond the baseline minimum, there should be additional staff persons to provide routine observation and assistance according to identified individual needs and the ability of residents to exit the unit or building by themselves in an emergency.

Provision for at least two staff for emergencies is currently found in proposed or existing requirements of some states. E. g., Virginia requires dementia units to have at least two direct care staff members awake and on duty at all times, unless fewer than six residents are present and at least two other direct care staffs are in the building.

National Committee to Preserve Social Security and Medicare, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs

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Staffing

S.08 Authorized Acting Administrator**Recommendation**

There shall be an individual authorized in writing to act for the administrator during absences.

Implementation

Guideline for State Regulation

Rationale

This recommendation is intended to ensure that an individual is designated to act in place of the administrator during their absence from the facility.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, Assisted Living Federation of America, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Adult Family Care Organization, National Center for Assisted Living, National Hospice and Palliative Care Organization, Pioneer Network

Organizations Opposing This Recommendation

Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.08
--

1) We dissent. As written, this recommendation leaves open the possibility that a person of no specified qualifications could be designated as acting administrator for any period of time. States should set minimum requirements for the qualifications of an acting administrator and limit the period of time an ALR can be directed by an acting administrator.

Consumer Consortium on Assisted Living, National Committee to Preserve Social Security and Medicare, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs

Staffing

S.09 Vaccinations**Recommendation**

All staff, including volunteers the ALR or state policy determine necessary, will be tested for and vaccinated against communicable diseases, consistent with the most current CDC and OSHA requirements and all applicable state requirements. A record of vaccinations and test results will be kept in the individual's confidential file.

Implementation

Guideline for State Regulation

Rationale

CDC's "Immunizations for Staff of Long Term Care Facilities" can be found in Prevention and Control of Vaccine-Preventable Diseases in Long Term Care Facilities, available at <http://www.cdc.gov/nip/publications/Long-term-care.pdf>. To briefly summarize:

- (1) Hepatitis B Vaccine: "Any health care worker who performs tasks involving contact with blood, blood-contaminated body fluids or other body fluids or sharps should be vaccinated."
- (2) Influenza Vaccine: "To reduce staff illnesses and absenteeism during the influenza season and to reduce the spread of influenza to and from workers and patients, all health care workers who work in long term care facilities should be vaccinated in the fall of each year." The CDC suggests ways to improve influenza vaccination use among employees.
- (3) Measles, Mumps and Rubella Vaccine: "While older residents of long term care facilities may have had these diseases and be immune, staff immunization requirements should comply with the ACIP recommendations for health care workers, i.e. demonstration of immune status either by means of a vaccination record or documentation of physician-diagnosed disease, or if they were born before 1957."
- (4) Herpes Zoster and Varicella Vaccine (125): "Varicella (chicken pox) is a highly contagious disease caused by the varicella zoster virus (VZV). Varicella vaccine is recommended for susceptible adults in the following high risk groups: a) persons who live or work in environments where transmission of VZV is likely (teachers of young children, day care employees, and residents and staff members in institutional settings); b) persons who live and work in environments where transmission can occur (college students, inmates, and staff members of correctional institutions and military personnel); c) non-pregnant women of childbearing age; d) adolescents and adults living in households with children; e) international travelers.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Center for Medicare Advocacy,

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Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, NCB Development Corporation, National Association of Social Workers, National Association of Activity Professionals, National Association of Home Care, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America, National Association for Regulatory Administration

Supplemental Positions for S.09

None Submitted

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Staffing

S.10 Discussion of Job Descriptions with Potential Employees

Recommendation

The ALR will ensure that relevant job descriptions are discussed with potential employees, students, and volunteers and that employees receive written copies of their job descriptions upon the start of employment, or before.

Implementation

Guideline for State Regulation

Rationale

It is important that potential employees, students, and volunteers understand the nature and responsibilities of their job prior to hire.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Network of Career Nursing Assistants, National Senior Citizens Law Center, Pioneer Network

Organizations Opposing This Recommendation

None

Organizations Abstaining From the Vote on This Recommendation

Assisted Living Federation of America

Supplemental Positions for S.10
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1) We dissent. Recommendation attempts to micromanage routine administrative paperwork by requiring ALRs to provide employees with written copies of their job descriptions. Recommendation does not provide guidance to the states that will improve quality in assisted living.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing**S.11 Qualifications for Administrators****Recommendation**

To qualify as an assisted living administrator, individuals who are not qualified nursing home administrators shall complete a state-approved ALR licensure course and pass a state-approved exam.

Minimum Qualifications of a Licensure Course and Exam

The licensure course and exam shall cover the following areas:

(1) Philosophy of assisted living; (2) Organizational management and governance; (3) Resident services; (4) Clinical services; (5) Environmental management; (6) Financial management; (7) Personnel management; (8) Applicable regulations.

Continuing Education

To maintain licensure, an AL administrator shall complete 18 hours of state-approved continuing education per year on subjects relevant to assisted living operations, management, and philosophy.

Current Assisted Living Administrators and Interim Administrators

Current assisted living administrators who have worked for a period of at least one (1) year should not be required to take an ALR licensure course, but still shall take and pass the state approved ALR Administrator exam within six (6) months. Interim administrators shall be licensed within 6 months.

Minimum Education and Experience

An individual shall have one of the following combinations of education and experience, in order to take the AL administrator licensure exam:

1. A high school diploma or equivalent plus 4 years experience working in assisted living or health or aging related setting, including 2 years in a leadership or management position
2. An associate's degree plus 2 years experience working in assisted living or health or aging related setting, including 1 year in a leadership or management position
3. A bachelor's degree plus 1 year experience in a health or aging related setting.

Implementation**Guideline for State Regulation****Rationale**

In developing the above recommendation, the topic group examined the qualifications for certification or licensure by national organizations and modified these to include additional skills recognized as important by the topic group. Modifications were also made to take into consideration differences in ALR size.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, National Network of Career Nursing Assistants, Consumer

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Consortium on Assisted Living, NCB Development Corporation, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of State Ombudsman Programs, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Assisted Living Nurses Association, American Seniors Housing Association, Assisted Living Federation of America, Center for Medicare Advocacy, Joint Commission on Accreditation of Health Care Organizations, National Association of Home Care, National Center for Assisted Living

Organizations Abstaining From the Vote on This Recommendation

National Association of Social Workers, National Association for Regulatory Administration

Supplemental Positions for S.11

1) We oppose the recommendation and the operational model. We believe each state is capable of determining the level of education and experience needed for assisted living administrators.

National Center for Assisted Living, American Seniors Housing Association

Staffing

S.12 Recruitment and Retention: Management Practices

Recommendation

To aid in the recruitment and retention of staff, management shall foster an assisted living culture that values, respects, and supports all residents, staff, family, and volunteers. Management shall implement operational and staffing practices that promote effective communication, collaboration, responsibility, and accountability among its members.

Implementation

Guideline for Operations

Rationale

Effective recruitment, staff development and retention practices lead to enhanced quality of life for both residents and staff members of the ALR. They have direct and significant implications for residents with respect to quality of care and services provided them; for staff with respect to job effectiveness and job satisfaction; and for providers with respect to operating costs associated with high staff turnover. Indeed, high turnover in the LTC workforce has long been associated with poorer resident outcomes--as it places greater, often unrealistic and unmanageable, workload demands on remaining staff. Decreased worker effectiveness, increased levels of stress, and increased job dissatisfaction have all been cited as negative outcomes of, and potential triggers for more, staff turnover. As Susan Eaton notes in her research paper "Keeping Caring Caregivers": "From the research literature in organizational behavior, management, sociology and human resources, it is known that supervisory relationships, staffing levels, wage levels, benefit levels, and even the organizational culture of care could make working in two apparently similar facilities a very different experience (Herzenberg et al 1999)." Indeed, her findings indicate that a well-managed organization that respects and develops caregivers and utilizes thoughtful work structures, implements positive and flexible human resource policies that build on workers intrinsic motivation, and maintains adequate staffing levels can do much to ameliorate staffing and quality care issues.

Susan Eaton in "Beyond 'Unloving Care:' Linking Human Resource Management and Patient Care Quality in Nursing Homes" (full text at <http://www.ksg.harvard.edu/socpol/eatonpaper.htm>): "The most striking characteristic of the working conditions in the higher quality nursing homes was that the facilities were not understaffed... Work organization also differed. Nurse aides often worked in teams, or "care partners", so they could assist each other. Information on resident health status was freely shared by nurse supervisors, often in a "team meeting" at the beginning of a shift."

Susan Eaton in "Keeping Caring Caregivers: How Managerial Practices Affect Turnover among Front-line Nursing Assistants": "...five areas stand out as distinguishing facilities with low nursing staff turnover:

- (1) High quality leadership and management, offering recognition, meaning, and feedback as well as the opportunity to see one's work as valued and valuable; Managers who built on the intrinsic motivation of workers in this field
- (2) An organizational culture, communicated by managers, families, supervisors, and

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Staffing

nurses themselves, of valuing and respecting the nursing caregivers themselves as well as residents

(3) Basic positive or 'high performance' Human Resource policies, including wages and benefits but also in the areas of 'soft' skills and flexibility, training, and career ladders, scheduling, realistic job previews, etc.

(4) Thoughtful and effective, motivational work organization and care practices

(5) Adequate staffing ratios and support for high quality care.”

Iowa Caregivers C.N.A. Recruitment/Retention Project

(www.gao.gov/new.items/d01750t.pdf)

Final Report details a pilot program of direct care worker interventions (including training on conflict resolution, workshops in communication and team building and a mentor training program) implemented to address CNAs' top concerns:

- 1) Short-staffing
- 2) Poor wages and benefits
- 3) Relationships (supervisors) and lack of respect from public
- 4) Inadequate job orientation and levels of training

CNAs reported the need for:

- 1) Better orientation programs
- 2) Better communication, teamwork, and improved relationships with co-workers, especially supervisors.
- 3) More training on the disease processes and in caring for dementia clients.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, American Seniors Housing Association, National Center for Assisted Living

Organizations Abstaining From the Vote on This Recommendation

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None

Supplemental Positions for S.12

1) We dissent. Recommendation is focused on instructing the ALR to implement operational and staffing processes, rather than focusing a quality monitoring component from the perspective of the consumer and determining the resident's views and opinions on the quality of life in the ALR.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing

S.13 Recruitment and Retention: Human Resource Practices**Recommendation**

Management shall implement human resource practices to promote the recruitment, professional development, and retention of direct and indirect care staff. Management shall consider short and long-term strategies and professional and personal support services that would be deemed most meaningful to their specific staffing populations including:

- a. Effective leadership and supervision offering strong, respectful organizational culture to support all staff so that staff can be effective, supportive caregivers;
- b. Living wages and benefits;
- c. Consistent resident assignments, with input from residents and staff;
- d. No mandatory overtime;
- e. Skills development (training including advanced skills, mentoring, train-the-trainer) and;
- f. Career advancement (career ladders, peer mentors).

Management shall develop, implement, monitor, and evaluate the recruitment, development, and retention of direct care staff.

Implementation

Guideline for State Regulation

Rationale

Effective recruitment, staff development and retention practices lead to enhanced quality of life for both residents and staff members of the ALR. They have direct and significant implications for residents with respect to quality of care and services provided them; for staff with respect to job effectiveness and job satisfaction; and for providers with respect to operating costs associated with high staff turnover. Indeed, high turnover in the LTC workforce has long been associated with poorer resident outcomes--as it places greater, often unrealistic and unmanageable, workload demands on remaining staff. Decreased worker effectiveness, increased levels of stress, and increased job dissatisfaction have all been cited as negative outcomes of, and potential triggers for more, staff turnover. As Susan Eaton notes in her research paper "Keeping Caring Caregivers": "From the research literature in organizational behavior, management, sociology and human resources, it is known that supervisory relationships, staffing levels, wage levels, benefit levels, and even the organizational culture of care could make working in two apparently similar facilities a very different experience (Herzenberg et al 1999)." Indeed, her findings indicate that a well-managed organization that respects and develops caregivers and utilizes thoughtful work structures, implements positive and flexible human resource policies that build on workers intrinsic motivation, and maintains adequate staffing levels can do much to ameliorate staffing and quality care issues.

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the working conditions in the higher quality nursing homes was that the facilities were not understaffed....Work organization also differed. Nurse aides often worked in teams, or "care partners", so they could assist each other. Information on resident health status was freely shared by nurse supervisors, often in a "team meeting" at the beginning of a shift."

Susan Eaton in "Keeping Caring Caregivers: How Managerial Practices Affect Turnover among Front-line Nursing Assistants": "...five areas stand out as distinguishing facilities with low nursing staff turnover:

- (1) High quality leadership and management, offering recognition, meaning, and feedback as well as the opportunity to see one's work as valued and valuable; Managers who built on the intrinsic motivation of workers in this field
- (2) An organizational culture, communicated by managers, families, supervisors, and nurses themselves, of valuing and respecting the nursing caregivers themselves as well as residents
- (3) Basic positive or 'high performance' Human Resource policies, including wages and benefits but also in the areas of 'soft' skills and flexibility, training, and career ladders, scheduling, realistic job previews, etc.
- (4) Thoughtful and effective, motivational work organization and care practices
- (5) Adequate staffing ratios and support for high quality care."

Iowa Caregivers CNA Recruitment/Retention Project (www.gao.gov/new.items/d01750t.pdf) Final Report details a pilot program of direct care worker interventions (including training on conflict resolution, workshops in communication and team building and a mentor training program) implemented to address CNAs' top concerns:

- 1) Short-staffing
- 2) Poor wages and benefits
- 3) Relationships (supervisors) and lack of respect from public
- 4) Inadequate job orientation and levels of training

CNAs reported the need for:

- 1) Better orientation programs
- 2) Better communication, teamwork, and improved relationships with co-workers, especially supervisors.
- 3) More training on the disease processes and in caring for dementia clients.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple

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Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Adult Family Care Organization, National Hospice and Palliative Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, Assisted Living Federation of America, American Seniors Housing Association, Catholic Health Association of the United States, National Center for Assisted Living

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.13

1) We dissent. Recommendation is focused on instructing the ALR to implement certain human resources practices rather than focusing a quality monitoring component from the perspective of the consumer and determining the resident's views and opinions on the quality of life in the ALR.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing

S.14 Orientation for All ALR Staff**Recommendation**

Within 14 days of employment, all ALR staff shall successfully complete an orientation program designed by the ALR to provide information on:

- the care philosophy of the ALR,
- understanding of dementia;
- understanding of the common characteristics and conditions of the resident population served;
- appropriate interaction with residents and family members,
- customer service policies, including resident rights and recognizing and reporting of signs of abuse and neglect;
- ALR fire, life safety, emergency disaster plans, and emergency call systems and use of ALR equipment required for job performance; and
- the ALR's employment/human resource policies and procedures.

All staff shall have specific orientation relevant to their specific job assignments and responsibilities.

Contract staff should receive an orientation on topics relevant to their job tasks, including orientation to ALR fire, life safety, emergency disaster plans, and emergency call systems.

Implementation**Guidelines for Operations****Rationale**

Practice and research on long term care and health care staffing and training have documented the need for these requirements, which can be presumed to extend to staffing and training for the assisted living workforce. Information and research is cited from studies conducted in nursing facilities as they provide the closest parallels to assisted living.

Research documents the frailty of residents in assisted living (Haas, 2002). Therefore ALR staff responsible for direct care of residents need a basic level of training and skills and ongoing training and skill development to ensure that the residents receive required care and services that meet generally accepted standards of care for the specific conditions of each resident. Research also suggests that staff training should cover ethical and interpersonal aspects of care as well as technical skills development (Feldman, 1994).

The Abt Associates, Inc. Phase II study on nursing staffing and training in nursing facilities conducted for the U.S. Department of Health and Human Services found that most of the nursing assistants and educators agreed that the federally mandated 75 hours of training was not enough to cover all the material that they needed to learn. A number of states require twice that amount. Since the care requirements of residents in assisted living generally are not as high as those of nursing home residents, the recommendation for 75 hours of training is reasonable.

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The medical profession has long practiced a successful training tool - learn a skill, do the skill, teach the skill. The paraprofessional workforce could benefit significantly from this learning method that focuses on competency. A study conducted by the Iowa Caregivers Association in 2000 found this axiom to be true.

Research shows that a high percentage of certified nursing assistant turnover occurs within the first three to six months of hiring (Institute of Medicine 2001). Lack of good orientation or mentoring appeared to increase early turnover among high-turnover facilities (Eaton, "Keeping Caring Caregivers"). The Iowa Caregivers 2000 study found that nursing assistants identified inadequate levels of education, training and orientation as one of the major reasons why they do not stay in the field. Careful attention therefore to direct care staff education, orientation, mentoring, and on-the-job training are essential to ensure a stable workforce.

On-the-job injuries are also high for this category of worker (OSHA). Good training and job preparation will help reduce injuries both to workers and to residents.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.14
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1) We dissent. The primary issue related to quality of care is if there is evidence of care needs not being met. States can determine this through substantiated complaints; comparison of assessed need with the service plan, accuracy of the resident's existing service plan relative to observed need; and measures of consumer satisfaction.

Absent data that correlates the ALW's prescribed requirements for orientation programs state

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agencies and ALRs should retain the flexibility to decide the best combination of staff training requirements and care monitoring that will result in high standards of care.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

Staffing

S.15 Staff Performance Evaluations**Recommendation**

All staff shall have performance evaluations conducted at least annually. The evaluation is prepared by a direct supervisor, based on established performance and competency standards for the employee's level of staff responsibility. The evaluation shall include measurable performance objectives for the next evaluation period and a plan for training or other activity to assist the employee to achieve these objectives. Copies of the evaluation and performance objectives and achievement plan shall be placed in the employee's personnel record. A copy of the evaluation shall be given to the employee and the employee provided an opportunity to discuss the evaluation with the supervisor and respond to unfavorable evaluations as part of employee grievance processes.

Implementation

Guideline for Operations

Rationale

It is appropriate that employers and employees understand the standards of performance and competency upon which the employee will be evaluated. Positive employment practices use evaluations as a method of assisting employees to improve their performance, therefore evaluations should be tied to a plan which will assist the employee, by training or otherwise, to achieve performance objectives. Employees should have a right to dispute unfavorable evaluations as part of employee grievance practices.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Catholic Health Association of the United States, Center for Medicare Advocacy, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Academy of Elder Law Attorneys, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association for Regulatory Administration, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Association of Local Long Term Care Ombudsmen, National Hospice and Palliative Care Organization, National Adult Family Care Organization, National Senior Citizens Law Center, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America

Organizations Abstaining From the Vote on This Recommendation

National Center for Assisted Living

Supplemental Positions for S.15
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1) We dissent. This recommendation attempts to micromanage administrative personnel functions of the ALR. Beyond the mandate of the ALW.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

***Topic Group Recommendations
That Did Not Reach Two-Thirds Majority
Staffing***

The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not have a voting record were unable to reach two-thirds majority during the development process.

Staffing

S.16 Personal Care Assistant (PCA) Training**2/3 Maj. Not Reached****Recommendation**

Personal Care Assistants (PCAs) are any staff providing direct care services. All staff providing direct care shall:

1. Be at least 18 years old unless enrolled in a state-accredited high school vocational education program; and
2. Successfully complete a state-approved training program including both classroom and clinical skills practicum and pass a written examination and skills competency test administered by a state-approved examiner prior to or within 4 months of hire. The learning and performance objectives for the personal care assistant training program shall include all of the following:
 - a. Demonstrate understanding of the philosophy and concepts of assisted living and how they guide caregiving
 - b. Successfully demonstrate the understanding of resident rights (e.g., privacy, freedom of choice, preserving dignity, encouraging independence, personalizing services, etc.)
 - c. Involve and support family caregivers
 - d. Demonstrate cultural competency
 - e. Successfully demonstrate ADL care techniques for dressing, grooming, bathing, oral hygiene, toileting, perineal care for incontinent residents, eating, and assistance with ambulation
 - f. Demonstrate understanding of the normal aging process, sensory changes in older adults, and common geriatric conditions
 - g. Recognize the signs and symptoms of depression and other common mental health conditions
 - h. Successfully demonstrate appropriate techniques for assisting residents with functional disabilities, physical frailties, and mental health issues
 - i. Successfully complete a CPR and First Aid program
 - j. Demonstrate understanding of quality of life needs in the four domains: physical, psychological, social, and spiritual
 - k. Demonstrate understanding of how to respond to emergencies, including falls
 - l. Demonstrate understanding of and demonstrate appropriate infection control measures
 - m. Demonstrate ability to measure, report, and document all vital signs (temperature, pulse, blood pressure, respiration, and pain) including appropriate techniques
 - n. Document tasks associated with the care needs of residents
 - o. Identify and report changes in health conditions
 - p. Document and report adverse outcomes (e.g., resident falls, elopement, lost teeth/hearing aid, etc.)
 - q. Use resources/references related to the care needs of residents
 - r. Demonstrate understanding of responsibilities under state regulatory requirements related to providing care
 - s. Successfully demonstrate the understanding of care needs for individuals with dementia, including: overview of Alzheimer's disease and related dementias, communicating with individuals with dementia, challenging behaviors, environment and safety, late stage care,

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assistance with ADLs, and integration of activities in daily life,

t. Demonstrate understanding of the use of advanced directives and DNR orders

u. Demonstrate understanding of the principles of palliative and end-of-life care

Current state-approved certification or licensure (e.g., certified nursing assistant, Medicare certified home health aide, licensed practical nurse, registered nurse) may be exempt from the above requirement. States will determine which certifications/licensures will exempt a person from participating in the PCA training. Training for the care of persons with dementia will be provided at the orientation in each ALR.

3. Work under the direct supervision of an experienced mentor who has passed the state-approved certification or licensure training program until they have completed and passed their certification or licensure program.

4. Receive annually at least 12 hours of relevant training and skills development to include at least 4 hours of specific training related to special needs of residents for whom care is provided (e.g., dementia-specific care needs). Completed training should be outlined in each individual's staff performance and training plan and be provided by a state-approved or accredited training source.

Contract staff shall meet the same qualifications as permanent staff, and there shall be a written contract between the ALR and the agency.

Implementation

Guideline for State Regulation

Rationale

This recommendation specifies performance objectives to be achieved, rather than specifying a minimum number of hours of training that shall be completed. The consensus of the ALW was that specifying performance objectives was a better approach than specifying number of hours.

See additional discussion/rationale after S.16 – Orientation for All ALR Staff.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

American Association of Homes and Services for the Aging, American Seniors Housing Association, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, Center for Medicare Advocacy, National Academy of Elder

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Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Association of Local Long Term Care Ombudsmen, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

American Bar Association

Supplemental Positions for S.16

1) The need for appropriate staff training is imperative in order to meet the needs of ALR residents. A national study of assisted living found, "most staff members were not knowledgeable about what constituted normal aging."* Because of the increasingly higher functional and health care needs of assisted living residents, personal care assistants need a thorough training program to adequately prepare them for working in assisted living. Additionally, because of the significant number of residents in assisted living that have dementia, staff need to receive specialized training in this area as well.

S. 16 carefully and thoroughly details the learning and performance objectives for personal care assistant training as well as conditions under which they are tested and supervised. This recommendation importantly addresses the need for contract staff to meet the same qualifications as permanent staff. The undersigned strongly support the importance and value of S. 16.

* Catherine Hawes, Charles D. Phillips, and Miriam Rose. *High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* (Washington, D.C., U.S. Department of Health and Human Services, November 2000), <http://aspe.hhs.gov/daltcp/reports/hshp.htm>.

AARP, American College of Health Care Administrators, Consumer Consortium on Assisted Living, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

2) We oppose this failed recommendation because no length of training is required. The federal minimum requirement for certified nurse aide training is 75 hours, and a number of states require more. The suggested personal care assistant curriculum would have little meaning in practice if training time is too minimal to assure staff competence.

National Committee to Preserve Social Security and Medicare, Center for Medicare Advocacy, National Association for Regulatory Administration, National Citizens' Coalition for Nursing Home Reform, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants, National Senior Citizens Law Center, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs

3) We dissent. Requires states to adopt a state-approved training program for PCA's, and specifies the learning and performance objectives that the state must include. Infringes on state authority and flexibility to decide how it will meet the intent of an appropriate recommendation.

The primary issue related to quality of care is not whether the PCA has passed an examination, but rather is there evidence of care needs that are not being met. States can determine this through

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substantiated complaints; comparison of assessed need with the service plan, accuracy of the resident's existing service plan relative to observed need; and measures of consumer satisfaction.

Absent data that correlates the ALW's prescribed requirements with an improved level of quality of care, states should retain the flexibility to decide the best combination of Direct care staff training requirements and care monitoring that will result in high standards of care.

Assisted Living Federation of America, National Association for Home Care, Joint Commission on Accreditation of Health Care Organizations

4) We believe by limiting employees to a minimum age of 18, that providers are losing a valuable and proven population within the workforce. The minimum age should be 16 years. This is critical at a time when the labor pool in our country is tight and long term care workers are in such high demand.

In addition, we believe PCAs should successfully complete a state-approved training program including both classroom and clinical skills practicum that could be offered at the facility level. Finally, we also believe the list of learning and performance objectives is too extensive for front line caregivers. States should determine what subject matter PCAs are trained in initially and should also be able to identify ongoing training needs.

National Center for Assisted Living, American Seniors Housing Association

Staffing

S.17 Staffing Workload**2/3 Maj. Not Reached****Recommendation**

The ALR shall ensure sufficient staff are on duty on each shift and manage staff activities in a manner that meets the needs of all residents and maintains a clean and safe environment at all times. Management shall implement practices for achieving realistic and reasonable workload levels based upon specific levels of assistance and care needed by residents and the staff time needed on each shift to provide required assistance to all residents assigned for care in a safe, competent, and caring manner.

The elements from the pre-move in screening process, initial assessment, on-going assessments and service plan, in addition to reviewing any change of condition residents may be experiencing shall be considered in determining staffing patterns for direct and indirect care staff.

State regulatory agencies shall develop or adopt a tool for use by surveyors to determine the adequacy of staffing levels to perform tasks specified in the ALR's resident service plans. This tool shall be freely shared with and may be used by ALRs, as well as ombudsmen and consumers.

Chronic understaffing should be cited as a serious deficient practice requiring imposition of immediate and meaningful penalties without the opportunity to be relieved of penalty.

To facilitate workload planning and compliance, states shall develop or adopt a standard curriculum for training personnel with decision-making authority for admission of prospective residents that will enable these employees to adequately assess whether a potential resident's care needs exceed what an ALR can provide, given its staffing level. All personnel involved in admission decisions shall complete this curriculum, and shall be regularly in-serviced with refresher material after completing the curriculum. The ALR will train the marketer on what is appropriate to disclose in the admission process.

Based on the needs of the residents, the assisted living residence shall assure that the resident receives health care services under the direction of a registered nurse and shall:

- a. Have at least one registered nurse available at all times, meaning at least on call and capable of being reached by telephone;
- b. Develop nursing practice policies and procedures and coordination of all health care services.

Implementation

Guidelines for State Regulations

Rationale

Because understaffing creates great potential for harm to residents, state regulatory agencies should consider chronic understaffing as a deficient practice in and of itself, irrespective of whether other care-related deficient practices are identified.

Research in nursing homes has shown that quality of resident care is contingent upon

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appropriate staffing workloads. Too little staff can not meet the full needs of residents. Additionally, when there are insufficient staff, more staff injuries occur -[Susan Eaton, "What a Difference Management Makes! Nursing Staff Turnover Variation Within a Single Labor Market," Abt Assoc. Inc. 2001 - "More injuries were reported by workers on short-staffed units and they also said that residents were more difficult to comfort and soothe, since time was scarcer."] creating expenses for workman's compensation and losing a staff member for an indefinite period of time.

Research has also shown that insufficient staffing workloads are a significant reason why staff resign. Estimates to replace and initially train each new direct care staff member range from \$1,750 to \$5,000 per hire. This is an expense that ALRs frequently do not consider.

Staffing plans shall consider the functional dependencies and care and service needs of residents. Some experts in the field of long-term care research recommend using an acuity-based staffing model. Acuity-based staffing is used frequently by hospitals, but has not been evaluated in assisted living.

1. Research needs to be conducted on developing an effective system for determining appropriate staffing workloads in ALRs.
2. Research needs to be conducted on developing an outcome measurement system to evaluate the effectiveness of ALR staffing practices.

Organizations Supporting This Recommendation

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American College of Health Care Administrators, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Adult Family Care Organization, National Association of Social Workers, National Hospice and Palliative Care Organization, Paralyzed Veterans of America, Pioneer Network

Organizations Opposing This Recommendation

Assisted Living Federation of America, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Network of Career Nursing Assistants, National Academy of Elder Law Attorneys, National Association for Regulatory Administration, National Association of State Ombudsman Programs, National Center for Assisted Living, National Citizens' Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

Organizations Abstaining From the Vote on This Recommendation

None

Supplemental Positions for S.17
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- 1) We oppose this failed recommendation because it does not advise states to set any minimum

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staffing standards to assure the presence of qualified licensed or certified staffs to provide necessary services at all hours.

Robust minimum staffing requirements should be developed in accordance with the numbers of residents, the extent of their care needs and dependency, and, where applicable, the level of licensure. Where there is no specified level of licensure or restriction on the facility's resident admission and retention practices, and/or where a facility is Medicaid certified to serve nursing home eligible residents, the facility must be staffed to provide the highest level of care and health-care oversight.

In developing its method to calculate the minimum staff required per shift, the state must address:

- A baseline staffing level necessary to carry out the facility's emergency plan and routine services applicable to all residents, commensurate with the general acuity level of the population in care or potentially in care according to its licensure level/restrictions or lack thereof;
- Staffs needed to perform the care and service plans for each resident; and
- The extent of nursing care and oversight needed for residents in care or potentially in care for purposes of (a) overseeing the adequate performance of care plans, (b) monitoring all residents for health status changes, and (c) serving residents with significant disabilities and dependencies, including nursing home-eligible residents, residents needing support technology, and those receiving hospice care.

Assisted living healthcare services must be planned and directed by a Registered Nurse (RN), who may delegate responsibilities to qualified staff but must oversee and is accountable for the care provided. Research by Philips, Hawes, and Rose for the U. S. Department of Health and Human Services (2000) "has shown the positive impact of RN care in facilitating 'aging in place' and preventing or delaying transfer from assisted living to a nursing home . . . Residents in facilities with a full time RN involved in direct care were half as likely to move to a nursing home." (Catherine Hawes, telephone conversation, 3-16-2003.) Indeed, at least one state, Alabama, has extensive requirements for RN involvement in Specialty Care dementia units (Ala. Admin. Code section 420-5-20-.06(2)).

National Citizens' Coalition for Nursing Home Reform, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Network of Career Nursing Assistants, National Senior Citizens Law Center

2) The need for appropriate staffing workloads in ALRs is extremely important. Understaffing creates great potential for harm to residents and at minimum unmet personal care needs. Additionally, research shows that insufficient staffing workload leads to increased staff injuries and is a significant reason why staff resign.

Advocates for nursing home reform have supported using a 'fixed ratio' system to determine appropriate staffing workloads, e.g., a minimum of 3.5 direct care staff hours per resident per day. The shortfall of this approach is that there is no research basis (as in nursing homes) for determining minimum staffing ratios for ALRs. Also, the 'fixed ratio' approach does not ensure that the actual needs of the residents are taken into account. Therefore, a 'fixed ratio' system might either provide too few staff if resident acuity needs were very high or too much staff if the resident care needs were quite low. The disparity in resident care needs is prominent in assisted living.

S.17 recommends an 'acuity-based' system that ALRs shall follow to ensure that direct care staffing

<p style="text-align: center;">Assisted Living Workgroup Report to the U.S. Senate Special Committee on Aging</p>
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Staffing

is based on the actual needs of residents. Many researchers and experts in long-term care promote the use of a resident acuity-based approach to determining appropriate staffing workload. This approach focuses on the scheduled and unscheduled functional dependencies and care and service needs of the residents within each ALR - not state-by-state or chain-by-chain, etc. Acuity-based staffing models have been used by hospitals, but have not been widely developed or evaluated in assisted living. Additional research needs to be conducted on developing an effective system for determining appropriate staffing workloads in ALRs.

S. 17 also addresses the need for each ALR to consider the needs of their residents to determine how much time would need to be provided by a registered nurse (RN) to support the health care needs of their residents. The core requirement for an RN is - Based on the needs of the residents, the ALR shall assure that at least one registered nurse is available at all times, meaning at least on call and capable of being reached by telephone. Each facility shall make individual determinations based on the needs of their residents about how many RNs are needed and whether they are staff or contracted professionals.

AARP, American College of Health Care Administrators, American Seniors Housing Association, Consumer Consortium on Assisted Living, NCB Development Corporation, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network

3) The use of healthcare professionals should be based on the needs of the residents. We would recommend keeping the first two paragraphs which are listed below and suggest deleting the rest of the recommendation. Therefore this recommendation should read:

The ALR shall ensure sufficient staff are on duty on each shift and manage staff activities in a manner that meets the needs of all residents and maintains a clean and safe environment at all times. Management shall implement practices for achieving realistic and reasonable workload levels based upon specific levels of assistance and care needed by residents and the staff time needed on each shift to provide required assistance to all residents assigned for care in a safe, competent, and caring manner.

The elements from the pre-move in screening process, initial assessment, on-going assessments and service plan, in addition to reviewing any change of condition residents may be experiencing must be considered in determining staffing patterns for direct and indirect care staff.

National Center for Assisted Living, American Seniors Housing Association

Appendix A

Best Practices / Operational Models

Accountability and Oversight**Operational Model****AO.06 Components of a State Accountability and Oversight System**

In addition to the traditional methods of survey and enforcement some states are using or introducing new programs of technical assistance for ALRs:

California

California's Technical Support Program is an example of a consultative approach that emphasizes prevention through education. TSP staff offer consultation in individual ALRs and provide group-training sessions for providers. TSP services are provided free of charge and on a voluntary basis. Attached is a detailed description of the TSP operated by the Community Care Licensing Division under the California Department of Social Services.

North Carolina

North Carolina enacted House Bill 1068, which directed the Department of Health and Human Services to establish a quality improvement consultation program. The purpose of the program is to assist providers in the development of quality improvement plans for each assisted living community. The NC legislature came to recognize that the imposition of penalties for deficiencies in meeting licensure requirements is not the exclusive method for ensuring quality of care in licensed adult care homes (the licensure term for assisted living in North Carolina).

House Bill 1068 will allow incentives toward the provision of quality, including, but not limited to: 1) amending current law to allow an extension of the licensure period and survey period for Adult Care Homes with a good record of compliance and in the absence of consumer complaints; 2) review aspects of the quality assessment/monitoring process that should be changed or modified under state law; and 3) the Department of Health and Human Services will offer joint training of Facility Services Consultants, county DSS adult home specialists and Adult Care Home Providers.

The bill also calls for the identification of rules that impede direct care of residents or prohibit resident choice, and allows for the development of proposals to repeal those rules as necessary.

Direct Care

Operational Model**D.10 Identification of Cognitive Impairment/Dementia**

To train staff to be aware of the signs and symptoms of cognitive impairment/dementia, assisted living facilities should use the Alzheimer's Association's 10 Warning Signs and the six symptoms listed in the Agency for Health Care Policy and Research (AHCPR) 1996 Clinical Practice Guideline, "Early Identification of Alzheimer's Disease and Related Dementias." The presence of these sign and symptoms does not show that the person has dementia, but rather that he/she needs a diagnostic assessment by an appropriately trained and qualified professional. (AHCPR, the Alzheimer's Association, and the other two consensus groups that have considered procedures for identifying people with possible dementia have recommended staff training about these signs and symptoms rather than formal screening with instruments, such as the MMSE.)

Once cognitive impairment/dementia has been recognized in a resident, assisted living staff may find it valuable to evaluate the person's level of impairment by using one of the available rating instruments. These instruments include the Global Deterioration Scale (Reisberg et al., 1982) and the Clinical Dementia Rating Scale (Hughes et al., 1982).

Operations

Operational Model**O.04 Emergency and Disaster Preparedness Plans**

The following should be considered when developing Emergency and Disaster Preparedness Plans:

- The means by which residents or their families or representatives are notified of the evacuation plan;
- The training that staff will receive related to the plan, specifically execution of the plan, how soon after hiring the training will occur, and how frequently review of the plan with staff will occur;
- The manner in which staff, residents and their families or representatives will be educated about changes to the evacuation plan;
- Specific responsibilities for staff members related to evacuation of residents;
- Current list of each resident who will need physical assistance or specialized equipment in order to evacuate the building and a designated location, known to all staff, as to where this list is kept;
- Identification of the staff member responsible for at a minimum each of the following:
 - Ensuring all residents are accounted for;
 - When time permits, ensuring medications for all residents for whom medications are centrally stored are taken from the building; and
 - When time permits, ensuring the residents' medical records are taken from the building.
- When time does not allow for gathering of medications and residents' medical records, a back-up plan shall be in place for obtaining medications and pertinent medical information following the evacuation.
- The method for notifying families or representatives of residents when an evacuation has occurred;
- The frequency with which execution of the plan will be practiced by staff, by residents and by both following these guidelines:
 - Every six months each shift shall evacuate the building;
 - When this occurs between 9 pm and 6 am, a coded announcement may be used instead of normal audible alarm signals. These practice executions of the plan may be conducted without disturbing sleeping residents by using simulated residents or empty wheelchairs.
 - Every month, on alternating shifts, tabletop evacuation practices should take place.
- A method for evaluation of the effectiveness of the plan.

An additional consideration for providers is to have a written agreement updated annually, which has been signed by all parties, with another location (e.g., hospital, nursing facility, community center, hotel, church, school) in case of the need to relocate residents during an emergency.

Operations

Operational Model**O.05 Contingency Plan**

Factors to be considered when developing the contingency plan include:

- Where the residents will be housed until the facility can again be occupied;
- How the residents will be transported to the alternate location;
- The method for notifying residents' families or representatives that the resident is in an "emergency" location;
- The manner in which adequate and appropriate materials and equipment consistent with the needs of the residents and the contingency location will be identified, gathered and transported;
- How the facility will ensure that there is adequate staff for assistance and transporting of residents and for providing the required care for the residents when they are residing at the contingency location.

All staff should be informed of the most current contingency plan and each individual's role in executing the plan. This should occur annually at a minimum.

Operations

Operational Model**O.06 Food Storage, Preparation and Transporting**

To ensure that food is safely stored, prepared and handled, assisted living residences should follow related guidelines from the Food and Drug Administration. This includes but is not limited to: storing, reheating, and serving food at appropriate temperatures; protecting food from contamination; preventing the growth of food borne pathogens; controlling lighting, ventilation and humidity to prevent moisture condensation and mold growth; thoroughly cleaning and sanitizing work surfaces, supplies and equipment after use; and requiring appropriate hand washing before transporting food and before and during food preparation.

A food service supervisor, who need not be a registered dietitian, should oversee general kitchen management, including ordering of food and supplies; receiving, storing and preparing foods; providing safe and sanitary kitchen areas and equipment; providing staff in-service training of food safety practices; and establishing and updating written food safety and food handling policies and procedures.

Staff involved in the storage, handling and preparation of food should be free of signs and symptoms of communicable disease. Smoking and the use of tobacco products should be prohibited in food preparation and service areas. Food preparation methods that retain nutrient values should be encouraged. The assisted living residences should segregate food from non-consumable supplies such as medical equipment and supplies, medications, cleaning supplies and poisons.

Soiled linen should be handled and transported so that there is no cross-contamination of food preparation, service and storage areas. In instances where this is problematic because of physical plant, soiled linens should be placed in bags for transportation to laundry areas.

Operations

Operational Model**O.08 Smoking**

If the assisted living residence permits smoking, the assisted living residence must have a written smoking policy which addresses: who may and may not smoke; when and where smoking may occur; appropriate signage in designated smoking areas; what information is relayed to residents regarding the impact of smoking on themselves and others and smoking related safety; what information is relayed to staff regarding the impact of smoking on themselves and others, smoking safety and handling smoking related emergencies; how smoking policies will be communicated and enforced throughout the assisted living residence, including smoking related move out criteria; what documentation is required to support individual resident smoking including intake, periodic screening, evaluation, education and informed consent; how and how often residents who wish to smoke will be screened for their ability to smoke independently or with assistance, with the components of a smoking screening process including the following risk factors at a minimum- level of cognition, ability to smoke unsupervised, medication use in relation to smoking, and safety issues (e.g. smoking and oxygen use); and maintenance of ventilation and fire protection systems.

Operations

Operational Model**O.09 Activities**

Staff, volunteers, family members, and students involved in planning or implementing activities must receive training that includes but is not limited to: the philosophy, intent and importance of activity services; the diversity of residents' learning styles; preparation and set-up of environment and materials; and how to provide positive interaction and communication.

Activity calendars must be current, understandable and accessible to resident, families, staff and volunteers. Repeated oral communication with residents must be utilized so that residents can be comfortable knowing what will be available during that month / week / day and have the opportunity to choose accordingly.

Operations

Operational Model**O.10 Activities for Special Care Residents**

The Alzheimers Association with input from National Association of Activity Professionals offer a course entitled "Activity Based Alzheimer Care: Building a Therapeutic Program" which encompasses philosophy, activity domains, and categories that can be incorporated into an ALR program for special care residents. The Alzheimers Association also has a course for staff training entitled "Alzheimers Care Enrichment Philosophy: Building a Caregiving Team." For further information, contact your local Alzheimer's Association Chapter.

Operations

Operational Model**O.13 Assisted Living Residence Councils**

Resident Council can find many worthwhile activities and projects in which to participate, including welcoming committees, get well committees, residence newsletters, recognizing individuals for special efforts, and employee of the month awards.

Resident Rights

Operational Model**R.09 Pre-Admission Disclosure on Advance Directives**

As part of the ALR's pre-move in screening process, the facility should provide to residents* information about their rights under state law to execute advance directives, which may include a booklet or statement provided by the State or other respected source outlining its advance directive legislation. The explanation approved for hospitals, nursing facilities, hospices and home health agencies by the state's medical assistance program under the federal Patient Self-Determination Act may be used as a model.

Resident Rights

Operational Model**R.10 Pre-Admission Disclosure on End-of-Life Care****Operational Model**

The ALR's pre-move in screening process should provide to residents information about any state laws or regulations which will limit its ability to provide certain types of end of life care and support. The ALR should state its philosophy about the provision of end of life care in the ALR including, but not limited to, access to palliative care or hospice services from outside providers. The ALR should provide a written statement (either separate or as part of other materials) of its philosophy and policies concerning limitations on delivery of medical services, food, or hydration as part of a palliative or hospice plan of care. In addition, the ALR should disclose how it implements or assists end of life care plans, including pain management, palliative symptom management, and the provision of psychosocial and spiritual support. Information and regulations affecting operational models include: Medicare Regulations, Publications of the Last Acts Campaign, Policies/procedures recommended by the National Hospice and Palliative Care Organization.

Staffing

Operational Model

S.11 Qualifications for Administrators

This is an operational model of a course to prepare individuals to take the AL certification or licensure exam.

Required Knowledge & Skill Areas for Each Domain

Organizational Management and Governance

- Governing body's mission, philosophy, goals, and ethics
- Equal Employment Opportunity Commission, Americans with Disabilities Act and immigration laws and regulations
- Area agencies on aging, assisted living, ombudsman programs
- Communication methods for disseminating goals and objectives
- Goal-setting and implementation
- Professional ethics
- Management – science, art, and practice
- Needs assessment
- Risk management principles
- Public relations and marketing of assisted living residences
- Planning, implementation, evaluation of strategies, methods, and outcomes
- Problem-solving and decision-making
- Resource allocation and management
- Forecasting techniques to anticipate demand for assisted living services
- Partnership development with health care providers in the community
- Information dissemination techniques for community awareness of the residence and its services
- Outreach services – their cost and impact on referrals and community opinion
- Federal, state, and local government regulations, standards, and guidelines that effect residence operation and methods of compliance
- Legislative process
- Requirements for the participation in experimental research
- Methods of estimating, and the uses for, resident turnover data
- Records systems, including automation, retention, security, and applicable laws and regulation
- Family, resident, and staff satisfaction procedures to monitor and improve quality of services

Resident Services

- Communication methods for disseminating and providing resident care services
- Resident assessments and implementation of care services
- Implementation of quality improvement program to insure quality and timely care to residents
- Move-out planning, discharge resources and associated liability issues
- Legal rights of resident including privacy, right to information, informed consent, self-determination, and advance directives
- Planning, implementation and evaluation of food service program that meets the

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Operational Model

- nutritional needs of the residents and promotes socialization
- Medical and psychosocial needs of the elderly and chronically ill
- Social services, activities, food services, residents records and pharmacology
- Determination and assessment of resident care goals and appropriate documentation
- Residents' Bill of Rights and Responsibilities
- Development of resident rules, regulations and policies
- Needs assessment and implementation of staffing patterns necessary for quality services and residence requirements

Clinical Services for Specialty Residences

- Basic requirements for special diets and administration protocols
- Rehabilitation Services
- Respiratory Services
- Procedures for teaching individuals about illness and care needs
- Basic disease processes, appropriate clinical care, infection control, and acuity requirements
- Development and implementation of systems for handling, administering, labeling, and destroying drugs
- Role of pharmacist and/or consulting pharmacist
- Process for medication management
- Infection control techniques and protocols related to care and services
- Basic medical terminology
- Medical services and their role in the organization
- Techniques to gather and utilize necessary information for resident and organizational outcomes

Environmental Management

- Architectural and environmental design to accommodate all age groups and those physically challenged
- Building code rules and regulations
- Community emergency resources
- Effective training for emergencies
- Evaluation procedures for housekeeping and physical plant
- Sanitation and infection control
- Materials management
- Preventative maintenance
- Procedures for designating responsibility in emergency planning
- Pest control
- Safety, fire, and disaster guidelines of the National Fire Protection Association and the Life Safety Codes as well as local ordinances
- Security measures

Financial Management

- Ancillary and other revenue producing sources
- Capital budgeting
- Computer management information systems for financial management

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- Cost components for services, programs, renovation/expansion of residence and new construction
- Financial analyses
- Generally accepted accounting practices (e.g., budgeting, cash flow, inventory, banking, auditing procedures, fixed costs, variable costs, investments, collection, billing, purchasing, etc.)
- Interpreting financial results
- Insurance needs for residence
- Loan acquisition
- Materials management, including inventory and purchasing
- Resident financial evaluations, banking procedures and account management
- Resident fund and petty cash management and liability
- Payroll procedures
- Regulatory requirements for budgeting
- Reimbursement regulations
- Tax laws and reporting (proprietary and nonprofit)
- Techniques for determining reasonable costs/pricing
- CPA audit reports

Personnel Management

- Labor laws
- Development of personnel policies, regulations and laws including grievance procedures; job descriptions, labor, tax, minimum wage and federal/state/local regulations; worker's compensation; benefits and wages; current market value of labor; employee recruitment, assessment, motivation and recognition methods; information, communication and counseling channels with the residence; in-service/training needs assessment, program planning, costs, implementation, and evaluation; analysis of absenteeism and turnover rate; organization theory, lines of authority and responsibility; job description development and maintenance
- Recruitment and interviewing
- Staffing methods and patterns, including job analysis
- Written and oral communication skills for effective employee relations

Staffing

Operational Model**S.12 Recruitment and Retention: Management Practices**

The complex issues regarding recruitment, development, and retention of staff throughout the LTC industry in the present, and into the future, may best be addressed by all sectors combining their resources and talents to create public/private collaborations that promote the creation, testing, implementation, and evaluation of new initiatives.

Such efforts may include, but not be limited to collaborations with public agencies, educational institutions, community-based initiatives, and/or other providers.

The report to the Pennsylvania Intra-Governmental Council on Long Term Care entitled "Pennsylvania's Frontline Workers in Long Term Care" (Polisher Research Institute at the Philadelphia Geriatric Center; Feb. 2001) represents one state-wide examination of these issues across the entire long term care continuum of facility-based and community-based providers, advocating public/private partnerships and "... close cooperation between various government departments and agencies and between the different provider segments within the long term care industry" as guiding principles for designing new statewide initiatives.

Massachusetts has established the Direct Care Workers Initiative, "...a coalition of consumer advocates, providers, labor unions and worker advocates that seeks to improve the quality of long-term care by improving the quality of jobs for direct care workers."

Effective structures and practices may include, but not be limited to:

- quality improvement teams to assist in developing, implementing, monitoring, and evaluating ALR practices
- interdepartmental and across-shifts information and communication practices
- interdisciplinary teams for collaborative resident care planning, implementation, and evaluation.

Susan Eaton in "Beyond 'Unloving Care': Linking Human Resource Management and Patient Care Quality in Nursing Homes" (text at <http://www.ksg.harvard.edu/socpol/eatonpaper.htm>) describes a regenerative community model. "This study examines the link between human resource management, work organization, and patient care quality in U.S. long-term care settings, proposing a key role for both management philosophy and improved front line staffing arrangements in delivering consistently higher quality care, defined to include both physical and psychological outcomes.... The original research includes case studies conducted in 20 facilities in California and Pennsylvania, USA." "The 'high quality' homes are distinguished by more nurses working on each shift at the RN, LVN, and NA levels, more gerontological training for all staff, greater information-sharing, more team-work and more continuity of care."

In "Recruiting and Retaining Frontline Workers in Long-Term Care: Organizational Practices in Ohio" Scripps Gerontology Center Miami University Oxford, OH, June 1999 (Full report at www.scripps.muohio.edu - under Publications section,) Jane Karnes

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Straker & Robert C. Atchley delineate "...conditions and management practices that differentiated organizations reporting minimal problems in recruiting and retaining staff in frontline positions from those that reported serious problems" in LTC facilities and home health care programs. "To keep employees once they are hired employers must provide adequate training to inspire confidence on the job, adequate staff to prevent overload and burnout, and time to maximize relationships with care recipients. Strategies used by low turnover organizations provide ideas of where other organizations can begin." "Only low turnover nursing homes were interested in offering additional opportunities for employee input, although at least one study has shown that the only factor that had a significant impact on nursing home turnover was the degree to which aides were able to contribute their own opinions about resident care. Where aides participated in care planning meetings, turnover was even lower (Wilner & Wyatt, 1999)."

Staffing

Operational Model**S.13 Recruitment and Retention: Human Resource Practices**

The complex issues regarding recruitment, development, and retention of staff throughout the LTC industry in the present, and into the future, may best be addressed by all sectors combining their resources and talents to create public/private collaborations that promote the creation, testing, implementation, and evaluation of new initiatives.

Such efforts may include, but not be limited to collaborations with public agencies, educational institutions, community-based initiatives, and/or other providers.

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Massachusetts has established the Direct Care Workers Initiative, "...a coalition of consumer advocates, providers, labor unions and worker advocates that seeks to improve the quality of long-term care by improving the quality of jobs for direct care workers."

Staffing

Operational Model**S.16 Personal Care Assistant (PCA) Training**

Dementia Care in Assisted Living: Resources for Staff Training

Note: In addition to the materials and programs listed, many local Alzheimer's Association chapters have programs to assist with staff training. Contact information for local Alzheimer's Association chapters is at www.alz.org/findchapter.asp.

Alzheimer's Association, *Activity Programming for Persons with Dementia*, 1995, 138-page guide, available from the Alzheimer's Association, 800-223-4405.

Alzheimer's Association, *Key Elements of Dementia Care*, 1997, 90-page guide for residential care settings, available from the Alzheimer's Association, 800-223-4405, \$25.

Alzheimer's Association, *Solving Bathing Problems*, 1999, 22-minute video and 68-page instruction book, available from the Alzheimer's Association, 800-223-4405 or from Health Professions Press, 888-337-8808, \$139.

American Association of Homes and Services for the Aging, *Assisted Living Needs, Practices, and Policies in Residential Care for the Elderly*, 2001, 344-page book, available from AAHSA, 1-800-508-9442, \$53.

American Psychiatric Nurses Association, *Choice and Challenge: Caring for Aggressive Older Adults*, training program for nurses and nursing assistants, 22-minute video, available from Terra Nova Films, tnf@terranova.org, \$139.

Assisted Living Federation of America, *Alzheimer's Care Series (Wandering: Is it a Problem? Resisting Care...Putting Yourself in Their Shoes, Agitation...It's a Sign)*, three 14-minute videos with study guides, available from Fanlight Productions, www.fanlight.com, \$169 each or \$400 for all three.

Assisted Living Federation of America, *Alzheimer's/Dementia Care*, a training program including participant manuals, final exams, instructor guides, and 5 videos for 10 CEU hours, available at 800-258-7030, cost varies according to materials selected.

Bell, V. & Troxel, D., *The Best Friends Staff*, 2001, 296-page book, available from Health Professions Press, 888-337-8808, \$32.95.

Caring for the Cognitively Impaired Patient, Lexington, KY: Alzheimer's Disease Research Center & College of Nursing, University of Kentucky, 1990.

Communicating with Moderately Confused Older Adults, 1997, video, available from Terra Nova Films, 800-779-8491, \$129.

Communicating with Severely Confused Older Adults, 1997, video, available from Terra Nova Films, 800-779-8491, \$129.

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Coons, D.H. & Metzler, L., *Manual for trainers of Direct Service Staff in Special Dementia Units*. Ann Arbor, MI: University of Michigan Press, 1990.

Greater Austin Alzheimer's Association Chapter, *Alzheimer's Disease Education Program: Training Program for Health Care Staff*, 1999, available from the Greater Austin Chapter, 512-454-5476, \$50.

Greater Washington Alzheimer's Association Chapter, *Person Centered Care: Skill Building for Caregivers of People with Dementia*, a 12-hour training program provided by the chapter with subsidies from the State of Virginia.

Los Angeles Alzheimer's Association Chapter, *How to Work with the Confused Older Adult: a Program for Certified Nurses Aids, Homecare Workers, and Caregiving Professionals*, 1998, 200-page manual, available from the Los Angeles Chapter, 323-938-3379, \$50.

Miami Valley Alzheimer's Association Chapter, *Dress Him While He Walks: Management in Caring for Residents With Alzheimer's*, 1993, video, available from Terra Nova Films, 800-779-8491, \$139.

Gwyther, Lisa P., *Caring for People With Alzheimer's Disease: A Manual for Facility Staff*, 2nd Edition, Washington DC: American Health Care Association, and Chicago, IL: Alzheimer's Association, 2001, 116-page book, available from the Alzheimer's Association, 800-223-4405.

Kuhn, D., Ortigara, A., & Lindeman, D. *The Growing Challenge of Alzheimer's Disease in Residential Settings*, Rush Alzheimer's Disease Center, 1999, 3-part training program with slides and a 100-page manual, available from the ADEAR Center, www.alzheimers.org, \$40.

Middleton, L., Johnson, K., & Alexander, L. *Long-term care of the Alzheimer's Patient: A Curriculum Guide*. Tampa, FL: Suncoast Gerontology Center, University of South Florida, 1990.

Optimum Care of the Nursing Home Resident with Alzheimer's Disease: "Giving a Little Extra." Durham, NC: Duke Family Support Program.

Philadelphia Geriatric Center, *Recognizing and Responding to Emotion in Persons with Dementia*, 22-minute video and instructors guide, available from Health Professions Press, 888-337-8808, \$139.

Robins, P.V., *Alzheimer's Care Kit*, University of Maryland School of Medicine, 3 videos (*Signs and Symptoms of Alzheimer's Disease*, 33 minutes, *Responsive Care Plans*, 21 minutes, and *Minimizing Care Problems*, 35 minutes), available from www.videopress.org, \$400.

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Operational Model

Rabins, P.V., *Assessing the Mental Status of the Older Person*, University of Maryland School of Medicine, 34-minute video demonstrating assessment of persons with Alzheimer's disease for students and nursing assistants, available from www.videopress.org, \$150.

Ricker, B., *Providing Dementia Care: A Teaching Manual for Educators*, 1997, 280-page manual, available from the Western and Central Washington State Alzheimer's Association Chapter, 206-363-5500, \$95.

Santo Pietro, M. & Ostuni, E. *Successful Communication with Alzheimer's Disease Patients: An In-service Training Manual*, 1997, Boston, MA: Butterworth-Heinemann..

Siciliano, P. *Alzheimer's Disease & Related Dementias: Training Manual for Health Professionals*, 2000, 150-page manual, available from the Utah Alzheimer's Association Chapter, 801-274-1944.

St. Louis Alzheimer's Association Chapter, *Training the Trainer: Building Creative Caregivers*, 1997, curriculum and manual for an 8-module training program, available from the St. Louis Chapter, 314-432-3422, \$40.

University of Arizona, *Alzheimer's Disease: Pieces of the Puzzle*, 1990, include 5 videos, available from Terra Nova Films, 800-779-8491, \$199.

University of Kentucky, *For Those Who Take Care: An Alzheimer's Disease Training Program for Nursing Assistants*, Lexington, KY, 1996, includes a 264-page manual in a binder with text for overhead projection and student handouts for 8 1-hour sessions, available from ADEAR, 1-800-438-4380.

University of Michigan, *Helping People with Dementia with Activities of Daily Living*, Institute of Gerontology, 22-minute video, available from Health Professions Press, 888-337-8808, \$110.

University of Texas Southwestern Medical Center, *Nurses' Aides—Making a Difference: Skills for Managing Difficult Behaviors in Dementia Victims*, includes a 31-minute video and 16-page manual, available from ADEAR, 1-800-438-4380.

University of Washington, *Managing and Understanding Behavior Problems in Alzheimer's Disease and Related Disorders*, Seattle, WA, Alzheimer's Research Center, includes 10 videos and an 84-page manual, available from Health Professions Press, 888-337-8808, \$295.

University of Washington, *STAR: Staff Training in Assisted Living Residences*, Seattle, WA, program to reduce problems and enhance care, (more information to be provided by 2/11/03).

Appendix B

List of ALW Recommendations

Accountability and Oversight

AO.01	Center for Excellence in Assisted Living	Pass
AO.02	Increased Funding for Long Term Care Ombudsmen	Pass
AO.03	State-level Public Meetings to Review ALW Recommendations	Pass
AO.04	Pre-licensure Review	Pass
AO.05	Supply Constraints	Pass
AO.06	Components of a State Accountability and Oversight System	Pass
AO.07	Public Access to Statutes, Regulations, Survey and Inspection Reports	Pass
AO.08	Federal Jurisdiction Over Assisted Living	Pass
AO.09	Licensure of Assisted Living	Pass
AO.10	Stakeholder Involvement in Federal Actions	Pass
AO.11	Measure of Resident Outcomes	2/3 Maj. Not Reached
AO.12	Consumer Reports	2/3 Maj. Not Reached

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Affordability

A.01	Consumer Directed Long-Term Care Benefit	Pass
A.02	Home and Community Based Waiver	Pass
A.03	Additional Federal and State Funding for Affordable Assisted Living	Pass
A.04	SSI Payment for Assisted Living	Pass
A.05	Government Reimbursement for Services and the Cost of Care	Pass
A.06	Medicaid Assisted Living Rate Setting Tool	Pass
A.07	Retroactive Medicaid Payments in Assisted Living	Pass
A.08	Governmental Subsidies and Resident Income Calculation	Pass
A.09	Tenant Service Payment and Housing Subsidy Income Calculations	Pass
A.10	Medicaid Program Rules: Family Contributions and Room and Board Maximums	Pass
A.11	Third Party Service Payments and Housing Subsidy Income Calculations	Pass
A.12	Medicare & Medicaid Physician House Call Payments in Assisted Living	Pass
A.13	Transportation	Pass
A.14	HUD and HHS Collaboration to Deliver Affordable Assisted Living	Pass
A.15	Federal Housing Subsidy Programs and Assisted Living	Pass
A.16	Federal Housing Subsidies and the Cost of Common Facilities in Assisted Living	Pass
A.17	HUD Assisted Living Conversion Program	Pass
A.18	Assisted Living Conversion Program for Public Housing	Pass
A.19	Affordable Assisted Living Demonstrations in Subsidized Housing	Pass
A.20	HUD Housing Choice Voucher Rules in Assisted Living	Pass
A.21	LIHTC QAP & Set Aside for Affordable Assisted Living	Pass
A.22	Assisted Living Tax Credit	Pass
A.23	Advisory Boards for Government Initiative in Affordable Assisted Living	Pass

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A.24	Aging Network Funding for Training	Pass
A.25	Paper Work Burden of Governmental Programs in Assisted Living	Pass
A.26	Food Stamps Usage in Assisted Living	Pass
A.27	Federal Development Subsidies and Private Units	2/3 Maj. Not Reached
A.28	Affordable Assisted Living Liability Insurance	2/3 Maj. Not Reached
A.29	Unit Hold	2/3 Maj. Not Reached

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Direct Care

D.01	Pre-Move In Screening Process	Pass
D.02	Initial Assessment	Pass
D.03	Service Plan	Pass
D.04	Reasons for Resident Transfer or Move-out from an Assisted Living Residence	Pass
D.05	Protocols for Resident Transfer or Move-out from an Assisted Living Residence	Pass
D.06	Palliative Care	Pass
D.07	Hospice Care	Pass
D.08	Advance Directives	Pass
D.09	Do Not Resuscitate Orders (DNR)	Pass
D.10	Identification of Cognitive Impairment/Dementia	Pass
D.11	Care for People with Cognitive Impairment/Dementia and Dementia Special Care Units and Facilities	Pass
D.12	Senior Wellness Programs in ALRs	Pass
D.13	Shared Responsibility Agreement	2/3 Maj. Not Reached
D.14	Access to ALR's for Individuals with Personal Healthcare Needs	2/3 Maj. Not Reached
D.15	External Professional Consultant	2/3 Maj. Not Reached

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Medication Management

M.01	Policies and Procedures	Pass
M.02	Policies and Procedures	Pass
M.03	Resident Assessment and Management of Medication	Pass
M.04	Resident Assessment and Management of Medication	Pass
M.05	Resident Assessment and Management of Medication	Pass
M.06	Medication Administration by Medication Assistive Personnel	Pass
M.07	Medication Assistive Personnel Job Description	Pass
M.08	Curriculum for MAP Training Program	Pass
M.09	Ongoing MAP Training	Pass
M.10	MAP Activities Related to Medication Administration	Pass
M.11	Medication Packaging	Pass
M.12	Medication Packaging	Pass
M.13	Storage	Pass
M.14	Medication Records	Pass
M.15	Definitions	2/3 Maj. Not Reached
M.16	Supervision of Medication Assistive Personnel	2/3 Maj. Not Reached
M.17	MAP and PRN Medications	2/3 Maj. Not Reached
M.18	MAP and Insulin Injections	2/3 Maj. Not Reached
M.19	MAP and Enteral Medication Administration	2/3 Maj. Not Reached
M.20	Telephone Orders	2/3 Maj. Not Reached
M.21	Quality Improvement	2/3 Maj. Not Reached
M.22	Consultant Pharmacist Role	2/3 Maj. Not Reached

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Operations

O.01	Building Codes	Pass
O.02	Life Safety Compliance	Pass
O.03	Communication of Life Safety Standards	Pass
O.04	Emergency and Disaster Preparedness Plans	Pass
O.05	Contingency Plan	Pass
O.06	Food Storage, Preparation and Transporting	Pass
O.07	Food & Nutrition	Pass
O.08	Smoking	Pass
O.09	Activities	Pass
O.10	Activities for Special Care Residents	Pass
O.11	Transportation	Pass
O.12	Environmental Management	Pass
O.13	Assisted Living Residence Councils	Pass
O.14	Community Environment & Standards	Pass
O.15	Security for Wandering Residents	Pass
O.16	Restraints	2/3 Maj. Not Reached

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Resident Rights

R.01	Consistency in Contracts and Marketing	Pass
R.02	Contracts and Agreements: Consistency with Applicable Law	Pass
R.03	Contracts and Agreements: Readability and Pre-Signing Review	Pass
R.04	Contracts and Agreements: Required Elements	Pass
R.05	Contracts and Agreements: Prohibition on Waiver of Right to Sue	Pass
R.06	Posting Contact Information	Pass
R.07	Pre-Admission Disclosure for Specialized Programs of Care	Pass
R.08	Contracts and Agreements: Third Party Responsibility	Pass
R.09	Pre-Admission Disclosure on Advance Directives	Pass
R.10	Pre-Admission Disclosure on End-of-Life Care	Pass
R.11	Resident Rights and Provider Responsibilities	Pass
R.12	Ethics Committee/Consultation	Pass
R.13	Room/Unit Hold During Resident Absence	Pass
R.14	Acceptance of Public Funds: ALR Policy and Information for Residents	Pass
R.15	Fee Increases, Security Deposits and Resident Finances	Pass
R.16	Resident Rights Upon Transfer or Discharge	Pass
R.17	Access to State Survey/Inspection Reports	Pass
R.18	Disclosure of Staffing Levels	Pass
R.19	Lost and Stolen Property	2/3 Maj. Not Reached
R.20	Medicaid Reimbursement	2/3 Maj. Not Reached

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Staffing

S.01	Staffing Qualifications: Communication	Pass
S.02	Federal Criminal Background Checks	Pass
S.03	Staff Qualifications: Use of Information from Criminal Background Checks	Pass
S.04	Federal Abuse Registry	Pass
S.05	Verification of Employment History	Pass
S.06	Compliance with Federal Employment Laws	Pass
S.07	24-Hour Awake Staff	Pass
S.08	Authorized Acting Administrator	Pass
S.09	Vaccinations	Pass
S.10	Discussion of Job Descriptions with Potential Employees	Pass
S.11	Qualifications for Administrators	Pass
S.12	Recruitment and Retention: Management Practices	Pass
S.13	Recruitment and Retention: Human Resource Practices	Pass
S.14	Orientation for All ALR Staff	Pass
S.15	Staff Performance Evaluations	Pass
S.16	Personal Care Assistant (PCA) Training	2/3 Maj. Not Reached
S.17	Staffing Workload	2/3 Maj. Not Reached

Appendix C

Glossary of Terms

Activities of Daily Living (ADL) – Physical functions that a person performs every day that typically include dressing, eating, bathing, toileting and transferring. Disability is often measured by limitations in activities of daily living. See also Instrumental Activities of Daily Living (IADL).

Acuity-Based Staffing – A model in which the number of staff is determined by the health care needs and functional dependencies “acuity” of the residents, as well as the number of residents with significant needs requiring hands-on care.

Advance Directives – The process of deciding in advance what course of action or approaches to care an individual would like to be followed in the event that he or she is incapable of making such decisions. Written forms of such directives would be living wills and durable powers of attorney.

Adverse Drug Reaction – In pharmacology, an adverse event is any unexpected or dangerous reaction to a drug.

Americans with Disabilities Act – A federal civil rights law enacted in 1991 to protect the rights of persons with disabilities regarding employment, transportation, public accommodations, and public programs.

Ancillary Services – Services beyond the basic package of everyday supportive services that are rendered to a resident on site. These services may be provided by the assisted living operator or by third party providers. Costs for such services are typically paid in addition to the basic monthly or daily fee.

Assisted Living Quality Coalition – A group of four provider organizations (American Association of Homes and Services for the Aging, American Health Care Association, American Seniors Housing Association, and Assisted Living Federation of America) and two consumer organizations (AARP and Alzheimer’s Association) that issued a final report on a quality initiative in August 1998.

Assisted Living Residence (ALR) – A setting that meets the ALW definition of assisted living, where residents live and receive services, used in preference to “facility” in the ALW report because the emphasis is on the housing and residential aspects of living rather than the more institutional aspects.

Assisted Living Workgroup (ALW) – A group of roughly fifty national organizations with interests in assisted living assembled to address the request of the U.S. Senate Special Committee on Aging for recommendations to promote quality.

Authorized Prescriber – A licensed health professional that meets the federal and state requirements for prescribing medications and treatments.

Board and Care Homes – Group living arrangements (sometimes called group homes, domiciliary care homes, or personal care homes) that provide limited services to persons with disabilities. Many board and care homes serve persons with very low incomes who receive funding through the Supplemental Security Income program along with state supplements where available. Board and care homes do not typically offer the level of

services or privacy provided in assisted living, though some states continue to use the same licensure category for both types of residential care.

Certificates of Need – A certificate of need is allocated to a provider permitting that provider to enter a market area and open an ALR. A state will describe a process that must be followed and criteria that must be met in order to award the certificate of need. For example, a state may require that an applicant ALR prove, through a specified methodology, that there is a need for the service being offered in the particular area where the ALR proposes to operate.

Clinical Skills Practicum – That component of a training program that provides training in and demonstration of the clinical skills that are required for personal care job responsibilities.

Colostomy – An alternative exit from the colon created to divert waste through a hole in the colon and through the wall of the abdomen. A colostomy is commonly performed by severing the colon to attach the end leading to the stomach to the skin through the wall of the abdomen. The end of the colon that leads to the rectum is closed off and becomes dormant.

Continuing Care Retirement Community (CCRC) – A community that provides more than one living and services option on the same campus. Typically these levels include independent living apartments, assisted living, and skilled nursing.

Contract Staff – All individuals who provide services to residents or within the assisted living residence based upon a written agreement between the ALR and the individual or an agency employing that individual.

Controlled Drug – means a drug or other substance, or immediate precursor, included in schedule I, II, III, IV, or V. The Controlled Substances Act places all substances that are regulated under existing federal law into one of five schedules. This placement is based upon the substance's medicinal value, harmfulness, and potential for abuse or addiction. Schedule I is reserved for the most dangerous drugs that have no recognized medical use, while Schedule V is the classification used for the least dangerous drugs. (DEA)

Dementia – A decline in cognitive functioning measured by impairment of memory, orientation, judgment, learning, and calculation. Often accompanied by emotional and behavioral manifestations, dementia is a group of symptoms caused by some underlying disease state such as Alzheimer's disease, Parkinson's disease, or stroke.

Direct Service Staff – All staff, paraprofessional (e.g., personal care assistants, medication assistive personnel) or professional (e.g., nurses or other health care professionals), who provide hands-on or direct services to residents and have most direct contact with families at any time. Also referred to as direct care staff.

Elopement – Inappropriate wandering from an ALR by a resident, usually by a resident with cognitive impairments to their judgment.

Full Disclosure – Complete and accurate written and verbal information presented by a residence that describes services, fees, conditions for move in and move out, and other information about a residence.

Home and Community-Based Services – Long-term supportive services provided to persons with disabilities outside of institutional settings.

Home and Community-Based Waivers – Funding for home and community-based services provided under the Medicaid program. States can receive waivers from certain Medicaid requirements in order to provide targeted assistance to different populations in different settings. Forty-one states now provide some Medicaid funding to assisted living, most frequently through home and community-based waivers.

Hospice – Programs that provide palliative and supportive services to persons who are terminally ill and their families.

Ileostomy – An opening into the ileum, part of the small intestine, from the outside of the body. An ileostomy provides a new path for waste material to leave the body after part of the intestine has been removed.

Indirect Service Staff – Staff who assist in providing services within the ALR or to residents but whose primary responsibilities do not include resident contact. Examples include maintenance, housekeepers, and food service personnel.

Instrumental Activities of Daily Living (IADL) – Functions that involve managing one's affairs and performing tasks of everyday living, such as preparing meals, taking medications, walking outside, using the telephone, managing money, shopping, and housekeeping. The amount of help a person needs in performing these tasks is frequently used as one measure of disability. See also Activities of Daily Living (ADL).

Licensed administrator – Administrator meeting the required qualification, completing and passing a state-approved licensure or certification exam of proficiency assessed and monitored by a recognized testing organization or board.

Long-Term Supportive Services – Personal care and health-related services provided to persons with disabilities or illnesses. The ALW uses "supportive services" in preference to "care" to stress a less paternalistic and institutional model of supporting people with disabilities.

Measures of Clinical Outcomes – Measures associated with the implementation of clinical activities such as resident assessment, service planning, medication management, and wellness/preventive programs.

Measures of Functional Outcomes – The measurement of an individual's ability to perform activities of daily living such as bathing, dressing or walking independently, and the degree to which that ability has improved, declined or been maintained with or without intervention.

Medicaid – A joint federal and state-funded program, administered by the states, that provides a broad array of health and personal care services to individuals with low incomes or to persons whose health-related needs have exhausted their financial resources.

Medicaid Waiver – See Home and Community-Based Waiver.

Medicare – Federally funded and administered health insurance program for persons aged 65 and older and for persons who have been eligible for Social Security disability payments for two years or more.

Medication Administration – Involves opening a container of medications, removing a proscribed dosage and giving the medication by injection, insertion in the mouth, eye, ear, or body cavity, or applying it to the skin. In most cases, only a nurse or specially trained assistant can administer medications.

Medication Management – Involves storing medications, opening medications for a resident, reminding residents to take medications and other assistance not involving the administration of medications.

Nebulizer – A device for administering a medication by spraying a fine mist into the mouth, nose or both. Also known as an atomizer.

Negotiated Risk Agreement – See Shared Responsibility Agreement.

Occupancy Agreement – An agreement between a resident and the assisted living residence that outlines the conditions for living in the residence and the conditions under which a resident will no longer be able to remain.

Over-the-Counter Medication – A drug for which a prescription is not needed.

Palliative Services – Services to relieve pain and suffering without the goal of curing the disease. Palliative services are most often given to people with a terminal diagnosis.

Performance Measures – A quantitative tool such as a ratio, rate, index or percentage that provides an indication of an ALR's performance in relation to a specific process or outcome.

Personal Care – Assistance provided by another person to help with walking, bathing, grooming, dressing, eating and other routine daily tasks.

Prescribed Medication – A drug requiring a prescription from an authorized prescriber, as opposed to an over-the-counter drug, which can be purchased without one.

PRN Medication – Abbreviation meaning "when necessary" (from the Latin "pro re nata", for an occasion that has arisen, as circumstances require, as needed). Used to refer to a medication that is taken when needed, rather than on a fixed schedule.

Provider Capacity – The ability of an ALR to meet minimum standards as defined by the state, both operational and financial.

Receivership – A legal proceeding in which a person is appointed to take charge of the funds or property of an ALR when there is danger that, in the absence of this appointment, the property will be lost, removed or injured.

Resident(*) – Consumers who live in assisted living residences. In the ALW report, the term resident often is followed by an asterisk (*) to indicate that the term implies family or other surrogate decision-makers where appropriate.

Residential Care – A term that often includes assisted living, board and care, adult foster care, and other types of supportive housing not licensed as nursing homes.

Responsive Complaint Investigation Process – This process would include the following elements:

- A state-adopted process for receiving complaints from residents* of ALRs; and
- A method for promptly tracking, responding to and resolving complaints.

Shared Responsibility – A shared responsibility agreement is a written agreement between the resident and the assisted living residence that memorializes the parties' discussions and agreements regarding preferences and how they will be accommodated in the community. Shared responsibility agreements, sometimes known as negotiated risk agreements, are generally used when the resident's preferences require a deviance from accepted standards or rules where the risk of an adverse outcome is substantial.

Significant Change – A new or markedly different physical, functional, cognitive or psychosocial condition in a resident that impacts the service delivery of the resident's individual service plan, to include:

- Deterioration or improvement in an individual's health status or ability to perform activities of daily living;
- A deterioration or improvement in an individual's behavioral or mood status.

Special Care Units – A section within an assisted living residence or nursing home with a specified number of units devoted to residents with specific needs. The most common type of special care unit is for residents with dementia.

Specialized Medication Packaging – Refers to medication packaging other than the traditional vial or bottle system.

State Plan Services – Those services that a state must provide to Medicaid recipients because they are identified in the state Medicaid plan submitted to CMS. Federal law requires some of those services and some are included at the option of the state. State plan services are an entitlement, which means that all beneficiaries who meet the eligibility criteria must be served.

Stomal – Refers to administering medications through an opening into the body from the outside created by a surgeon. Typically used in reference to a colostomy or ileostomy. (see *colostomy*)

Sublingual – Underneath the tongue. A sublingual medication is dissolved under the tongue.

Supplemental Security Income – Federal program under the Social Security program that guarantees a minimum monthly income to every person who is age 65 or older, disabled or blind and meets income and asset requirements.

The Aging Network – An organizational structure that includes the U.S. Administration on Aging at the federal level, the State Units on Aging at the state level, and the Area Agencies on Aging at the local level. The Aging Network also extends to public and private service providers such as social service agencies, senior centers, and advocacy groups. Each part of the network operates from a different perspective, but all have the common goal of improving the quality of life for older people and their caregivers.

Topical – A medication that is applied to the surface of the skin, often in the form of an ointment or cream.

Unit Dose – Unit-dose packaging means an individual drug product container, usually consisting of foil, molded plastic or laminate with indentations into which a single solid oral dosage form is placed, with any accompanying materials or components including labeling. Each individual container is fully identifiable and protects the integrity of the dosage form (Massachusetts Department of Public Health).

