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ASSISTED LIVING REEXAMINED: DEVELOPING POLICY AND PRACTICES TO ENSURE QUALITY CARE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

WASHINGTON, DC

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ASSISTED LIVING REEXAMINED: DEVELOPING POLICY AND PRACTICES TO ENSURE QUALITY CARE

TUESDAY, APRIL 16, 2002

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

The committee convened, pursuant to notice, at 2:30 p.m., in room SD–192, Dirksen Senate Office Building, Hon. John Breaux (chairman of the committee) presiding.

Present: Senators Breaux, Wyden, and Craig.

OPENING STATEMENT OF SENATOR JOHN BREAUX, CHAIRMAN

The CHAIRMAN. Thank you all for coming. We appreciate the opportunity to gather in sort of an informal atmosphere to talk about the efforts that a number of groups and organizations and individuals have put together on the question of one of the greatest challenges, I think, that face this country, and that is how do we ensure that people in this country have the opportunity to not only live longer lives, but also to live better lives. Part of that question is the question of what type of care is going to be available for the nation's seniors in the future years.

It is very clear that we are not going to be able to have people living longer and better lives unless there is an assurance that there will be adequate measures and facilities that give them the services they so desperately need which is a huge challenge. It is going to get even much more serious in the future.

I think that it is clear that when we look to the traditional way of helping people meet their special needs as they get older, that one way we have done it is to try and take one of our government programs that was never intended to provide long-term care and to try and make it fit. I am talking about the Medicaid program, which was never intended to be a long-term care provider. It was supposed to be a mechanism to provide health care for indigent and low-income people.

Now we have the situation in this country where, unfortunately, we have people who have to spend themselves into the poorhouse in order to get any kind of help to basically find themselves placed in nursing homes that for some are absolutely necessary, but for many are not. So we have a lot of incredible challenges.

We have looked very carefully at assisted living facilities as an alternative. We have also looked through our hearings at a number

of problems that exist in 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, whether States will have rules and regulations about the quality of care in these facilities, and found that there were a lot of unanswered questions.

Rather than have Congress just go running into this area and legislating without a good background for what we are trying to do, we thought it was appropriate to try and get organizations and groups together to come up with ideas about what needs to be done, to discuss honestly what is, in fact, being done, and also to make some recommendations. I think as an outgrowth of those suggestions, you all have come together and have been meeting and I applaud and congratulate you for doing that. Hopefully, something can come out of this that will be beneficial from a policy standpoint.

When you look at some of the existing rules and regulations that cover many of the beneficiaries of the Medicare program, you find that they are very complicated. The Medicare program itself has 133,000 pages of regulations, what you can do, when you can do it, how you do it.

I would hope that with this particular industry, we could maybe come up with some guidelines, if you will, that will prevent the type of massive rules and regulations and red tape operations that we have in the nursing home program.

I know you have been working. I congratulate you for doing it. Maybe if we could go around the table and get everybody to introduce themselves, and tell us who you represent and maybe start, Ms. Brewer, on your side.

[The prepared statement of Senator John Breaux follows:]

PREPARED STATEMENT OF SENATOR JOHN BREAUX

Good afternoon. I want to thank you all for being here today to discuss an issue of utmost importance for our nation's seniors. Assisted living, though still a relatively new phenomenon, is a popular choice for seniors who need varying levels of assistance as their long-term care needs increase. As indicated by my multi-part series of Aging Committee hearings on long-term care, I am devoted to examining the continuum of care options for our elderly. No longer are older Americans limited to nursing homes and at-home caregiving when they need assistance—they now have a multitude of options and people are demanding that good care be inherent in those options. It is my duty as Chairman of the Aging Committee to assist in ensuring that not only are such choices made by informed consumers but also that these choices instill confidence and comfort in the residents. I need your help to do this and the time is now.

Assisted living is not a new focus for this Committee. In 1999, the GAO informed us of the lack of uniformity in state law—including the fact that there is not even a singularly adopted definition for what assisted living is. At that hearing, it was resolved that federal regulation of assisted living was premature and that instead, accreditation of facilities could be a beneficial tool in improving quality of care in facilities. In 2001, we held another hearing and learned that the self-policing of accreditation was not the tool we had hoped. Further, the industry and the consumer advocates were not working together even though witness testimony at the hearing seemed to indicate that all the groups shared a mutual goal—providing quality care for seniors.

This Committee gave the assisted living community its charge—work together and come up with a set of recommendations for how this goal can be achieved. You all answered by forming the "Assisted Living Workgroup." Undeniably, those of you involved deserve accolades for devoting such an immense amount of time and resources to this process. I think there is inherent value in the simple fact that industry groups and consumer groups are sitting down at the table together on a regular

basis to develop consensus, and then report back to Congress. This is truly a new way of developing policy and a new way of implementing Congressional oversight.

Last month I held a hearing on abuse in nursing homes. I don't want to hold a similar hearing in five years that sheds light on similar patterns of abuse in assisted living. Through your consensus building you have a chance to make sure that I don't have to. I think that many in the health care industry see the nursing home industry as one that is very closely regulated yet is still fraught with quality of care problems. We decided to tackle the problems in assisted living in a new way. I am not saying that there is no role for the federal government in this arena—rather I am saying that we need to consider all options before determining where our energies are most appropriately placed. I am pleased to learn that the Workgroup is addressing the tough questions surrounding implementation of change—and the roles of the federal government, state governments, facilities and consumers.

The time is exceedingly ripe for change. With 77 million baby boomers starting to weigh their care options as they age, the public is demanding more choices when it comes to determining where to spend the final years of their lives. And it is not only the wealthy who are looking. Most Americans cannot afford the monthly payments of $3000–$6000 a month that assisted living facilities charge. So, in addition to quality of care issues I am pleased to learn that this group is addressing questions surrounding affordability as well. In my home state of Louisiana we do not have a progressive attitude when it comes to long-term care. There is still no Medicaid waiver for assisted living. Through this and other programs I hope to help make it possible for our nation's poor seniors to have the same access to quality care as those who are more financially secure.

The timeline this Committee established last August remains unchanged—I look forward to hearing this group's recommendations come next April. I understand that with any diverse group the development of consensus recommendations will undoubtedly produce some issues for which minority opinions cannot be avoided. However, I expect that these minority opinions will be the exception and not the rule. And I will be expecting substantiation on issues for which agreement cannot be reached.

As we told you last year, you are the experts. You are the primary drivers behind the development and direction of your recommendations. I would like to commend you all for your hard work over the last few months. You are doing a service for our nation's seniors. And by working with each other and with the Special Committee on Aging you are truly doing a remarkable thing. With this innovative and inclusive way of crafting policy together we can make history.

Thank you and I now turn to my colleague(s) for any additional opening comments.

Ms. BREWER. Miriam Brewer, Alzheimer's Association.

Mr. KYLLO. David Kyllo, National Center for Assisted Living.

Ms. FLORES. Sandra Flores, the American Assisted Living Nurses Association.

Mr. JENKENS. Robert Jenkens, the Coming Home Program for Affordable Assisted Living.

Mr. PACE. Doug Pace for the American Association of Homes and Services for the Aging.

Mr. MINNIX. Larry Minnix with the American Association of Homes and Services for the Aging.

Ms. LOVE. Karen Love with the Consumer Consortium on Assisted Living.

Mr. HARRIS. Rick Harris, National Association of Health Facility Survey Agencies.

Mr. PREEDE. Ken Preede with the American Seniors Housing Association.

Ms. LENHOFF. Donna Lenhoff with the National Citizen's Coalition for Nursing Home Reform.

Mr. SHEEHY. Ed Sheehy, Assisted Living Federation of America.

Ms. WRIGHT. Bernadette Wright, AARP.

The CHAIRMAN. I thank all of you and I think the way we have this thing structured is that three of you will make some presentations. Would the three presenters go ahead and proceed. Larry.

STATEMENT OF LARRY MINNIX, CHIEF EXECUTIVE OFFICER, AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING, WASHINGTON, DC.; ACCOMPANIED BY MIRIAM BREWER, ALZHEIMER'S ASSOCIATION; SANDRA FLORES, AMERICAN ASSISTED LIVING NURSES ASSOCIATION; ROBERT JENKENS, NCB COMING HOME PROJECT; DAVID KYLLO, NATIONAL CENTER FOR ASSISTED LIVING; DONNA LENHOFF, NATIONAL CITIZEN'S COALITION FOR NURSING HOME REFORM; DOUG PACE, AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING; KEN PREEDE, AMERICAN SENIORS HOUSING ASSOCIATION; KEN SHEEHY, ASSISTED LIVING FEDERATION OF AMERICA; AND BERNADETTE WRIGHT, AARP

Mr. MINNIX. Thank you, Senator, and I thank the committee. We appreciate the opportunity to do this. Our organization, AAHSA, represents 5,600 mission-driven not-for-profit members that represent the various components of the continuum of care, including assisted living. We serve more than a million people every day. AAHSA and its members have long been committed to a vision of healthy, affordable, and ethical long-term care for Americans.

I am here today, Senator, representing the Assisted Living Workgroup, which has been a remarkably productive process representing 50 organizations, consumers, providers, government, and others, to try to responsibly deal with the growing issues of assisted living. We appreciate the opportunity to develop this road map. There is a lot of ownership to this process by the group and we will continue to work diligently to finish our job and give you a report this time next year to outline specifically how we would recommend assisted living should operate.

We realize we have one last chance to take responsibility for shaping the future of assisted living. You built the fire under us last year because of problems in the field and now it is time for us to be consumer-oriented so that we can assure that the residents and families of assisted living have the highest quality of care and quality of life that they deserve. We have little time to be competing among ourselves about issues and there has been a minimum of that kind of activity.

We believe that assisted living can be tailored to the complex changing needs of the residents served. We believe it can be affordable. We believe it can be responsibly managed. We believe it does not have to be turned into the new nursing home. We believe that the public can trust us to do it well and we hope that by this time next year, we can lay out a plan that you can feel confident about, as well.

Issues of disclosure, quality, and unclear expectations have raised questions about confidence in us, which prompted you to ask our organizations to convene and to address this problem. Through a consensus-building process, we are hopeful we will be able to produce a document that will be a blueprint for assisted living, which is, no question, an important component of care for older and some chronically impaired populations, which, as you know, are growing dramatically in our country.

Not only do we want to maintain and improve quality, but help consumers understand what they are getting for their money so

that there is proper disclosure. When families turn to assisted living care, sometimes it is out of desperation and they do not know what to ask for. They move into the closest place to relieve themselves of some of the pressure they feel, and so oftentimes they do not know what they are getting themselves into. From our standpoint, we have not made it clear what we offer and what the limits of assisted living could and should be. So we are committed to full disclosure to consumers to let them know what we offer and why we offer and how it works.

Assisted living has experienced phenomenal growth over the past 15 years due largely to the recognition that it provides that desirable cost-effective, dignified living environment that is not a nursing home, and that is important for consumers' choice. They favor it because they get the help they need with everyday living tasks without being forced into a nursing home or hospital-like model.

We like to call it a wellness model, which is a blend of social kinds of support with physical kinds of support and the appropriate health backup when needed. Supportive services are provided in a way to maximize the residents' dignity, autonomy, privacy, independence, and safety. We will help you take care of yourself versus we will take care of you, and that is really a good way to distinguish between assisted living is and what nursing home care is.

The beauty of assisted living is that it covers a diverse array of services and settings to meet the varied and often complex needs of residents, and we hope that flexibility could and should be maintained.

A typical assisted living resident is a woman, aged 82 or older, who is ambulatory but often needs assistance with two to three or more personal activities, such as bathing and dressing and medication, and the resident needs our best effort in this process. Frequently, these people have multiple medical diagnoses that are stable and you need to make sure, the family needs to make sure that these conditions remain stable and that there is a process in place when someone has an acute problem, that they can be responded to in the appropriate way.

We thank you again for the opportunity to take responsibility for this important dimension in long-term care and services and we will continue to work hard this next year to give you the blueprint that, again, the bottom line is that that 82-year-old and her family can have confidence that we are doing the right thing the right way and we think that is possible to do, Senator.

The CHAIRMAN. Thank you very much, Mr. Minnix.

[The prepared statement of Mr. Minnix follows:]

Testimony by Larry Minnix

American Association of Homes and Services for the Aging

Assisted Living Workgroup Update

Senate Special Committee on Aging
April 16, 2002

Mr. Chairman and members of the Committee and staff,

Thank you for the opportunity to speak to the Committee today. I am Larry Minnix, CEO of the American Association of Homes and Services for the Aging (AAHSA).

AAHSA is a national nonprofit organization representing more than 5600 mission-driven, not-for-profit profit nursing homes, continuing care retirement communities, assisted living and senior housing facilities, and community service organizations. Every day, our members serve more than one million older Americans across the country. AAHSA and its members have long been committed to providing quality care and to meeting the needs of these individuals in a manner that enhances their self-worth and dignity, and that allows them to function at their highest level of independence.

I am here today representing the Assisted Living Workgroup (ALW). The ALW formed as a result of this Committee's hearing on assisted living held in April 2001. The ALW is over 50 national organizations encompassing the consumer community, providers, long-

term care and healthcare professionals, accrediting organizations, and state and federal organizations and agencies.

The ALW appreciates the opportunity that you have given us to develop a roadmap for assisted living. We take great ownership of this process. We are working diligently to furnish the Committee with a report in April 2003 that will outline specifically how the ALW recommends assisted living should operate.

We have been given one last chance to take responsibility for shaping the future of the assisted living field. Now is the time for us to be more consumer-oriented so that we may ensure that residents of assisted living have the highest quality of life and quality of care. We have very little time to be competing among ourselves, to be debating issues that are not "big picture issues". The ALW has made significant progress to reach these goals and we look forward to presenting our final report to you.

Issues of disclosure, quality, and unclear expectations have raised questions of confidence, which prompted you to ask organizations interested in the future of assisted living to convene. The ALW has begun to look at these issues and more as we work towards preparing a final report for this Committee. Through a consensus building process, we are hopeful that we will produce a document that will help shape a blueprint for assisted living in the future. One that not only maintains and improves quality, but also helps consumers understand the necessity of matching the services they require with the services that a facility can offer. By facilities being committed to fully disclose the

varying services they provide and consumers understanding the diversity of choices of settings, services and affordability this field has to offer, assisted living will continue to be a viable option for older Americans. The organizations that comprise the ALW are committed to the field and this process.

Assisted living has experienced phenomenal growth over the past 15 years due largely to the recognition that it provides a desirable, cost-effective and dignified living environment. Consumers favor it because they get the help they need with everyday living tasks and usually some health care in a residential setting – and they have a range of assisted living settings and services from which to choose. Assisted living's popularity is also due to a philosophy which values a wellness model- a blend of social and health services. Supportive services are provided in a way to maximize resident's dignity, autonomy, privacy, independence, and safety, i.e. "we will help you take care of yourself" versus "we will take care of you." The beauty of assisted living is that it covers a diverse array of services and settings to meet the varied and often complex needs of residents. A typical assisted living resident is a female aged 82 or older who is ambulatory but needs assistance with two to three personal activities, such as bathing, dressing, and medications. This resident needs our best effort in this process.

We thank you again for the opportunity to face these issues squarely and guide the future of this important part of the long-term care continuum.

The CHAIRMAN. Ms. Love, do you want to go ahead and go next.

STATEMENT OF KAREN LOVE, CHAIR, BOARD OF DIRECTORS, CONSUMER CONSORTIUM ON ASSISTED LIVING, FALLS CHURCH, VA

Ms. LOVE. Thank you. Chairman Breaux and Senators Craig and Wyden, thank you for the opportunity to speak today. I am here on behalf of the Consumer Consortium on Assisted Living and my Assisted Living Workgroup colleagues. We commend you for providing the unique opportunity to jointly work on ensuring quality care for those residing in assisted living communities.

I would like to start off by presenting an image that highlights the humanity of the work before us. Imagine if you went to see a play and the orchestra was seated in the first five rows of the audience. The lighting and sound technicians were running cables, microphones, and lighting on stage. Set and costume changes were made before the audience. Orchestra members were talking out loud in between the musical interludes. The director was providing audible instructions to the actors and the technicians. Can you imagine enjoying such a play? Even worse, what if this play was your everyday life?

Unfortunately, the typical long-term care residential experience too often is functioned like this play. Staff and their operation take center stage instead of the residents. The provisions of meals, housekeeping, maintenance, health care service, and facility administration should actually be done behind the curtain and not detract from the actual living experience that makes up the everyday life of the individuals who reside in these communities.

So besides the simple process of collaborating over 15 national organizations, we are also reframing how care is provided.

The participants of the Assisted Living Workgroup represent the broad array of stakeholders in assisted living, providers, consumers, consumer advocates, long-term care, health professionals, regulators, direct care staff, aging and long-term care organizations, disability organizations, State and local government, and others, in all, over 50 national organizations, and a full list of the participants is attached to my testimony.

While there is great diversity among the Assisted Living Workgroup participants, our common ground centers on ensuring quality care for these residents. The ALW is working to develop a report of consensus recommendations to present to this committee in a year. We have entitled this report, "Ensuring Quality Care in Assisted Living: Best Practices and Guidelines for State Regulation, Federal Policy, and Operations," in order to capture the wide range of information being considered. Our work is focused on setting the bar for regulations, policies, and operations.

The ALW decision process relies on consensus building. A two-thirds majority of ALW participants move a recommendation forward to a vote. Again, a two-thirds majority is necessary to adopt a recommendation. Participants not able to adopt a majority recommendation must form consensus on a minority position. The report will clearly indicate the specific organizations agreeing to a recommendation, those organizations that have a minority position,

and finally, if there are any organizations that cannot agree with either.

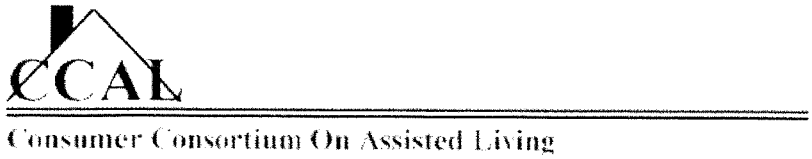
The Assisted Living Workgroup developed a working definition of assisted living that is attached to the testimony. Additionally, we have six topic groups that meet at least once a month to discuss and work on the substantive issues surrounding each topic. These groups are Resident Rights and Facility Ethics, Staffing, Medication Management, Operations, Direct Resident Care, and Affordability.

While the substantive issues are generally unique to each topic group, the ALW recognizes that there are a number of overarching interests that each topic group should take into consideration as recommendations are crafted. These specifically are quality indicators, best practices, outcome measures, research, considerations for individuals with cognitive impairment, accountability, facility size, affordability, and education and training.

Again, as we work to develop consensus recommendations on State regulations, Federal Policy, and facility practices, we need to be ever mindful of the need to focus on the living experience for residents and not to accidentally place staff and services on center stage. Thank you again for the opportunity.

The CHAIRMAN. Thank you, Ms. Love.

[The prepared statement of Ms. Love follows:]



STATEMENT OF

KAREN LOVE
Chair, Board of Directors
Consumer Consortium on
Assisted Living

BEFORE THE
UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING

Washington, DC: April 16, 2002

Chairman Breaux, Senator Craig, and members of the Committee, thank you for the opportunity to speak today. I am here today on behalf of the Consumer Consortium on Assisted Living and my Assisted Living Workgroup (ALW) colleagues. We commend you for providing the unique opportunity to jointly work on assuring quality care for those residing in assisted living communities.

I would like to present an image that highlights the humanity of the work before us. Imagine if you went to see a play and the orchestra was seated in the first 5 rows of the audience; the lighting and sound technicians were running cables, microphones, and lights on the stage; set and costume changes were made before the audience; orchestra members were talking out loud in between the musical interludes; and the director was providing audible instruction to the actors and technicians. Can you imagine enjoying such a play? Even worse, what if this 'play' was your everyday life?

Unfortunately, the typical long term care residential experience too often has functioned like this play. Staff and their operations take *center stage* instead of the residents. The provision of meals, housekeeping, maintenance, health care services and facility administration should be *behind the curtain* and not detract from the 'living' experience that makes up the everyday life of the individuals who reside in assisted living communities.

The participants of the ALW represent the broad array of stakeholders in assisted living: providers, consumers, consumer advocates, long term healthcare professionals,

regulators, direct care staff, aging and long term care organizations, disability organizations, state and local government and others - over 50 national organizations. A full list of participants is attached.

While there is great diversity among the ALW participants, our common ground centers on assuring quality care for residents of assisted living. The ALW is working to develop a report of consensus recommendations to present to this Committee in April 2003. We have entitled this report "Assuring Quality Care in Assisted Living: Best Practices and Guidelines for State Regulations, Federal Policy and Operations" in order to capture the range of aspects being considered. Our work is focused on "setting the bar" for regulations, policy, and operations.

The ALW decision process relies upon consensus-building. A two-thirds majority of ALW participants moves a recommendation forward to a vote. Again, a two-thirds majority is necessary to adopt a recommendation. Participants not able to adopt the majority recommendation must form consensus on a minority position. The report will clearly indicate the specific organizations agreeing to a recommendation, those organizations having a minority position on a recommendation, and those organizations that can not agree with either.

The ALW developed a working definition of assisted living [see attachment #2]. Six topic groups meet at least once a month to discuss and work on the substantive issues surrounding each topic. The topic groups are:

- Resident Rights and Facility Ethics;
- Staffing;
- Medication Management;
- Operations;
- Direct Resident Care; and
- Affordability

While the substantive issues are generally unique to each topic group, the ALW recognizes that there are a number of overarching interests that all topic groups should take into consideration as recommendations are crafted. These are: quality indicators, best practices, outcome measures, research, considerations for individuals with cognitive impairment, accountability, facility size, affordability, and education and training. A list of the key areas of discussion from each topic group is also attached.

As we work to develop consensus recommendations on state regulations, federal policy and facility practices, we need to be mindful of the need to focus on the 'living' experience for residents and not to accidentally place staff and services on *center stage*.

Thank you again for the opportunity to appear before the Committee today.

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Nat'l Conference of Gerontological Nurse Practitioners	Karen Kauffman		karen.s.kauffman@verizon.net
National Hospice and Palliative Care Organization	Cherry Meier	(512) 252-2843	cmeier@nhpco.org
AGING/LTC ORGANIZATIONS			
American Gerontological Society	Barbara Resnick	(410) 740-3252	bresnick@umaryland.edu
NCB Coming Home Project	Robert Jenkens	(202) 336-7653	rjenkens@ncbdc.org
National Academy of Elderlaw Attorneys	Brian Lindberg	(202) 789-3606	bwlind@erols.com
National Association of Professional Geriatric Care Managers	Linda Aufderhaar	(703) 502-0240	seniorcare@erols.com
National Council on Aging	Diane Lifsey	(202) 479-6658	diane.lifsey@ncoa.org

ACCREDITATING ORGANIZATIONS			
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Joint Commission on Accreditation of Healthcare Orgs.	Marianna Grachek	(630) 792-5722	mgrachek@jcaho.org
DISABILITY COMMUNITY			
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Assisted Living Workgroup

WORKING DEFINITION OF ASSISTED LIVING -

A congregate residential setting that provides or coordinates personal services and care, 24-hour on-site support and assistance (scheduled and unscheduled), activities and health-related services by qualified individuals. It is designed to: minimize the need to move (as disclosed); accommodate individual resident's changing needs and preferences; protect resident's rights; maximize resident's dignity, autonomy, privacy, independence, choice, safety, quality of life, and quality of care; and encourage family and community involvement.

ALW TOPIC GROUPS and KEY ISSUES

ξ Resident Rights and Facility Ethics
- Autonomy
- Privacy (including private rooms)
- Resident and family councils
- Contracts
- Marketing practices
- Admission and discharge criteria
- Negotiated risk agreements
- Aging in place

ξ Staffing
- Training
- Skill development
- Qualifications
- Background checks
- Appropriate staffing levels
- Universal worker
- Human Resource practices
- Wages and benefits
- Volunteer and student orientation

ξ Resident Direct Care Services
- Care coordination
- Levels of service
- Resident assessments
- Service plans
- Dementia care
- Emergency medical services
- Advance directives
- Infection control

ξ Operations
- Nutrition and food services

- Activities
- Life safety
- Dementia safety and environment
- Emergency evacuation plans and drills
- Transportation
- Smoking policies

ξ Medication Management
- Administration
- Oversight
- Staff qualification and supervision
- Pharmacy criteria

ξ Affordability
- Medicaid waivers
- HUD Section 202s
- Public entitlement to assisted living

The CHAIRMAN. Mr. Harris.

STATEMENT OF RICK HARRIS, DIRECTOR, BUREAU OF HEALTH PROVIDER STANDARDS, ALABAMA DEPARTMENT OF PUBLIC HEALTH, MONTGOMERY, AL

Mr. HARRIS. Thank you, Senator. I am the State regulator on the Assisted Living Workgroup and my fellow State regulators around the country and I live and work in a landscape of conflicting demands.

We are, for example, told that we must establish high standards for quality of care and quality of life in assisted living, but we must not drive the cost of services beyond an affordable range. We are told we must encourage providers to offer alternatives to nursing home care, but not at the cost of running local nursing homes out of business. We are told we must promote autonomy and independence for residents, but we must also keep them safe from abuse and neglect. Of course, we have to inspire public confidence by inspecting facilities frequently and thoroughly, but keep regulatory program costs down.

The fact is, the assisted living industry has received a lot of regulatory attention recently. According to the National Association of State Health Policy, at least 32 States have adopted legislation covering assisted living facilities in the past 2 years.

A couple weeks ago, I took an informal poll of all the State directors around the country, and out of 26 who responded to the poll, 20 said that their State is currently considering changes to assisted living rules or regulations. Assisted living is a very hot issue in many, many States.

We actually, State regulators, face two big challenges in regulating the assisted living industry. The first challenge is that we do not have enough resources. It is a significant source of anxiety to us. What would make me and my colleagues better able to sleep through the night would be having a sense that assisted living facilities are being inspected often enough that it would be unlikely for serious abuse or neglect to go undetected for a very long period of time.

Unfortunately, not many of us believe that is the case. Most States do not have enough assisted living surveyors and do not have the money to hire more. I venture to say my State is not an atypical example. We spend about $5.5 million a year inspecting 244 nursing homes. At that rate, we are constantly struggling to meet our workload requirements and we do not always make the mark. In our assisted living program, which has over 330 facilities, we are spending only about half-a-million dollars a year.

There is also another challenge that is confronting State agencies. In the nursing home regulatory program, my State, every State, relies on well-established national standards. I can acknowledge to you there is some controversy over the survey and enforcement methodology that is used in nursing homes today, but I have never heard anybody really come forward and argue that the nursing home standards, the care standards, need to be changed in a significant way.

When it comes to the assisted living industry, though, it is an incredibly different experience for us. Basically, the States have been

left completely to their own devices. There is no national standards, no independently devised model rules, no national consensus on any of the significant regulatory issues involving the assisted living industry. This necessarily means that there are as many ways of regulating assisted living facilities today as there are States that regulate assisted living facilities.

If a State agency director were to decide to write new assisted living standards, he or she might look to other States for guidance, but out of the other 49 States, what choice should that person make? Right now, States do not agree about who can live in assisted living facilities, who gets to say who gets to live in assisted living facilities, who can do what to the residents who are in the assisted living facilities, nor do we even agree about what an assisted living facility is. So how is a State agency director supposed to have any confidence that another State's approach or an entirely new approach would be an adequate way to govern the assisted living industry?

I think the Assisted Living Workgroup will be a very valuable tool for State agencies because it brings together a wide variety of people and organizations from around the country who come to the table with expertise and with perspectives. In our individual State regulatory deliberations, we are not very often exposed to such an extensive range of viewpoints as we get at the Assisted Living Workgroup.

When the Assisted Living Workgroup can achieve consensus around the issues that are faced by the States, it will establish some very useful benchmarks by which we can measure ourselves. It can also help us bring some resolution to some incredibly thorny issues. But I think even more importantly, the Assisted Living Workgroup can help State agencies think through some of these very complex regulatory issues. So even if there are issues where the workgroup can achieve consensus, there would still be value if the final report of the workgroup would include some discussion of different considerations that surround an issue.

For example, there would be a benefit if we could achieve at long last a national consensus on the definition of assisted living, but there will be even more benefits if we can describe how that definition was derived, if we lay out the questions that the definition is designed to answer, and if we set out alternative definitions that were not adopted and explain why they were not.

My own participation in the workgroup has been very rewarding to me and it is going to help my own agency in Alabama as we grapple with assisted living issues. I look forward to the opportunity to share my experiences on the workgroup with my colleagues from around the country, but I am particularly looking forward to this final report from the workgroup. I think it is going to be a very valuable tool for all the States who are currently updating their regulatory systems and for all those who will do so in the future.

So for that reason, Mr. Chairman and members of the committee, I thank you. These thanks are from me and they are also offered on behalf of State survey agency directors from around the country. We appreciate your work and the work of your very dedicated staff in bringing the Assisted Living Workgroup into being.

The CHAIRMAN. Thank you, Mr. Harris.
[The prepared statement of Mr. Harris follows:]

Statement of

Rick Harris
Director
Bureau of Health Provider Standards
Alabama Department of Public Health

Before the Special Committee on Aging

April 16, 2002

I am a state regulator. As you know, to the extent that the assisted living industry is regulated at all, it is regulated by state agencies such as the one I work for. My counterparts in other states and I have been given the task of devising regulatory approaches to this industry. In doing so, we face conflicting demands. We are told we must establish high standards for quality of care and quality of life-- but we must not drive the cost of services beyond an affordable range. We are told we must encourage providers to offer alternatives to nursing home care-- but without running local nursing homes out of business. We are told we must promote autonomy and independence for residents-- but keep them safe from abuse and neglect. We are told we must inspire public confidence by inspecting facilities frequently and thoroughly-- but keep regulatory program costs down.

The assisted living industry has recently been the focus of urgent regulatory scrutiny by the states. According to the National Academy of State Health Policy, at least 32 states have, within the past two years, enacted new legislation governing assisted living facilities. I recently polled my colleagues, and, out of 26 states responding, 20 say they are currently considering changes to assisted living regulations or laws. Clearly, assisted living is a hot issue in many, many states.

State agencies face two major challenges in developing a regulatory approach to the assisted living industry. The first is that we have too few resources. For many state regulatory agency directors, the assisted living program is a significant source of anxiety. What would make us better able to sleep through the night would be a sense that assisted living facilities are being inspected often enough to make it unlikely for serious neglect and abuse of vulnerable residents to be undetected for very long.

Unfortunately, not many of us believe that is the case in our respective states. Most states simply don't have enough assisted living surveyors and don't have the money to hire more. I venture to say my state is not atypical: we spend about $5.5 million each year in our nursing home regulatory program, which covers 244 facilities. Meeting our workload requirements in that program is a constant struggle and we often miss the mark. But in our assisted living program, which covers 309 facilities, we are only spending about $500,000 during the current fiscal year.

There is another difficult challenge confronting state agencies. In our nursing home regulatory program, my state and all other states rely on a well-established corpus of national standards when making compliance decisions. There may be controversy over the survey and enforcement methodology used in the federal nursing home program, but I have yet to hear a serious argument from providers, consumers, or regulators that the federal nursing home standards ought to be changed in a significant way.

When it comes to the assisted living industry, though, there is no consensus on what regulatory standards ought to apply. We state agencies have been left to our own devices. This necessarily means that there are today as many regulatory approaches to the assisted living industry as there are states involved in regulation. Should a state agency employee attempt to write new assisted living standards, he or she might look to other states for guidance, but in doing so would face a bewildering array of choices. For example, states do not agree about who may be appropriately

admitted to assisted living facilities, who ought to determine who may be admitted to assisted living facilities, who can do what to residents who are admitted to assisted living facilities, nor do we even agree about what an assisted living facility is. How can a state agency director have confidence that any regulatory approach adequately addresses the many risks faced by assisted living residents?

The Assisted Living Work Group will be valuable to state agencies because it brings together a wide variety of people and organizations from around the country who come to the table not only with expertise but with new perspectives on various issues. In their individual regulatory deliberations, state agency personnel are not often exposed to such an extensive range of viewpoints.

To the extent that the Assisted Living Work Group can achieve consensus around issues faced by the states, it will set useful benchmarks by which we may measure ourselves. It may also help us bring resolution to some thorny questions.

The Assisted Living Work Group can also help state agency staff in thinking through complex regulatory issues. Even if there are issues on which the Work Group will be unable to achieve consensus, there will still be value if the final report includes discussion of the considerations that might inform a state's own decision-making. I'll say it another way. There will be a benefit if we can achieve a national consensus on, for example, a definition of assisted living. But there will be yet more benefits if we can describe how the definition was derived, if we can explicitly state the questions that the definition is designed to answer, if we set out alternative definitions that were not adopted, and if we can explain why they were not.

My own participation on the Work Group has been rewarding to me and will be an enormous help as we grapple with assisted living issues in my state. I look forward to the opportunity to share my experiences on the Work Group with colleagues from around the country.

I look forward even more to the final report of the Work Group. I believe it will be a valuable tool for all the states currently updating their regulatory systems, and for all those who will do so in the future. For that reason, Mr. Chairman and members of the Committee, I thank you on my own behalf and on behalf of state survey agency directors around the country for your work, and the work of your staff, in creating the Assisted Living Work Group.

The CHAIRMAN. I thank the three presenters.

Senator Craig, do you have any comments you would like to make?

Senator CRAIG. Thank you, Mr. Chairman. I apologize for running a bit late.

The topical areas that you are now investigating and that you have arrived at, I think are tremendously important, from the residents' rights and facility ethics all the way through to medication management and affordability. Are you ready to start questions, or do you——

The CHAIRMAN. Let me just go to Ron to see if he has any——

Senator CRAIG. Then I will hold off. I do have one question as to how all of that comes together in this final report and whether you have got State regulators looking at this in a favorable light or in a rather critical light. We hope it is the first instead of the latter.

Mr. Chairman, thank you for keeping this moving. We think it is necessary and important to set a national standard here from which we can judge, and if in the end, as you have said, Rick, if we can just come to a definition of what we are about, that is clearly steps gained and maybe some direction gained. But thank you, Mr. Chairman.

The CHAIRMAN. Let me just go ahead and take out the first question. I thank all of you, and those who are not presenters, if you have some different recommendations, we will try and give you the opportunity to make those statements, but we will try and direct, I guess, the questions to the three presenters, and then for those who are not one of the three, we will certainly have the record open and have people be able to make submit testimony if they feel that they want to.

Let me just start with a general thing. What we are trying to do is to solve problems before they become crises. We spend so much of our time looking at nursing homes and other deliverers of health care systems about what is wrong, what is right, what is not being handled properly. This system, this industry, this way of providing help to seniors is kind of in its infancy, but it is growing very rapidly. We want to try and come up with some ideas about where we want to go and how we want to get there before we have a lot of problems. This is the sort of preventative type of preparation I think that we are trying to encourage the industry and consumer groups to engage in.

Let me just ask a general question, and that is that some may argue that, look, government does not have any business being involved in this, that most assisted living residents are private pay customers. We are not funding this under Medicaid to any large extent. We are not paying for it under Medicare. The government has no business being involved in it, particularly the Federal Government. Let the States do what they think as long as it is private pay customers. You do not need to have Congress involved in this at all. Do any of you have any comments about that argument and that recommendation?

Mr. MINNIX. I have a comment about that, Senator. I think the government always has a responsibility for people who are vulnerable, and you look at some of the senior populations that use as-

sisted living, the stress that the family is under. Government has to be concerned about that.

Do you need to regulate assisted living to the extent that, say, hospitals and nursing homes are regulated? I do not think so, if we can take responsibility for ourselves.

I think Mr. Harris is correct that if over the next year we can give some guidance to States on just such basic things as definitions and what types of assisted living guidelines, and then you would have to decide, of course, from the Federal level how you would express your interest in that, but I think, generally, this is one of these things that comes under the heading of we need to think global and act local. But there do need to be some guidelines and the public does have an interest in these kinds of populations and you would be remiss in not expressing that in some way.

The CHAIRMAN. I take it that no one would disagree, then, with that position?

Ms. LENHOFF. Mr. Chairman, I would actually have something to add about that, which is that, although I think you are right that the Medicaid proportion is small, in some places, it is greater. I was surprised to learn that in Wisconsin, for example, 50 percent of people in assisted living facilities are drawing down Medicaid. That was what I just heard from the State ombudsman yesterday and I want to check that out because it struck me as high, but if it is even half that, that is more than I thought it was.

The CHAIRMAN. It is likely the exception rather than the rule.

Ms. LENHOFF. Yes, that is probably true, but it is growing. I think, also, that assisted living facilities have a strong impact on interstate commerce and they have a strong impact on Federal spending in that if there is bad private pay care, it is going to lead quickly to increased Medicare and Medicaid bills down the line. So from the point of view of protecting the taxpayers' interest, we do have to pay attention to the quality of care.

There are also consumer protection questions that are implicated by assisted living and immigration law issues that are implicated as it applies to staffing in assisted living, for example. So I think that there are reasons why Congress quite rightly is concerned.

I agree with Larry that that does not necessarily mean that you get a comprehensive soup-to-nuts regulation, but rather each problem needs to be looked at individually and see what the Federal role is or ought to be.

The CHAIRMAN. Let me ask, from a structural and organizational standpoint, you have about 50 groups, organizations, that are participating in this advisory committee. Later, we going to be facing organizations and groups saying, look, we wanted to be involved in this process but the workgroup did not let us in or anything of that nature? How do you get in?

Ms. LENHOFF. We are begging them to come on in.

The CHAIRMAN. Just volunteer and you are in?

Mr. PACE. In November, we did send a letter out to just about everyone we could think of that is involved or has an interest in long-term care and aging services. We contacted those people by letter and told them of this workgroup and told them they could be involved. In that ongoing process, it is still very much of an open

door process and anyone that wants to join the Assisted Living Workgroup is welcome to do so.

The CHAIRMAN. I think it is important to have it as open as possible. I mean, you do not want to have every person in the country on the workgroup, otherwise it would not be a workgroup. Obviously, you have a unique opportunity, I think, that we have tried to give you and sort of urge you to take, because I do not know of any other area, particularly in health care, where we have actually told the people who are involved in receiving the care and providing the care, to work together and recommend to Congress what systems would be most appropriate.

I mean, this is a very unique thing that you are doing and it could be, I think, the flagship of how we can do things in the future as far as an example, if it is successful. If it falls flat on its face, there will be some that say, it does not do any good to listen to all these people. Congress might as well go ahead and write the rules.

What we are doing is asking you in advance, what do you think the system should be? How should it work? Give us your thoughts and ideas before we get involved in writing rules and regulations that may not fit. So we are doing it a little bit differently. I think it is probably unique, but it is also a real opportunity to set the stage for perhaps other things we may be able to do by listening to the people first that are going to be most directly affected.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. I want to commend you in particular for your leadership in going at this task in this fashion. I also want to thank Senator Craig. As you both know, you gave me the opportunity to be involved in this from the beginning. I want to talk for a moment with the group about my sense of really where we are at this point.

The origins of this effort really stem from debate about nursing home regulation in this country. As many of you know, I was Director of the Gray Panthers in Oregon for about 7 years before I went to the House and have strong views about these issues. The whole goal of this exercise with respect to assisted living is to not have people 20 years from now debating the very same problems that we are starting to see develop today. That is what happened with nursing homes we did not have a debate like this 20 years ago, and now Senator Breaux, demonstrated when the Committee held a hearing on elder abuse just a few weeks ago, we are debating questions now that you like to think would have been handled 20 years ago.

So this is an important exercise, and as the chairman has noted, the question is, can we make this work? Can we show that there is a patient, consumer, and provider coalition out there that can make this happen? I want to ask some questions designed to elicit where we are. What I think is important today is to get a sense from all of you, the presenters what are the major areas you seem to agree on and what are the major areas that are most contentious where agreement is hard to reach.

In the second GAO report that was done for the chairman and myself and Senator Grassley, at page 13 of the report, there is a section by the General Accounting Office saying much information considered key by consumer and industry groups is not routinely

provided in writing. Now, what that means is that the patients and the families are basically in the dark with respect to making these choices about assisted living and they like to be able to compare apples to apples and make choices that are helpful to both of them.

I would like to start my questioning by way of seeing where we are among the industry and the consumer people. With respect to consumer protection is this an area now, where it is fair to say there is agreement now between the patient advocacy groups and the industry?

Mr. MINNIX. I believe that we are in agreement on a working definition of what assisted living is because there are all kinds of definitions. It is called personal care in some States, assisted living in other States. I believe we are in agreement there.

I think we are in agreement on issues related to full disclosure, and that was a hard one to work on because that is one of the problems that you brought to our attention a year ago, was the absence of full disclosure.

I think there is an awful lot of agreement on what the program of assisted living is, how it ought to be defined, but there is still debate on whether that needs to be in levels of assisted living and just how should that be expressed.

There is some general perception among, I think, most of us that there needs to be some kind of medical involvement in some types of assisted living without making it a medical director in a nursing home. We are still working on issues of staffing, how do you define that. We generally agree that it needs to be according to the needs of the residents of the particular facility it is serving, so in some cases, that may need to be an RN present for part or all of the day. In other cases, it may not be, depending on what the defined limits of that assisted living facility are.

So I think we are working on some of the mechanics of all of that, but some of the general things like definition, disclosure, we have come together on.

I think that one issue that will be discussed, and Donna Lenhoff mentioned it, how is it going to be financed? If we are really going to have something that is affordable, what are our recommendations going to be, because assisted living is still not accessible to modest and low-income people very easily.

Well, one way to do that is to work with HUD on converting some existing low-interest financing housing to make that affordable, but in some States, you are inevitably going to turn to Medicaid. Is it possible to include long-term care insurance in some of the financing models, as some policies do now. So we are going to have some things like that that will be brought to you, especially around the financing.

I am confident that by this time next year, we will agree on the blueprint of what a program of assisted living ought to be, because I think we are very close about that, and yet there is some debate that still needs to occur.

Senator WYDEN. Ms. Love, Mr. Minnix essentially said that on that key GAO recommendation, so that families can compare and make choices in advance that make sense for them, he thinks that there is industry and consumer agreement. Do you share his view on that?

Ms. LOVE. Yes, I do. I think that we have made a lot of strides in this last year. The next step Senator Wyden, is to operationalize it. At a public policy level, we are in discussions additionally we need to integrate this out into the field so when you actually walk into an assisted living facility, you have this happening. That is going to be part of our challenge.

The other part of the challenge, as you put out there, and we have not worked this out yet so we do not want to come before you with all of our answers today because they have not all been clarified, but we can come up with this good blueprint that Mr. Minnix talks about. That does not necessarily mean that 50 States and the District of Columbia are going to adopt and operationalize them. So that is a challenge still before us.

Also, it is a dynamic process. It is something that we continually need to work on. We cannot just simply develop it and put it on a shelf and rub our hands and say, gee, we are done. We have got to develop a system that continues to review and evaluate the recommendations. We do not have this aspect developed yet. Maybe, as you said, Senator Breaux, that is another thing we flagship on, is a method to be able to do that.

Rick Harris talked very succinctly about the need for survey and oversight systems. So we have got a lot of work still before us.

Senator WYDEN. Tell me, if you would—I want to just see if I can get a couple out quickly, and then hopefully maybe we can have a second round, Mr. Chairman—on the staffing issue. Mr. Minnix mentioned that staffing was an area where there were significant differences at this point between providers and consumers. That is an important area because that goes right to the heart of the quality debate and that was what Chairman Breaux and I and Senator Grassley zeroed in on from the beginning. We said there are really two issues that are critical, the consumer protection questions and the quality questions.

Why do you not tell us, if you would, your sense of where things stand on the staffing question and, if you could, what are the areas of agreement, what are the areas of disagreement on staffing, because I believe this issue is at the heart of quality.

Ms. LOVE. You are absolutely right. Again, we do not have answers yet. Fortunately, we have still got a year. We have a topic group on staffing. Some of the points that you bring up are the issues that we are trying to work through.

One of the ways that we are looking outside the box is about ratios. We are trying to look at this in an entirely different way and utilize on some of the research that is both underway currently and some just finishing up to analize an acuity-based staffing model. The four provider organizations that have been actively involved in the ALW have been working to improve quality.

Senator WYDEN. Let me ask just one other question on this round. I am unclear as to the collective sentiment with respect to the role of the national government and the State government in this issue.

As you know, at the hearing that we held after the second report came out, I had gotten the sense from consumer organizations that the idea of a model State statute, an area of baseline protections at the State level that addressed quality and consumer protection

issues, was an area where there was at least some growing interest and growing support. During the last few months as this has been discussed, I have heard more talk about national standards in some areas and State in other areas. Could you give me the consumer perspective on the comparative merits of a model State statute versus a more national approach.

Ms. LOVE. That was part of what the ALW wrestled with on the title something that would adequately describe what the final product will be a year from now. We settled on "Best Practices and Guidelines for State Regulation, Federal Policy, and Operations.

We have looked at some of the other industries that are regulated on a State level. There is a challenge in getting all the States to set a similar bar and we do not quite have the answer to how we are going to work that part out yet. There are, ways that working effectively with states Congress and Federal agencies we can collaboratively develop a successful plan.

I will give you an example. In our staffing topic group discussion just this last week, one of the things that we were looking at was background checks. If checks are conducted on individuals in just one State, then that is all you get. You get somebody that is cleared in one State. But what if we tapped into a national resource, the FBI data bank? Here is an example of where we could utilize Federal national resources that would work significantly well across the country.

Senator WYDEN. I hope that you will look at a variety of approaches to address the State and the Federal area, and one I would offer up, actually, we have not talked about it as we have been at this issue, is in the Medigap area, the area where there is an actual program that has been a huge difference for older people in this country.

When I was Director of the Gray Panthers, you saw senior citizens with seven or eight policies, health insurance policies to supplement their Medicare, and we wrote a law to change that and it, in effect, lets the State take the lead, but then has a national backup, a sort of national backup that ensures that if a State were to slough off, that there would be a specific way to protect consumers, and my assessment is that this has made a real difference for patients and consumers and families and is also something that provides enough flexibility to providers that it is attractive to them, so perhaps you might want to look at that Medigap model for the relationship between the State and the Federal Government.

The chairman has given me a lot of time on this round and hopefully we can do a little more.

The CHAIRMAN. Thanks. I was reading an article in the New York Times and it talked about the things that people were concerned about, what things they did not have information on when it came to the question of assisted living facilities. What I wanted to do is ask whether you think your recommendations will cover these areas. The ratio of patients to staff?

Mr. MINNIX. Yes, sir, we will have a recommendation about staffing.

The CHAIRMAN. Qualifications of staff members?

Mr. MINNIX. Yes, sir.

The CHAIRMAN. What a facility must disclose about their fee structure?

Mr. MINNIX. You bet.

The CHAIRMAN. Financial stability?

Mr. MINNIX. Yes, sir.

The CHAIRMAN. Policies for discharging patients?

Mr. MINNIX. Yes, sir, and also, in addition to that, how they are assessed to begin with, what happens in certain circumstances, like emergencies. It will cover a full range of those kind of policies.

The CHAIRMAN. On discharge, you mentioned, and I guess it is also the question of accepting a patient. If a family tries to put a relative in an assisted living facility, I think there should be some standard as to when the assisted living facility would say no.

Mr. MINNIX. Yes, that is right.

The CHAIRMAN. This patient is sicker than should be accepted in this facility. Perhaps this patient, this family member needs a nursing home.

Mr. MINNIX. That is correct.

The CHAIRMAN. OK. I take it that, and maybe, Mr. Harris, you can address this, how many States—I am reading this and it says, unlike 29 other States, New York has not undertaken to regulate the emerging industry in ways that would consistently protect residents. Does that mean that only 29 States have done that? How many States have policies, if you will, for assisted living facilities that set out standards on licensing procedures that they have to meet?

Mr. HARRIS. I think almost every State has some sort of system for licensing assisted living facilities, certifying them, and that can vary from just requiring them to register and maybe send in a small fee to get back a piece of paper that says they have registered, to some fairly extensive regulatory requirements being imposed.

It is even more complicated than that because I think what has happened to the assisted living industry is that as States have developed regulatory models, the industry in that State, in each State, has grown to accommodate the regulatory model. So in, for example, Connecticut, they seem to follow a model where the assisted living facility is more or less an apartment building and then people contract out to have services brought in. Some States allow just about anybody to live in an assisted living facility and then they regulate how extensive the care needs to be that is provided in that facility. Other States regulate pretty closely who can live in an assisted living facility and have various levels of assisted living facilities.

So it would be very difficult, I think, to develop a one-size-fits-all approach for States without doing a lot of violence to what can be a fairly well-established industry in that State and a model that may be working there.

The CHAIRMAN. I take it that you all have or will have contacted some of the larger industries that are becoming involved in this, Marriott, Hyatt. It would seem to me that if I was running their operations in this area, I would really want some national standards so that I would not have 50 different sets of rules and regula-

tions, depending on where I have facilities. Have you all heard from any of them? Are they represented in any way?

Mr. MINNIX. I think they are involved through ALFA and I think you would find those organizations generally wanting to meet high standards. One of the things that I will say as CEO of AAHSA, what I think is possible here, it may be possible in this unprecedented way to present to you with a blueprint and a set of standards in which we might even have a self-governed accreditation kind of process that could be accountable to the public in a disclosure kind of way from the ground up and make that work.

The CHAIRMAN. Giving you a unique opportunity to write the bill.

Mr. MINNIX. I think we can do that and prove to the public that we can be responsible. Now, that gets everybody a little nervous because of the nursing home experience in this country, but it is possible to do.

The CHAIRMAN. I do not reject it out of hand. I think there is a natural tendency on consumers' parts to go back to the old adage of not letting the fox guard the chicken coop. I mean, obviously, if you are going to let the people who are benefiting financially from running the program regulate the program, you really have to have a tightly drawn set of rules and regulations as to what standards are going to be met and also some type of provision for when you have some bad actors who do not want to meet those standards.

Mr. MINNIX. Yes.

The CHAIRMAN. Have you all discussed the question of what do you do if you have a set of rules and principles that you all can agree with, then you have one provider of assisted living facility services that consistently and repeatedly do not meet those standards, do you have any thoughts or ideas about how to self-police in those areas if that, in fact, is the result?

Mr. MINNIX. Well, you kick them out and tell them they are no longer accredited if we are willing to put teeth in it. The problem oftentimes in self-accreditation, as you know, is that people get soft on their friends and we cannot have that kind of thing. If we would have a self-governance kind of process, it would have to include strong representation from consumer groups and other types of businesses, like the insurance industry, for example, and maybe even representation from State government if we are going to have a strong public accountability process, but I believe it is possible.

The CHAIRMAN. Ms. Love, can you comment on that? I mean, how do we do that? If you come up with rules and standards and somehow Congress blesses that as a national program for assisted living facilities, how do we ensure that the bad actors would be dealt with in a way that would not allow them to continue?

Ms. LOVE. I think that Larry talked about the right direction. We must have a strong enforcement system. Something that has teeth in it. Some of the States, for example, may have good regulations in place, they may have a survey system, but then there are no teeth in it and we can tell that those States have the higher facilities that do not perform well. So we have got some anecdotal data.

Not all of us are willing to sign off on a deeming self-accreditation process, but in the spirit of our collaborative nature, I think that is something for us to talk through. So I do not have any answers yet.

The CHAIRMAN. Any other comments on that, Rick?

Mr. KYLLO. Senator, I would like to comment.

The CHAIRMAN. Yes?

Mr. KYLLO. I come from an organization which represents both assisted living facilities and nursing homes, so I think we are in a position where we have had the experience and watched enforcement of standards. I think we have an opportunity here as we look forward to really create a secondary role for government, which is that of consultant, and I think that we can work together in partnership.

That does not mean you do not have in place an enforcement system with teeth, but I think it does mean that you work more in partnership trying to solve problems as they arise, so you have a more open dialog. This was a concept that the Assisted Living Quality Coalition embraced 2 years ago when it came out with its document, and there are several members around this table.

The CHAIRMAN. I think that is very important. I think to the extent that you can devise something that really deals with those who are consistently bad apples, if you will, No. 1, it is in the industry's interest. You do not want to have members in your industry that are doing poor jobs and reflecting badly on the industry as a whole, not to mention the problems it causes for individuals who are not adequately served. You do not want them in your accredited, approved operation if they are not getting the job done.

So you have to have, I think, some type of clearly defined standards as to what they are expected to do and how they are expected to meet those goals, and then some type of penalty, if you will, for those who do not meet the standards.

This can be made to work. It is not going to be easy. But if you do not do it, I will tell you, Congress is going to do it, and I will guarantee you, just as much as sure as I am sitting here, if you all do not come up with something that is workable, you are going to end up having Congress pass rules and regulations and end up micromanaging this industry, which I would imagine that probably most of the providers do not think is in their best interests. Maybe even consumers would think that if we could do it a different way, residents could end up with a better result.

Mr. HARRIS. Senator, if I may add, I think there is a difference between having a lot of provider and consumer input into the development of standards and having an enforcement system that is essentially self-policing. It is very appropriate and necessary, in my view, to bring as many people to the table as we can as we look at these standards and that we listen to the points of view of everyone and make sure they are fully considered.

But in the end, health care providers are like everybody else. They are human beings and their behavior falls on a bell curve and there are going to always be bad actors in the industry. I think the only effective way to deal with that is to have disinterested third parties, and I think a well-motivated State regulatory agency that is close to the situation is in the best position to do that. We in my state are dealing with about 12 operators right now in various stages of enforcement actions and that has a salutary effect on the behavior of some of the other providers.

The CHAIRMAN. These are assisted living facilities?

Mr. HARRIS. Yes, sir.

Mr. SHEEHY. Senator, I would just like to maybe add another thought to that. I think that, from our standpoint and I hope others, that the real value we see coming out of the Assisted Living Workgroup recommendations is that to the extent that we are able to build a national consensus is we will be able to take that back to our respective constituencies back in the States and create the motivation and the catalyst to then take those recommendations and use them as a benchmark. So as the States go through their revision and updates of their rules, they will have the assisted living recommendations to work with.

So I really think there is real value that the people around this table and in this room are building this consensus so we can take that back with us to the States. We echo your thoughts there that we do not want to see the Federal Government come in and with a heavy hand and regulate us, so I think we are all motivated to make sure that we are not just a Washington-based coalition creating some recommendations that will sit on the shelf. We are motivated to take that back to our members and to our constituents and have everybody step up to the plate and really make a difference.

The CHAIRMAN. Thank you. I think that Rick has pointed out something that is obvious, and that is that there are really two questions. No. 1, what should the standards be, and you are all working on that in all these areas we talked about, patient ratios, qualifications for the acceptance and discharge and all of those very complicated procedures about the day-to-day running of an assisted living facility. You are going to be very helpful in coming up with those recommendations for the first time, which could become the standards for the industry.

The second question then is, what happens when you do not meet those standards, and the question becomes whether you take actions within your own industry to police yourself or do you take those recommendations, give it to Congress, and we set up a system whereby we try to moderate and supervise and, in effect, regulate to make sure people are meeting the standards that we can agree on.

I think that as there is going to be more and more of an incentive to have tax credits, for instance, to be used for long-term health planning, there will be more of an urging that since we are helping to pay for it through the use of the taxes, that we should be more involved in actually supervising it and make sure it is being run properly. Those are the big issues we have to address.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman.

I want to stay with this enforcement question for the industry and the consumer groups for just a moment, because I think all of you understand, unless there is an enforcement system in place that is seen as credible, it is really not on the level, that it is not seen as something that addresses the concerns of the public and families have a right to expect.

Tell us by way of continuing sort of the way I approached it in the first round, what are the areas on enforcement where the pro-

viders and the consumers seem to agree and what are the areas where there is disagreement?

For example, take the inspection question, which is right at the heart of an enforcement program that is credible. Walk us through on enforcement, including inspections, where providers and consumers seem to agree and then where providers and consumers seem to disagree. Larry, why do you not start that.

Mr. MINNIX. I will start by saying that I would say there is probably too little public oversight, and it varies by State, because of what Rick Harris is saying. They do not have enough personnel. The standards are, in many cases, loose. So that varies all over the waterfront.

I would say from my standpoint, if my mother were to go into an assisted living facility today, I am not sure I could feel comfortable with her being in certain types of assisted living facilities in certain types of areas, so I do not think we are there yet, to be perfectly honest about it.

Senator WYDEN. How about on the inspection question? Do providers and consumers seem to be making headway in terms of an approach on inspections that both could support?

Mr. MINNIX. I would say that we are very close to agreeing on definitions of care and services to be rendered and, therefore, standards, and I will bet we can get to the point within the next few months of how public accountability ought to be done.

I do not think that I could support a public accountability system where the foxes just talk about the hen house. I think it has to be broader consumer, ombudsman, some kind of formal State connection to that process to keep everybody honest because human nature is what it is. At the same time, I do not think you need the kind of enforcement in assisted living that you have got in nursing homes today, where you send in a team of five surveyors for 5 days and look at everything going on.

We all know what has led to that and it is a process that is where it is and it is going to be a while before anybody will trust the nursing home—and we represent nursing homes—it is going to be a while before the public trusts us enough to make that process different. Here is a chance to do it right and have the right balance of professional self-accountability along with public representation on that. I think we have got a chance to do that.

Senator WYDEN. Ms. Love, enforcement and inspections.

Ms. LOVE. I think Larry Minnix hit it on the head. We are probably about that far apart, but that far apart is going to have a lot of discussion, a lot of work to be done on it.

For example, if we look at the nursing home system as a model, one of the things that comes out in the survey and inspection process are deficiencies. That whole concept is a very negative approach to how a facility operates. We want to restructure and reframe what that looks at and put it in a more positive framework.

But again, I think we will have a lot more of those answers in a year.

Ms. LENHOFF. Senator, if I may add to that, as well——

Senator WYDEN. Sure.

Ms. LENHOFF. Although it is true that deficiencies may be unfortunate and may be very negative, sometimes they are necessary

and enforcement actions are necessary. One of the things I think that we would be very concerned about in a system, whatever the system of public accountability is going to be as we go forward on assisted living, is to make sure that where we have inspections and other public accountability that is working on the State level, that we not lower the bar, that we be looking at what the States are doing.

That is one of the reasons why it is so important that we have Rick and the State regulators involved, so that we can have a good sense. I think that is work that we really need to do, is look and see what, not just what legislation is out there, but what is effective, what is working, what are we seeing specifically with enforcement, and I do not think we have really, unless some of the topic groups that I have not been involved in have been looking at this, I do not think that we have gotten there yet.

So I, for one, am very appreciative of your interest in this area. I think it gives us something more to chew on.

The CHAIRMAN. If I could just jump in here, I think that one of the things—I think information to consumers is incredibly important so they can make wise and informed decisions. People make bad decisions when they do not have good information to base those decisions on. People many times make choices in life about utilization of services not knowing anything about the choices they are making.

I think it is very important in this age of personal computers that we ultimately have a system whereby when I am making a decision on the assisted living facility for a loved one in the family or parents or what have you that I can go to some site and look up the record of a particular facility and find out, what is the track record here? Is the facility financially secure? How many people have had problems with this facility? That type of information allows me to say, look, this one is better than this one. I am going to take A over B.

But if they do not have that information available anywhere, then they do not have the information to make an accurate decision. As I have said before, we can find out more information on the repair of a toaster oven in many cases than we can on hospitals, doctors, nursing homes, and things that are really truly important. I mean, you get on the Internet and you can find out from Consumer Reports how much it costs to buy a toaster oven how much it costs to fix it, how often it breaks, and what is the life expectancy of the product and all kinds of things about products. But it is sometimes very difficult to find out that same type of information about providers of something as important as health care in this country.

So I would hope that in looking at ways that you can give the maximum amount of information to consumers, we find some way of presenting these facilities so that consumers can look at them through the computer system and find out what is there and what is good and what is bad, knowing that nothing is perfect, just so they can make their choice. Give them enough information so that they can make informed choices.

Is that, Larry, possible?

Mr. MINNIX. It is not only possible, Senator Breaux, it is essential because you can go to the Internet today and find out everything from electric razors to SUVs and we do not have any reliable information that is an indicator of quality in health care. In fact, I think we need to make as a part of this process some kind of standardized consumer satisfaction survey.

There is no standardized consumer satisfaction survey in health care today. We have been talking with CMS about that on the nursing home side because there is no way to really know, unless a facility does it itself, how consumers view the care and services that they are receiving and I think this would be essential in assisted living.

Senator WYDEN. Can I just follow up on the chairman's point, because this is potentially a real breakthrough. As all of you will recall, Tom Scully, when he was appointed CMS, went and gave what he thought was going to be a very innocuous speech about basically saying he was going to make quality information available that the government already had on hand. He was not going to do anything else but just go to his files and make it available. There was such an uproar, a national uproar, that the proposal essentially was pulled back on and they have been working on this information to date.

So there would be a potential breakthrough here, if I understand it right. There would be two areas. The first that you all would look to is what the General Accounting Office talked about in the report that we asked for, and that would be that the consumer protections people would be entitled to would be set out in writing so that families would know in advance and that would be online, and both of you said that would be available.

The second is, as I understood it, were you telling the chairman that you are also interested in coming up with ways to make facility-specific information about quality available online, as well, because if that is going to be done by this coalition, that would be a huge step forward in terms of health care in this country. If you went the second step to make facility-specific information about quality available and the two sides, the provider side and the consumer side, could agree on how to do it, that would be a very, very significant development.

Mr. MINNIX. I can tell you that from the time you said it, we supported Administrator Scully's view of beginning to learn to quantify quality indicators and disclose to the public. Many of our members have resident satisfaction surveys now. Some have encouraged all of their member homes in the State to use it. It is very good information, very revealing information. I would be prepared to make that recommendation. I obviously cannot speak for the whole group, but we need to get to that point.

The CHAIRMAN. It is more than just a webpage for the provider to put up there.

Mr. MINNIX. Sure.

The CHAIRMAN. They will have the pretty pictures and everything else, and that is all important, but, I mean, also what we are talking about is really sort of a grading system that shows how well this facility has done. That encourages better practices by the

good operators and it sends a message to the bad operators that maybe they should not be in this business.

I want to say that is what we are trying to do, I want to encourage this. I think all of us are saying that this is something that is important for seniors. It is important for this country. I think it is going to be a very strong and growing industry. I think anyone providing services to seniors has a very bright future if they provide good services, because No. 1, you are going to have a lot more seniors because of the baby boom generation and those seniors are going to be living a lot longer. So this is a huge market out there, and what we are just trying to say is, let us get it right from the very beginning.

Mr. MINNIX. I think a consumer satisfaction survey, it does not need to be something that somebody does on their own. It needs to be independently validated and administered. But there is no standardized tool for that that I know of anywhere in health care, and when you think about it, that is a huge oversight on everyone's part.

The CHAIRMAN. Let me just say as we—go ahead.

Senator WYDEN. On disagreements, I understood this business about two-thirds and one-third and all of this, which I think all of us would acknowledge that that is the old kind of approach. The idea is to just kind of pack your side. If——

The CHAIRMAN. That was the Medicare Commission's standard. [Laughter.]

Senator WYDEN. If we are going to do this, and I want you to walk out of here knowing that we really are excited and interested about the possibilities here. This has the potential to be the wave of the future in terms of dealing with health care issues. Now, it may not. It may be that you break now on a whole host of issues, and we know that this is very significant work.

But to say that you are going to agree on consumer protections and that there is going to be a coalition of consumers and providers that agree on that and that you are going to try to work together to make facility-specific information available online, that could be a huge opportunity to empower families in this country in an area that there is significant growth in.

This is significant in terms of its potential and I am curious how you all deal with the disagreements that are inevitable as opposed to just the two-thirds voted and one-third did not vote and all that kind of thing. How is that going to work? Karen?

Ms. LOVE. This is probably one of the most challenging aspects before us. We all come with our special interests and they do not always line up, and that is where we find we did come to a two-thirds/one-third majority, because we needed a system to go forward. Otherwise, we would be still talking about the definition of assisted living, trust me. [Laughter.]

But I think the underlying value, and Dr. Minnix talked about this early on, is that if we can sign off on the final report as a group of organizations, that is significant. That means that we are involved and we are invested in what we have just crafted.

We also have to have a process, though, that allows an organization to say we just cannot agree with a recommendation. We just cannot go there. So it has got to be dynamic. It has got to have

enough flexibility built in so that we can do that and give people an out, basically is what it is. But when we get to the point where we are really stuck——

Senator WYDEN. Then call Senator Breaux.

Ms. LOVE. We will. [Laughter.]

But I think the key word here, if we were to walk away, and if I can speak for my many wonderful colleagues in the room today, is listening. This process has allowed us to listen to one another. We can come thinking what we are thinking, but where we really break down our differences is when we listen to what somebody else has to say.

Mr. SHEEHY. Senator, may I just add to Karen's?

The CHAIRMAN. Sure.

Mr. SHEEHY. I think that, and Senator Wyden, I think you made a good point about how we determine what a consensus is, whether it is a two-thirds or you have a one-third minority. I think the true value of what comes out of the Assisted Living Workgroup will be a consensus truly composed of consumers and State regulators and providers. That will truly make the recommendations work at the State level. So that is the consensus that has to emerge out of this workgroup and that we are committed to.

The CHAIRMAN. I think that what we have here is a centrist coalition of providers of assisted living care for seniors, and I think that is so important. I think that what Karen just said is really important.

You know, you never have a disagreement if you only listen to yourself talking, and that is what we do far too much of in the Congress. I mean, we only listen to one side, and there is never a disagreement if you only listen to one side.

What we tried to accomplish here is to get all of the sides, at least three, in this case, to listen to each other and to recognize that others have valid points that need to be discussed and need to be factored into the ultimate solution and that both sides have to listen to each other in order to come up with something that is workable, instead of gridlock and not getting anything done.

So I congratulate each and all of you and all of the other colleagues that are not represented today—many in the audience perhaps are—to thank them, because each one of you is intrinsically involved and very important in this process working. Everybody needs to be heard. Everybody's suggestions need to be considered. Hopefully, when we come back in April of next year, we will have a package of recommendations from you that will be most helpful to the Congress and ultimately helpful to the people that assisted living is intended to provide quality assistance to, the American public.

So we encourage you to continue to move forward. I am very pleased with what we have seen so far and we will continue to work with you. Thank you all.

[Whereupon, at 3:43 p.m., the committee was adjourned.]

APPENDIX

Written Statement of

David Kyllo

On Behalf of

The National Center for Assisted Living

For the Forum Before the
U.S. Senate Special Committee on Aging

Update on the Assisted Living Workgroup

Submitted April 16, 2002
For the Hearing Record

Chairman Breaux and members of the Committee, on behalf of the National Center for Assisted Living, I would like to submit the following statement for insertion in the official record of this proceeding. My name is David Kyllo, and I am Vice President of the National Center for Assisted Living.

The National Center for Assisted Living (NCAL) is the assisted living voice of the American Health Care Association. NCAL represents 2,400 proprietary and non-proprietary assisted living and residential care facilities nationwide. NCAL is committed to fostering growth in assisted living and ensuring that people have access to quality assisted living services by supporting responsible public policies, providing professional education and development services and by being an information and research resource for consumers, academia, state and federal policymakers and the media.

I would like to begin by thanking Chairman Breaux and the committee for showing leadership at a critical time in the history of our nation when we are on the cusp of one of the greatest challenges we will face as a nation – the baby boomers ascension to the ranks of the elderly. Assisted living plays a vital role in the care of our nation's elders. That role will only grow in coming years. The committee is to be commended for having the foresight to address the assisted living framework now, so that the assisted living profession has a strong foundation for meeting this daunting challenge.

Following our meeting with staff of the Senate Aging Committee in August 2001, some 20 organizations gathered and began to respond to the charge from the Committee: determine how to ensure quality in assisted living throughout the U.S. The Assisted Living Workgroup (ALW) was created and now has members from more than 50 organizations that have some level of interest and involvement in assisted living. The ALW includes advocates for seniors, representatives from provider organizations, direct care staff, regulators, health care professionals, advocates for individuals who have disabilities, representatives for state and local government, accrediting organizations, and representatives from governmental agencies. In an effort to be inclusive, the ALW continues to extend an invitation to any organization that has a sincere interest in assisted living and the need to ensure quality for the residents of assisted living.

The ALW created six topic groups that are to develop consensus recommendations in six broad areas, including:

- Resident Rights and Facility Ethics
- Medication Management
- Operations
- Resident Direct Care
- Staffing
- Affordability and Accessibility

Representatives from ALW member organizations may serve on as many topic groups as they would like. Each topic group meets at least monthly.

The work of the ALW has embodied a true sense of collaboration between consumers, providers and representatives from various health care disciplines. NCAL is pleased to be part of that process. The time that ALW members have spent together (four or five hours every month in the ALW meeting and additional time in topic group meetings) has given us the opportunity to discover that there are far more issues on which we agree than on which we disagree. The members of the Assisted Living Steering Committee that you have invited here today have additional opportunities to meet and discuss issues on a monthly basis. All these meetings have provided us all with an opportunity to focus on the most important individuals affected by the ALW's work – assisted living residents.

The working title of the final product that will be submitted by the ALW to the Committee next year is: *Assuring Quality in Assisted Living: Best Practices and Guidelines for Sate Regulations, Federal Policy, and Operations.* NCAL is confident that the final recommendations of the ALW will be of value to the assisted living profession, state regulators and, most importantly, to consumers, and we plan to work with our membership to see they are implemented. We also believe that by organizing the myriad ALW member organizations, we have the talent necessary to create a dynamic resident-centered framework that can serve as a model for other care settings in the future.

NCAL firmly believes that regulatory oversight of assisted living should remain at the state level, and that is where we believe many of the changes will be made. By developing guidelines for states, the intent is to ensure that those elements that are most critical to ensuring quality, as recommended by the ALW, are consistent from state to state. This consistency should not require that states take a single, standardized approach to assisted living, or that every facility within a state be required to look like and operate exactly the same way as the assisted living facility down the street. Each state should retain the flexibility to design an assisted living program that best meets the needs of the individuals in that state.

Often, it's difficult for those of us who live "inside the Beltway" to understand how "different" public policies can be good. There is a natural tendency to look for a federal fix to make sure a problem cannot, in theory, recur anywhere. Yet assisted living is a perfect example of how the millions of Americans beyond the Beltway rejected the long term care model built over the years by governments and embraced a model that was defined and built by seniors in the marketplace. This is not to say there are not areas where oversight and quality assurance for assisted living needs improvement. That is why this Committee so wisely urged the creation of the ALW. However, as we look to a future oversight structure for assisted living we must not lose sight that assisted living residents and their families are consumers who deserve the right and dignity to determine the services they want. The single greatest fear in the assisted living community is that it will be regulated into looking and behaving exactly like nursing homes. This would be a travesty and a disservice to America's seniors.

We are committed to working with state legislatures and regulators, through our state affiliates, to adopt the recommendations that are included in the final ALW document. We

understand that a partnership of providers, consumers, regulators and legislators will be essential as we strive toward the goal of ensuring quality in assisted living.

NCAL is committed to helping shape the long term care design of the 21st century and hopes that the work of the ALW will lead the way for building this system. We must be open to new ideas. We must be open to change. The design we develop must include a method for measuring and ensuring quality of life.

We also must accept that we all must partner to provide the care that the unprecedented number of baby boomers will need. The existing nursing home model for inspecting and regulating is antagonistic, punitive and demoralizes staff. Sadly, many states have simply duplicated that nursing home regulatory model when building monitoring systems for their assisted living facilities. This is a mistake.

The primary goal of a survey and enforcement oversight system for assisted living should not be to generate revenues for governments through fines. It should be to promote consistent quality service for assisted living residents. Systems that rely solely on a series of fines discourage facilities from seeking assistance and usually catch problems after they have occurred and someone's safety has been jeopardized or violated. Systems that utilize a consultant model are better designed to ensure consistent quality service delivery for assisted living residents by fostering communication between regulators and providers and encouraging the sharing of best practices.

NCAL supports programs that utilize state-employed consultants that assisted living providers and managers can call to help troubleshoot problems, answer questions about state requirements and share best practices. This type of assistance is invaluable to the provider community, and such programs have real potential to stop minor problems or misunderstandings from becoming serious problems or catastrophes. Washington state currently utilizes this model, and it should be replicated.

It's important to note that we believe these types of consultant programs are a supplement to – not a substitute for – a state's existing enforcement system. Such systems must remain for the operator who refuses to provide or is not able to provide appropriate care and services.

NCAL also believes continued research and testing of quality measurement systems and performance outcomes is needed as we develop the long term care model of the 21st Century. It is important to view these measures and outcomes from the perspective of the resident and not solely on what providers, consumer groups, academia or various health care interests think they want and need. Taking this approach will help create a reasonable and responsive model that can truly be what the consumer wants.

We look forward to continue working with the Senate Special Committee on Aging, committee staff and the Assisted Living Work Group.

As a national organization representing more than 240 of the nation's seniors housing owners and operators housing over 500,000 older Americans, we would like to commend Senators Breaux and Craig for creating the Assisted Living Workgroup (ALW) in August 2001, and for hosting this forum on assisted living quality. As this process continues, we would like to share the following critical points of support:

- We are, and will continue to be, strongly committed to the process and function of the ALW. The work of that group has embodied a true sense of collaboration between consumers and providers and we are pleased to be part of that process.

- Our members are committed to creating environments that allow people in need of assistance to maintain a high quality of life in a safe residential setting. We will continue to work with the ALW, the Aging Committee, and state regulators to explore any and all ideas that will help our members maximize high quality assisted living in a cost-effective manner for consumers.

- We strongly support state-based oversight of assisted living and believe the recommendations of the ALW will help the states to continue their efforts to ensure quality in assisted living residences without creating a "cookie cutter" approach that hinders innovation and creativity.

- Assisted living will continue to grow and evolve as an option for millions of American seniors in the 21st Century. We encourage those who oversee and regulate assisted living to reject excessive bureaucracy and continue to encourage practices that focus on improving outcomes and a quality of life that are consistent with the needs and desires of residents.

We look forward to our continued work with the Senate Special Committee on Aging and with the ALW in the coming months.

Bill Kaplan

William B. Kaplan
Chairman of the Board
Senior Lifestyle Corporation
Chicago, IL

David S. Schless

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President
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April 16, 2002

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Written Statement of the

Assisted Living Federation of America

for the

Senate Special Committee on Aging

Assisted Living Reexamined:
Developing Policy and Practices to
Ensure Quality of Care

Submitted for the Record

April 16, 2002

Written Statement of the
Assisted Living Federation of America
to the Senate Special Committee on Aging
Assisted Living Reexamined:
Developing Policy and Practices to Ensure Quality of Care
April 16, 2002

Chairman Breaux, Senator Craig, and members of the Committee, the Assisted Living Federation of America (ALFA), greatly appreciates your leadership and commitment to our nation's elderly. ALFA shares your commitment and commends the Committee and staff for proposing the formation of the Assisted Living Workgroup (ALW).

ALFA is the largest assisted living trade association in the United States representing more than 6,000 members. ALFA members, both large and small, for-profit and not-for-profit, specialize in assisted living or offer it in combination with other forms of senior housing and health care. Regardless of size, assisted living offers choices in personal care and health-related services in a safe residential setting to individuals who need some assistance with the activities of daily living, while preserving the individual's dignity and encouraging independence.

A key characteristic distinguishing assisted living from nursing homes is the emphasis on respecting a resident's right to make lifestyle choices and decisions about the care they receive in their assisted living home as they would in their own private home. Even residents with mild to moderate cognitive impairments can express life-long values and wishes regarding the care they are currently receiving or will need in the future.

Public policy, whether at the state or federal level, must preserve and respect an individual's right to make choices about where they live and the services they wish to receive.

Currently, all 50 states, the District of Columbia, and Puerto Rico have regulations providing for the licensure and oversight of assisted living. The pace of change in state assisted living regulations has been nothing short of extraordinary. Most of this regulatory activity has occurred in the last few years as states adapt to changing consumer expectations. ALFA's 45 state affiliates have been active partners with the states in a collaborative process to ensure that these regulatory changes lead to quality of care and quality of life for all assisted living residents.

The following principles summarize ALFA's mission and commitment to the Assisted Living Workgroup:

1. **ALFA is strongly committed to ensuring the highest level of quality care for assisted living residents and the consumer's right to full disclosure.** Since its founding in 1990, ALFA has been dedicated to championing quality of care and quality of life, and enhancing consumer choice for all residents in assisted living communities. Our members are united in a shared commitment to quality care, and full disclosure of all of the fees, services, and terms and conditions of residency. The first step in providing quality care is to give consumers clear and accurate information on which to make an informed choice about the long-term care services that will best meet their needs.

2. **ALFA is strongly committed to the work of the ALW and the continued collaboration between consumer advocates, providers, state policymakers and other stakeholders.** We believe that the recommendations of the ALW can help states continue the progress they are already making to ensure quality care without creating a "one size fits all" model that hinders flexibility, innovation and consumer choice. Assisted living has succeeded because of the diversity of models the states have created and allowed to flourish. Moreover, assisted living has been designed to fill gaps in a state's long-term care system that is unique and distinct to that state.

Consensus among all of the major ALW stakeholders can serve as a catalyst for their respective constituencies at the state level to use the final recommendations as a benchmark tool when working with policy makers to revise and update state assisted living regulations.

A measure of the success of the ALW's final recommendations will be the degree to which consistency is achieved while preserving the variety of choices of assisted living models that consumers have consistently said they want.

3. **ALFA is strongly committed to strengthening our partnership with the states to ensure proper and effective oversight of the quality of care delivered to residents in assisted living.** ALFA's state affiliates work closely with state policy makers to improve quality care in all assisted living residences. Much of the progress to improve state regulations is directly attributable to the collaborative efforts among providers, state policy makers and consumer groups to develop an assisted living model that is uniquely responsive to the needs of consumers in their states.

   ALFA does not believe that federal regulation of assisted living would ensure quality of care. In fact, we believe federal regulation would be highly counter-productive and jeopardize the flexibility of states to address regulatory issues quickly and in a way that is specific to the needs of their constituents.

   The growth of assisted living, as a new approach to long-term care requires that we look at new ways to assess quality by incorporating the perspective of the consumer.

   Which leads to our fourth point.

4. **ALFA is strongly committed to developing new approaches for measuring and improving quality in assisted living by focusing on outcome measurements that directly affect the resident's quality of life.** Consumer-centered care is what has made assisted living a successful alternative to nursing homes. Just as there are a

wide variety of assisted living models to fit the diverse needs of many residents, we must think "outside the box" and consider new models of measuring quality from the consumer's perspective. These new models of quality measurement should strike an appropriate balance between public accountability for health and safety with respect for consumer choice, autonomy, dignity and independence.

Empirical evidence for making consumer and family empowerment the cornerstone of a quality assurance strategy has been documented in a study of Medicaid-funded consumer-directed care programs in home and community-based long-term care.[1] The challenge is to find ways to appropriately apply these consumer empowerment strategies to the survey and oversight process currently in place for assisted living.

Several states are pioneering new models of quality improvement using consultants who encourage providers to formulate innovative solutions, using their own staff and physical resources. The quality improvement consultative approach focuses on systems improvement, provider education and collaboration designed to improve outcomes for assisted living residents. The state of Washington has recently implemented a quality improvement consultation program for assisted living that could serve as a model for other states.

ALFA remains committed to the ALW process and the shared goal of developing recommendations that ensure quality of care while preserving consumer choice, dignity and independence. We are committed to preserving state oversight of assisted living, and will continue our ongoing partnership with state policy makers to ensure the development of regulations that improve quality care. And finally, ALFA is committed to helping develop new approaches for measuring and improving quality in assisted living by focusing more on resident outcome-based measurements.

Thank you for the opportunity to present a written statement for the record on the progress of the Assisted Living Workgroup and the importance of providing quality care to our nation's elderly. We would be pleased to provide additional information or answer any questions.

[1] Doty, Kasper, and Litvak, *Consumer-Directed Models of Personal Care: Lessons from Medicaid*, The Milbank Quarterly, Vol.74, Number 3, 1996

A national organization of long term care physicians committed tp quality care

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Rolla, Missouri

Executive Director
Lorraine Tarnove

April 16, 2002

Patricia Hameister
Chief Clerk
Senate Special Committee on Aging
SDG-31
Dirksen Senate Office Building
Washington, DC 20510

Dear Ms. Hameister:

I am writing on behalf of the American Medical Directors Association (AMDA) to thank you for the opportunity to submit comments in reference to the Senate Special Committee on Aging's April 16, 2002, update meeting on the goals, process, and activities of the Assisted Living Work Group. AMDA members are grateful to the Senate Special Committee on Aging for its efforts to improve the quality of care provided to residents in assisted living facilities (ALFs) across the country. The quality of medical care available to the aging population is of the utmost importance to AMDA members.

AMDA is an 8,800-physician member national professional association committed to continuous improvement of quality patient care by providing education, advocacy, information and professional development for medical directors, attending physicians, and other professionals in the long term care continuum.

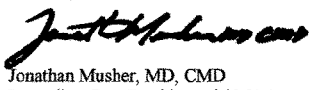
As a member of the Assisted Living Work Group, we applaud the significant progress of the work group and would like to take this opportunity to express our concern with current practices in many ALFs. AMDA members are concerned that many residents of ALFs are frequently cognitively impaired and have multiple medical illnesses requiring careful physician care. Since many AMDA members provide care to residents in ALFs, they are concerned that current practices, such as accepting patients with medical conditions and profiles they cannot handle, may jeopardize their health and well-being.

To that end, the AMDA House of Delegates, which represents 43 states, overwhelmingly passed a resolution that conveys our desire to have a common national definition for assisted living and stresses the importance of physician involvement in maintaining the highest quality of care to ALF residents. We hope

to implement this resolution, which is enclosed for your information, in conjunction with other groups through participation in the Assisted Living Work Group.

We encourage you to continue your support of the Assisted Living Work Group and to listen to professionals who provide direct care to the aging population. If we can be of further assistance to you, please feel free to contact Meg LaPorte, Government and Public Affairs Specialist, or Kathleen Wilson, Director of Government Affairs. They can be reached at (410) 740-9743. To learn more about AMDA, I encourage you to visit our web site at www.amda.com.

Sincerely,



Jonathan Musher, MD, CMD
Immediate Past President of AMDA
Liaison from AMDA Work Group on Assisted Living

AMERICAN MEDICAL DIRECTORS ASSOCIATION
HOUSE OF DELEGATES
SUBSTITUTE RESOLUTION FOR I02 AND J02

SUBJECT:	**POSITION STATEMENT ON ASSISTED LIVING**
INTRODUCED BY:	**AMDA WORK GROUP ON ASSISTED LIVING**
INTRODUCED IN:	**MARCH 2002**

AMDA feels that there must be a common national definition for assisted living, and

BE IT FURTHER RESOLVED, that AMDA strongly recommends development of systems in ALFs that recognize the importance of physician involvement in maintaining the highest quality of care of ALF residents.

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