

Assisted Living Quality Initiative

Building a Structure that Promotes Quality

A Document of

The Assisted Living Quality Coalition:

Alzheimer's Association
American Association of Homes and Services for the Aging
American Association of Retired Persons
American Health Care Association/National Center for Assisted Living
American Seniors Housing Association
Assisted Living Federation of America

August 1998

ASSISTED LIVING QUALITY COALITION

Memorandum of Understanding

The Assisted Living Quality Coalition (ALQC), consisting of the Alzheimer's Association, the American Association of Homes and Services for the Aging (AAHSA), the American Association of Retired Persons (AARP), the American Health Care Association (AHCA), the American Seniors Housing Association (ASHA) and the Assisted Living Federation of America (ALFA), believes that:

- to provide the highest level of quality and consumer satisfaction in assisted living, the assisted living industry must have a consumer-oriented, performance-based system for quality improvement;
- the most effective quality initiative for assisted living will be developed collaboratively between consumers and providers, with input from other assisted living stakeholders.

Sharing these beliefs, the ALQC member associations have worked since January 1996 to develop a collaborative quality initiative for assisted living. To date, the ALQC has produced an overall framework for the initiative, including guidelines to states on setting minimum standards for providers of assisted living. The framework and guidelines to states on setting minimum standards, as articulated in the ALQC's final report *Assisted Living Quality Initiative: Building a Structure that Promotes Quality*, are the product of the ALQC's research, brainstorming, numerous input forums from all interested parties, and most importantly, compromise.

In releasing this final report, all members of the ALQC confirm that they:

- support the framework and guidelines to states on setting minimum standards as agreed to in the ALQC's final report, *Assisted Living Quality Initiative: Building a Structure Promotes Quality*, dated August, 1998;
- understand the enormous complexity and diversity in assisted living programs from state to state but will work together to see that the elements of this quality initiative are implemented to the greatest degree possible in as many states as possible;
- understand that the framework and guidelines to states on setting minimum standards offer guidance to state legislators and administrative agencies for implementing their own quality initiatives but are not intended as "standards of care" for use in legal proceedings;
- understand that the framework and guidelines to states on setting minimum standards will evolve over time to reflect progressive and innovative state programs and experiences, additional research, new caregiving techniques, particularly for special populations such as dementia, and the development of new ways to measure and promote quality outcomes in assisted living;

- will work together to research the feasibility of a National Assisted Living Quality Organization to house the ongoing work of revising the framework and the guidelines to states on setting standards as well as validating new tools for measuring and promoting quality outcomes in assisted living; and
- understand that any member of the ALQC may disengage from the ALQC if the framework or guidelines are implemented in a manner that they cannot support.

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Assisted Living Quality Initiative

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Summary of Recommendations

#1 The members of the Assisted Living Quality Coalition, along with other partners, should study and, if feasible, establish an independent National Assisted Living Quality Organization with sufficient staff to develop the information sources and manage the quality improvement system we are proposing to implement.

#2 Among the first tasks undertaken by a National Assisted Living Quality Organization should be the development and validation of performance measures in areas such as consumer satisfaction, clinical, and functional performance outcomes.

#3 Based on the guidelines developed by the Assisted Living Quality Coalition (see Appendix B), the National Assisted Living Quality Organization should establish, regularly review and update as necessary, guidelines for minimum standards for the assisted living industry. These guidelines should improve the ways in which standards are established through:

- a. The process by which the guidelines are established – Guidelines issued by the NALQO should be established by a consensus approach involving all interested parties.
- b. The substantive emphasis of the guidelines – The focus of the NALQO guidelines should be enhancing consumer autonomy and promoting industry innovation in the delivery of quality services.
- c. The rigor with which the guidelines are tested and updated – NALQO guidelines should be routinely tested against practical experience and outcomes data generated from quality indicators to assure that they are the best predictors of quality outcomes.

#4 The NALQO should develop model practice protocols and intervention strategies for commonly experienced problem areas.

- #5** Each assisted living setting should establish and effectively use its own internal quality improvement team to identify problem areas, develop action plans, and monitor the results of actions taken.
- #6** The NALQO should examine ways to recognize excellent performance.
- #7** The NALQO should promote consumer choice and a competitive assisted living market by ensuring that consumers and their advocates have access to appropriate setting-specific information necessary to do effective comparison shopping.
- #8** The experiences of consumers and their advocates should be tapped by each setting's internal quality improvement team.
- #9** States should enlist the input of consumers, their advocates, and other parties who have contact with assisted living settings as incidental monitors of performance.
- #10** States should enlist the input of ombudsmen and other community resources.
- #11** States should adopt any future guidelines established by the National Assisted Living Quality Organization as the basis for their minimum standards for regulating quality. In the interim, the Coalition encourages states to use the general guidelines in Appendix B in developing their regulations.
- #12** States should improve licensure review by focusing on both provider capacity and past performance. States should never use certificates of need, license moratoria, or any other means to artificially limit the supply of assisted living or other supportive housing settings.
- #13** State monitoring efforts should evolve in the following directions:
- a. Greater focus on performance outcomes.
 - b. Greater focus on quality improvement through consultation.

- c. Greater reliance on other actors who can demonstrate that they are better equipped to accomplish specific monitoring roles.
- d. Greater reliance on ongoing communication and less reliance on annual survey approaches.
- e. Greater targeting of monitoring efforts on settings that serve more disabled residents and settings that have histories of poor performance.
- f. Greater focus on specific areas of problematic performance.

#14 States should employ a consultative role when possible to correct problems but vigorously enforce standards when:

- a. the consultative approach has failed to achieve acceptable results within a reasonable time frame;
- b. the problems identified through monitoring are extensive, or result in actual harm or an immediate threat to health and safety;
- c. outcomes data are inaccurate due to fraudulent or negligent behavior by provider staff with respect to their data-gathering responsibilities.

#15 The NALQO should assist states with the task of implementing new quality improvement systems.

#16 In introducing assisted living coverage, third party payers, both public and private, should reward outcomes consistent with the philosophy of assisted living – especially those related to consumer satisfaction and quality of life. In particular, third party payers should reimburse services at a level that permits private rooms for all consumers who want them and assures adequate reimbursement for the services provided.

#17 The NALQO should provide a forum for discussing risk factors that affect financial underwriting of projects in order to assure that the philosophy of assisted living is not jeopardized.

#18 Nurse practice acts should be amended to allow delegation of nursing services with appropriate professional oversight within assisted living settings.

#19 Accessibility standards set under the Americans with Disabilities Act should be modified to give greater flexibility in dealing with different types of disabilities – especially those most common among the frail elderly.

#20 Guardianship laws should ensure that guardianship occurs only when the individual is unable to make decisions, and then only on a limited basis in order to maximize the independence and autonomy of the individual.

#21 Building codes should be reviewed to ensure that assisted living services can be provided in buildings with residential scale and characteristics while assuring life safety and encouraging affordability.

Executive Summary

Background

In early 1996, several organizations representing consumers and providers formed the Assisted Living Quality Coalition to address issues of quality improvement in assisted living as the industry rapidly expanded. Coalition members have been united by two common purposes:

Promote the highest possible quality of life for older persons and consumers with disabilities by advocating for the assisted living philosophy of independence, privacy, dignity and autonomy.

Lay a foundation for the continued growth of assisted living by fostering a quality improvement system that demands and rewards high quality outcomes.

During its deliberations, the Assisted Living Quality Coalition sought the counsel and advice of numerous individuals and organizations representing consumers, providers, state regulators, ombudsmen, third party payers, and investors. The Coalition also examined a variety of approaches to promoting quality, including traditional state regulation, accreditation, contracts, and quality indicators.

The Coalition borrowed freely from the best of these various approaches and attempted to address the inherent weaknesses of each as it attempted to construct a solid system for promoting quality and balancing the interests of various parties. The report that follows includes two major sections: 1) the first section is a quality initiative outlining how the roles and responsibilities of the various interested parties would change under a system emphasizing quality outcomes; and 2) the second section includes guidelines to states on minimum standards. Perhaps the best way to understand the quality initiative is to summarize the roles that each of the interested parties would play.

National Assisted Living Quality Organization

Providers

The Coalition believes that the best way to enhance the quality of life experienced by consumers is to support and build upon the provider's own efforts. Imposing quality from outside the setting has its limits if a provider lacks the commitment or the organizational capacity to promote quality from within. The success of the Coalition's proposed quality improvement system hinges on the assumption that providers will create organizational structures, including quality improvement teams, that regularly monitor quality and take actions to promote quality outcomes.

Such quality improvement teams should draw broadly from staff at all levels, residents, family members, local service providers and state consulting agents, and should take advantage of the tools approved by the NALQO to measure and improve quality. On the basis of this information, the quality improvement teams should review practices and take appropriate action to improve performance.

Consumers

Consumers can improve quality by becoming informed and selecting providers known for high quality. To do this, consumers and their advocates must receive more comparative information about quality to enhance their decision-making capacity. The inclusion of residents and their advocates on the setting's internal quality team is essential to the team's capacity to focus on quality as the residents experience it.

Providers and states should develop better means to enlist the input of consumers, their advocates and other parties who have contact with assisted living settings as incidental monitors of performance. Ombudsmen, in their role as independent consumer watchdog, are an additional valuable source of input to providers, consumers and their advocates, and state monitors.

States

The Coalition's quality improvement approach calls for a reinvention of the state role in licensing, establishing minimum standards, monitoring and enforcement.

- **Licensing** – Many quality problems in assisted living settings could be averted if states would effectively use licensing standards to predict performance and weed out poor performers. State licensure review should consist of two parts: a capacity review and a performance review.
- **Establishing minimum standards** – The Coalition encourages states to use the general guidelines developed by the Coalition in developing their regulations. NALQO will provide further refining and updating for states to adopt in the future.
- **Monitoring performance** – By using performance measures, such as quality indicators developed by the NALQO, state monitoring efforts can focus more on outcomes and continuous feedback. Such an approach is intended to allow for a more consultative approach to routine monitoring, more delegation of monitoring roles to other actors, and a significantly diminished role for formal on-site surveys for settings that have solid performance histories. Such an approach should also allow states to target monitoring efforts on settings that serve residents with greater service needs or have poor performance records, as well as on specific areas of problematic performance within settings.
- **Enforcement** – States should vigorously enforce standards when: a) the consultative approach has failed to achieve acceptable results within a reasonable time frame; b) the problems identified through monitoring are extensive or result in actual harm or an immediate threat to health and safety; or c) outcomes data are inaccurate due to fraudulent or negligent behavior by provider staff with respect to their data-gathering responsibilities.

Third Party Payers

In introducing assisted living coverage, third party payers, both public and private, should reward outcomes consistent with the philosophy of assisted living – especially those related to

consumer satisfaction and quality of life. In particular, third party payers should reimburse services at a level that permits private rooms for all consumers who want them and assures adequate reimbursement for the services provided.

Investment and Financial Communities

Efforts by the Coalition and the NALQO to establish a clearer product definition and develop performance measurements should help underwriters for investors and financiers to evaluate current risk and potential rewards in the assisted living industry. The NALQO may also provide a useful forum for discussing and researching important investment and financing issues such as the consequences of separating the financing of housing and services and the development of underwriting criteria.

Conclusion: Phasing in a System of Quality Improvement

Not all of the Assisted Living Quality Coalition's recommendations are likely to be implemented immediately. Fully implementing the quality improvement system will require a sustained commitment by all interested parties over several years. The quality indicators, practice protocols and intervention strategies have yet to be developed and validated. Effective consultation and intervention strategies will require some experimentation. While continuing to assure quality during the transition, states should begin to phase in these aspects of the quality improvement system as they prove effective. For its part, the Coalition will examine the feasibility of a National Assisted Living Quality Organization, its potential tasks, and its potential impact upon all stakeholders.

I. Introduction: Assisted Living Quality Issues

The Assisted Living Quality Coalition

In early 1996, an informal group representing consumers and providers decided to establish a Coalition that would address issues of quality improvement in the assisted living industry. The Coalition includes representatives of the:

- Alzheimer's Association;
- American Association of Homes and Services for the Aging (AAHSA);
- American Association of Retired Persons (AARP);
- American Health Care Association (AHCA)/National Center for Assisted Living (NCAL);
- American Seniors Housing Association (ASHA); and
- Assisted Living Federation of America (ALFA).

Coalition members are united by two common purposes:

Promote the highest possible quality of life for older persons and consumers with disabilities by advocating for the assisted living philosophy of independence, privacy, dignity and autonomy.

Lay a foundation for the continued growth of assisted living by fostering a quality improvement system that demands and rewards high quality outcomes.

Growth and Change in Assisted Living

The assisted living industry is currently experiencing a period of phenomenal growth. This growth has been compared to the earlier, equally phenomenal expansion of the nursing home industry in the 1960s and 70s. While the growth patterns in these two industries may be similar, the underlying causes of that growth are very different. The expansion of assisted living is part of a much larger revolution in the delivery and financing of health and long-term care services. This revolution is driven by five main trends:

1. Greater consumer demand for alternatives to institutional care.
2. Changes in service delivery practices.
3. Civil rights changes that recognize the right of persons with disabilities to choose from a wider range of living settings.
4. Changes in the ways health and long-term care are financed.
5. Public policy changes.

1. Consumer demand

To a large degree, the introduction of federal Medicaid reimbursements in 1965 stimulated the tremendous growth of the nursing home industry. Assisted living, on the other hand, has had little federal monetary support. Instead, its phenomenal growth reflects the substantial unmet demand for housing and services among older persons and consumers with disabilities. These consumers and their families have a greater capacity to pay for services than earlier generations and are demanding a higher quality of life when faced with the functional disabilities of old age. They want housing that enhances independence and dignity and provides quality services.

2. Changing service delivery practices

Recent changes in industry practices -- many of them driven by technological innovation -- now enable services to be delivered in a wider range of settings. For example, new drugs have made many invasive and expensive medical treatments less necessary. A wider variety of professionals and paraprofessionals -- including home health nurses, home care aides, inhalation therapists and physical therapists -- now routinely provide medical and supportive services that previously were provided only by doctors or other institutionally-based professionals.

3. Civil rights developments

Changes in civil rights laws, pursued by disability advocates, have also had a major impact on the delivery of health and long-term care services. Beginning with the Rehabilitation Act of 1973, which forbade discrimination in federally supported services based on disabilities, the disability rights community has had considerable success in adding protections through the Fair Housing Amendments Act of 1988 and the Americans with Disabilities Act of 1991. These acts give civil rights backing to the demand that supportive services be provided to persons with disabilities of any age in living arrangements that they choose.

4. Changing market conditions

Dramatic changes in market dynamics require that industries related to health and long-term care service delivery become more diversified, specialized, competitive and innovative. These trends are most pronounced in acute care delivery, where managed care plans require that providers show price and quality advantages when they contract for services. Managed care plans strongly encourage providers to control costs through innovative technologies and practice protocols that shorten hospital stays and expand the variety of service settings. As managed care insurers become more involved in long-term chronic care, they will apply the same pressures to assisted living providers.

5. Public Policy Changes

The market, technological and legal changes that gave birth to assisted living have presented new challenges to federal and state policy makers. Policy making at both levels of government is driven by the desire to control rapidly escalating health and long-term care costs. Much of the cost cutting has created problems for consumers and providers alike. However, the need to contain costs has also made policy makers more receptive to innovative financing and service delivery approaches. For example, Medicaid and Medicare have done some experimental demonstrations to reimburse integrated services and are likely to move in this direction on a much larger scale. States, which bear much of the Medicaid cost-burden, are experimenting with a variety of reimbursement and delivery systems to encourage more efficient service delivery. Specifically, many states are experimenting with limited Medicaid reimbursements through

waivers to assisted living in order to provide access to assisted living services for frail older persons with low incomes.

New Thinking About Quality

The members of the Assisted Living Quality Coalition believe that all interested parties must act now to develop an innovative quality initiative for assisted living. Such an initiative will prepare assisted living providers to meet the challenges and take advantage of the opportunities to change the way that quality is promoted as the assisted living industry continues to evolve and grow.

New opportunities and challenges require new thinking. Coalition members believe that a competitive and innovative service-delivery marketplace is not compatible with regulations that stifle innovation or restrict competition. The new model for promoting quality should be consumer-centered, performance-oriented and responsive to quality of life issues. It must also enhance consumer choice and protect quality of life for vulnerable consumers whose choices may be limited due to their cognitive incapacity or lack of financial resources.

This document, which concludes the first step in the Coalition's efforts, represents the group's best thinking to date. The Coalition is grateful to the hundreds of reviewers who offered thoughtful comments and criticisms of this document. The members of the Coalition do not believe they have resolved all the issues, but they do believe that their efforts reflect sufficient agreement to be useful to states and other interested parties. In addition, this document will serve as a foundation for further collaborative efforts as the Coalition moves to carry out its ambitious recommendations.

This document outlines a series of recommendations to be carried out as part of a quality assurance framework for assisted living. The Coalition intends to conduct a feasibility study of the entire framework. The feasibility study will determine the program and financial viability of the many recommendations contained within this document.

The Coalition continues to seek responses from all who have a stake in the future of assisted living to the issues raised in this document. This document is a possible blueprint for the future of quality improvement for assisted living, but it is a blueprint with many of the details remaining to be filled in.

II. Balancing Approaches to Quality

During its deliberations, the Assisted Living Quality Coalition sought the counsel and advice of numerous individuals and organizations including: consumers, providers, state regulators, ombudsmen, third party payers and investors. Different constituencies defined quality in different ways and suggested differing ways of measuring and promoting quality.

The Coalition examined a variety of approaches to promoting quality. These approaches and their benefits and drawbacks, are described below. To some extent, the different approaches reflect the different and somewhat competing interests of parties involved in assisted living and related industries. The Coalition sought to understand the strengths and weaknesses of each approach so that it could construct the best system for improving quality and balance the legitimate interests of the various parties concerned.

Traditional State Regulation

The Assisted Living Quality Coalition recognizes four essential roles for state regulation in a quality improvement system:

1. Define the assisted living market by creating minimum standards.
2. Establish licensure requirements for admission to the market.
3. Protect public welfare and safety by assuring that compliance with minimum standards is monitored.
4. Enforce standards and impose penalties, when necessary, on providers whose performance is inadequate.

State regulation is indispensable. State regulatory systems are best equipped to oversee this process because states have unique legal authority in the areas of licensure and enforcement.

However, critics complain that many regulatory structures do not assure or promote quality in assisted living. Specifically, say critics, regulatory systems that rely too heavily on easily observable structural and process requirements tend to:

- focus on punitive actions rather than quality outcomes;
- be very expensive; and
- lag far behind the market in promoting innovative new ways of delivering services and addressing consumer demands for more autonomy and independence.

Accreditation

Because of these perceived state regulatory shortcomings, some providers have expressed interest in establishing a private accreditation process administered by a national quality organization. Standards established and continuously reviewed by a body representing all interested parties would:

- enjoy broad credibility;
- be seen as reflecting current service delivery trends; and
- help bring some national standardization to assisted living without federal regulation.

Attempts to accredit segments of the long-term care industry have typically reached only a small minority of settings and have limited effect on the quality of services in the vast majority of cases. Critics complain that accreditation can be:

- too process oriented. Self-imposed accreditation standards can be just as stringent or inflexible as regulatory requirements.
- burdensome and expensive. Without regulatory relief or widespread consumer awareness, accreditation's rewards often are not apparent to providers.
- inadequate, by itself, to enforce quality. Consumer advocates are critical when accreditation replaces the state's essential roles, especially the enforcement of state minimum standards.
- partial to providers. Advocates complain when providers are allowed to arrange accreditation surveys in advance or select and pay the accrediting agency that carries out inspections.
- too private. The information gathered in the accreditation process is proprietary and therefore not generally disclosed to consumers, regulators, or other interested parties. This lack of disclosure limits accreditation's usefulness to parties who make critical decisions about assisted living providers.

Contracts

Rather than using regulations to prescribe the types and levels of assisted living services, a contract approach would make those areas subject to negotiations between providers and consumers. Such an approach has the virtues of being:

- very flexible;

- immediately responsive to consumer demands; and
- adaptive to the local service availability.

Critics complain that two inherent features of the contracting process make it less workable for assisted living consumers, who may be frail or have disabilities.

- Power imbalances. The inherent inequality between providers and consumers can make it especially difficult for consumers with disabilities to negotiate as equal partners. Critics worry that family members also would be at a disadvantage if they negotiate under stressful conditions or have limited information about their options or rights.
- Enforcement difficulties. The contractual approach moves enforcement from regulators to the courts. Critics worry that frail older persons are unlikely to go through the physical and emotional ordeal of going to court to enforce their contracts. Family members are often making decisions on the older person's behalf, under stressful conditions, and with limited information on their options or rights. Because of the circumstances often surrounding the decision to leave one's home to enter a setting that provides supportive services, many advocates have argued for protections making potentially unscrupulous practices illegal and unenforceable.

Quality Indicators

Quality indicators measure actual outcomes of the clinical/medical, functional, and consumer satisfaction/quality of life activities in a long-term care setting. Providers who participate in this approach continually enter performance data into a large database. When these performance data are pooled, providers can compare their own facility's performance against national or local industry norms.

Government and health care industry groups are investing heavily in outcomes research. They see outcome measures as a way to encourage providers to continually improve performance compared with industry norms. This approach allows the regulatory system to rely less on pass/fail compliance with minimum standards when providers display acceptable levels of performance outcomes. Although quality indicators have only been recently developed for use in long-term care settings, early use indicates great promise for assessing service delivery in such settings.

Quality indicators can give assisted living settings a way to demonstrate to managed care insurers their price and quality advantages, especially in consumer satisfaction and quality of life. These data will help assisted living settings as they prepare to become involved in integrated health and long-term care systems.

Quality indicators have a value beyond managed care. They can:

- provide feedback on performance to a facility's internal quality-improvement team;
- provide objective comparative performance data to help consumers and their advocates choose between assisted living settings; and
- give state monitoring agencies the information they need to focus on actual performance outcomes rather than just compliance with minimum standards.

After considerable discussion, the Coalition decided to incorporate the use of quality indicators as a critical part of its quality assessment approach. However, because quality indicators are relatively new, many issues must be resolved before a full system of quality outcomes measurement can be instituted. The Coalition urges a sustained research effort on ways to effectively:

- develop and validate quality indicators, including clinical, functional and quality of life measures;
- adjust quality measurements to account for differences among settings and residents;
- measure quality of life outcomes, including autonomy, independence, and dignity;
- develop indicators that are thorough enough to instill confidence but not too cumbersome or expensive to administer;
- finance the costs of implementation, including staff training;
- monitor data collection to ensure its reliability; and
- release setting-specific data in a way that is most useful to consumers and other interested parties.

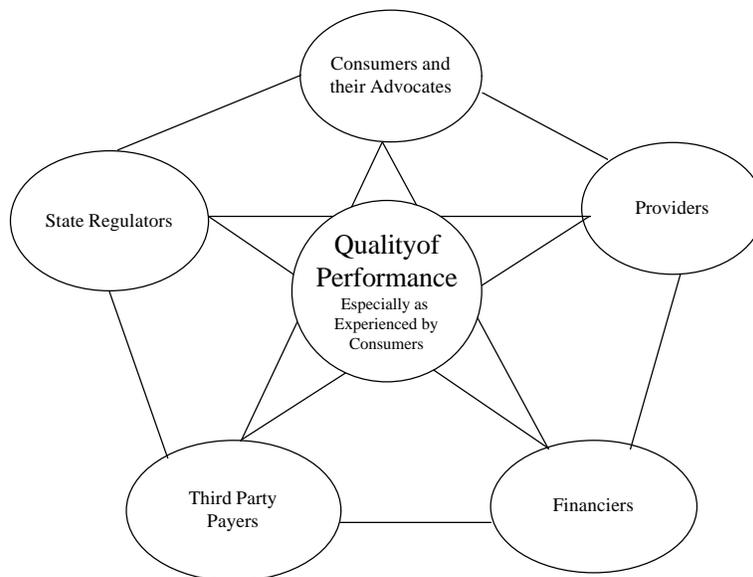
Some of these issues are discussed in more detail beginning on page 24.

III. Systematic Approach to Quality

Principles of Quality

The Coalition did not base its new approach to quality promotion on any one approach. Rather, the Coalition borrowed freely from the best of the various approaches and attempted to address the inherent weaknesses of each. Its goal was to create a new way of looking at quality that focuses on the key participants in the assisted living industry and the relationships that are responsible for producing quality outcomes. The following schematic drawing portrays these actors and relationships in a “Quality Star”:

Figure I. The Quality Star



The "Quality Star" calls attention to four guiding principles that serve as the foundation of the Coalition's innovative new approach to quality improvement:

1. **Quality Performance.** The primary focus of any quality improvement effort should be that of providing a residential setting and services that enhance the independence, autonomy and dignity of the consumers being served.

- 2. Internal Efforts.** The best way to enhance the quality of life experienced by consumers is to support and build on the provider's internal quality efforts. Imposing quality from outside the setting has its limits if a provider lacks the commitment or the organization to promote quality from within.

- 3. Outside Interests.** State regulators, consumer representatives, third party payers and financiers all have legitimate interests and critical roles to play in quality promotion. Quality can be promoted successfully if each actor has clearly defined roles and the information needed to play those roles effectively.

- 4. Dynamic Process.** Achieving quality is a dynamic process whose key component is the flow of information among the relevant actors. Consumers are most likely to experience quality when each actor in the quality improvement system receives full and accurate information on quality outcomes. This information must be tailored to meet each actor's needs and communicate relevant information to all participants.

The "Quality Star" seems deceptively simple. The Coalition realizes that developing its quality improvement system will require vastly improved information systems and a change in the relationships among the key actors. The following sections explore these issues in more depth.

Managing a Quality Improvement System

Recommendation #1

The members of the Assisted Living Quality Coalition, along with other partners, should study and if feasible, establish an independent National Assisted Living Quality Organization with sufficient staff to develop the information sources and manage the quality improvement system we are proposing to implement.

The Assisted Living Quality Coalition discussed at considerable length the essential roles played by all of the actors portrayed in the Quality Star: consumers and their advocates, providers, states, third party payers and financiers. During these discussions, the Coalition sought to create a complete quality framework that would include the interests of each of these actors and the tools that each might use to optimize their respective roles. The goal was to make each actor part of an integrated, mutually reinforcing system of quality improvement.

The National Assisted Living Quality Organization

To achieve this ambitious goal, the Coalition proposes the establishment of the National Assisted Living Quality Organization (NALQO) to promote quality and innovation in the assisted living industry. *As a prelude to the establishment of the NALQO, the Coalition will initiate a study to explore the financial and practical feasibility of the various functions outlined in this paper for the new organization. The recommendations that follow are therefore contingent on the findings of this study and on subsequent decisions made by the Coalition to establish such an organization.* The central roles of this new organization would include:

- providing a forum for research;
- developing recommendations for policy development; and
- acting as a consultant on quality improvement issues.

The NALQO would be modeled on the organizational experiences of similar national bodies in related fields. It would be structured so that it could operate effectively and maintain its independence from any individual interests. That structure would feature:

- 1. Broad representation.** The NALQO would have a board of directors that represented consumer organizations, providers, states, third party payers, financiers and other interested parties. This representation should ensure that no single interest could dominate.
- 2. Professional staff.** The NALQO's professional staff would fully research and analyze pertinent issues, provide options for the board's consideration and carry out the board's decisions.
- 3. Independent financing.** Developing an independent means of financing early on would establish the NALQO's credibility.

The NALQO would continue and extend the work initiated by the Coalition. It would work with various parties -- beyond those involved in the development of this document -- who can promote the goal of a truly innovative, outcomes-oriented, consumer-driven assisted living industry. Specifically, the NALQO would develop and update three foundational information sources that would help redefine the relationships among the actors involved in the assisted living industry. These include:

- **instruments designed and used to measure performance** in such areas as consumer satisfaction, clinical, and functional outcomes;
- **guidelines to states for minimum standards** that define structural and process practices for the industry; and
- **practice protocols and intervention strategies** that would be useful to facilities and state regulators developing action plans to correct problems as they arise.

Instruments Designed to Measure Performance Outcomes

Recommendation #2

Among the first tasks undertaken by a National Assisted Living Quality Organization should be the development and validation of performance measures in areas such as consumer satisfaction, clinical, and functional performance outcomes.

If achieving quality outcomes is the goal, then providers must be given the tools to assess, compare and improve their performance. Other industry participants must also have these information tools so that each can assess a provider's performance.

The Coalition has drawn heavily from the promising work on quality outcomes measures in the health care industry. More recently, several industry groups have sought to develop and validate similar measures for nursing homes. Research and experimentation on quality outcomes measures for the assisted living industry are just being developed. The Coalition believes that NALQO could hasten the necessary development and validation of these instruments.

Before quality indicators can be useful to the assisted living industry and states, the NALQO has several tasks to complete, including:

1. Develop Quality Indicators

To enjoy credibility as a monitoring instrument, quality indicators must be developed, validated and updated by a credible, independent body. These quality indicators should include those that measure consumer satisfaction, quality of life, and clinical and functional outcomes. The Coalition recognizes that some measures may be available quickly while others will take much longer to develop and validate. Some measures may be adapted from those used in related industries, while others will reflect the unique philosophy of the assisted living industry. As a first step, the Coalition urges the development and validation of the minimum set of quality indicators that can measure performance and flag potential problem areas.

2. Adjust Data for Risk Factors

The NALQO must focus its attention on risk-adjusting the raw data it receives from providers to account for differences in participating settings and their resident populations. Risk-adjusting data will be a particularly difficult area of performance measurement. However, these adjustments will help the NALQO establish a basis for comparisons among settings and even within a facility over time as its resident population changes. The adjustments will allow outcome measures to recognize that some outcomes are more important than others and that residents with different levels or types of disabilities are likely to have different outcomes than others.

3. Conduct research

Research must be a high priority for the data-intensive system of quality monitoring. Validating quality indicators, developing appropriate risk adjustments, and investigating the best predictors of quality outcomes are sure to present difficult research issues. The NALQO should rely on established organizations to conduct this research, rather than creating such research capacity within the new organization. However, staff expertise on research issues will still be essential to the NALQO's success.

Participating providers and/or states could contribute a fee to finance ongoing research over the long-term, as the quality monitoring system becomes self-sustaining. However, short-term start-up costs are likely to require substantial, up-front money from other sources. The funding sources should be independent and balanced enough to make the research and development process broadly credible. The Coalition will examine the feasibility of a National Assisted Living Quality Organization, its potential tasks and its potential impact on all stakeholders.

4. Process Data

The quality indicator monitoring system will require an organization to receive the raw data, adjust them for identified risk factors, and develop normative guidelines to interpret the results. The NALQO could develop this capacity in-house with adequate resources and staffing, or it could hire an academic or other research body, or states may choose to do it themselves.

5. Release Setting Specific Data

Having a competitive market is an important factor in promoting quality outcomes, and one of the critical factors in achieving a competitive market is adequate consumer information. Any system based on promoting innovation, choice and quality will have to make a major effort to provide potential consumers the information they need in a form they can use to make the right decisions for them. An essential function of the NALQO will be ensuring that consumers, providers, third party payers, state regulators and financiers are able to use collected performance information to assist them in their respective decision-making and/or quality monitoring activities. The organization will have to make further decisions about the appropriate content, frequency and recipients of different types of information, depending on the needs of the interested parties.

Guidelines to States for Minimum Standards

Recommendation #3

Based on the guidelines developed by the Assisted Living Quality Coalition (see Appendix B), the National Assisted Living Quality Organization should establish, regularly review and update as necessary, guidelines for minimum standards for the assisted living industry. These guidelines should improve the ways in which standards are established by:

- a. **The process by which the guidelines are established** – Guidelines issued by the NALQO should be established by a consensus approach involving all interested parties.
- b. **The substantive emphasis** – The focus of the NALQO guidelines should be enhancing consumer autonomy and promoting industry innovation in the delivery of quality services.

- a. **The rigor with which the guidelines are tested and updated – NALQO guidelines should be routinely tested against practical experience and outcomes data generated from quality indicators to assure that they are the best predictors of quality outcomes.**

The federal government has expressed little interest in regulating assisted living and providers have expressed little enthusiasm for an enhanced federal role. As an alternative, the Coalition set out to develop a set of guidelines that states might use to establish minimum standards for providers of assisted living. The Coalition's attempt to negotiate guidelines for minimum assisted living standards took considerable time and generated considerable controversy. However, the Coalition continues to believe that addressing the need for generally accepted minimum standards is absolutely critical at this juncture in the industry's development.

Minimum standards are an essential element of any major human services industry. They:

- define the service being offered, and the practice processes and structural capacities necessary to operate in a given industry;
- establish minimally acceptable practice guidelines; and
- provide the basis for corrective action when problems arise.

At their best, minimum standards are closely linked to -- and should serve as predictors of -- desired outcomes. Minimum standards should be scrutinized and revised regularly based on empirical data and experience. This way, one can confidently predict that following the prescribed processes and structural requirements outlined in the standards will lead to successful outcomes.

The Coalition is particularly concerned with the lack of product definition that results from the absence of assisted living standards. Most assisted living providers must comply with

ill-suited requirements designed for other forms of residential care. Only half the states have regulations that specifically define assisted living. Even states that have assisted living regulations range widely in the types of settings and services included within that definition.

The lack of generally accepted standards has created great market confusion. In some states, any facility can call itself assisted living, whether it is a small boarding home with few services or a very service-enriched facility that seeks to compete with skilled nursing care. Consumers and third party payers have no assurance that the term “assisted living” refers to a specific type or level of service. Similarly, financiers interested in assisted living investments have no accepted standards by which to judge their risks.

The Coalition participants spent a considerable amount of time discussing the level at which these guidelines should aim. We are aware that if states set minimum standards too high, they could add unnecessary costs and diminish the ability to serve consumers with modest means. On the other hand, we are also aware that setting minimum standards too low could undermine quality and fail to realize the distinctive philosophy of assisted living. Accordingly, the Coalition sought to develop guidelines that are sensitive to potential costs while supporting the important goals of the assisted living philosophy.

The Coalition also debated whether we should set general principles for quality in assisted living or work on developing a more detailed package. We have opted to present a comprehensive and rather detailed package so that we could give clear illustrations and solicit detailed, concrete feedback on the direction in which the assisted living industry should go. We hope however, that the feedback we receive extends beyond the details of the guidelines to address the ways in which the guidelines relate to the overall quality initiative and the processes by which guidelines could be established and updated as models for innovative state assisted living quality programs.

Unfortunately, the Coalition was unable to achieve agreement on all issues in the guidelines. Coalition members could not agree on:

- how consumers would pursue judicial enforcement of state minimum standards that they believe have been violated and
- whether or not to require private rooms in assisted living. The private room issue is discussed in detail in Appendix C.

Generally, the Coalition's guidelines are based on three principles shared by its members: the need for consensus, the value of consumer choice and industry innovation, and the need to continually test guidelines.

Consensus Approach

The Coalition set out to develop its guidelines in the belief that state minimum standards will be better suited to assisted living if they reflect input from the consumers, providers, and other parties most directly affected. We also believe that state minimum standards will improve if they are based on guidelines developed in conjunction with the development of an outcomes-oriented quality initiative encompassing new approaches to monitoring and quality improvement. Our goal is to establish an ongoing process to establish and update guidelines that can confidently be used by states as the basis of outcomes-oriented performance standards.

To address changes and innovations in this rapidly evolving industry will require a process of regular review and updating. The NALQO would be best suited to this task for three reasons:

- 1. National scope.** As a national organization, the NALQO could provide a measure of standardization in industry regulation without federal regulations.
- 2. Widely accepted guidelines.** Adopting NALQO's widely accepted guidelines (or portions of the guidelines) could help states greatly speed up the processes of developing and approving new standards. States rarely have the staffing and resources to thoroughly review industry developments on a regular basis and to make necessary adjustments.

- 3. Representation and staffing.** NALQO's representation and staffing will provide the best guarantee that the most recent industry developments and innovations can be addressed in a timely manner and with a direct knowledge of the day-to-day issues that arise in assisted living. The Coalition believes broad representation is the most promising way to keep the focus on outcomes and processes that matter most.

Choice and Innovation

Coalition guidelines are part of a comprehensive system for promoting quality by encouraging consumer choice and industry innovation. To meet this goal, the Coalition's guidelines are more flexible and less prescriptive than most regulations because they anticipate a strong monitoring system based on quality outcomes. The Coalition opted for greater specificity only in those areas where new procedural or legal precedents were created.

Recognizing the importance of the quality of life to most consumers, the Coalition based its guidelines on the philosophy of independence, dignity, autonomy and privacy. The Coalition realizes that demands for safety and sound clinical practice sometimes conflict with this philosophy. Guidelines developed by an independent NALQO should enable states to balance these demands in a way that respects consumers' desire to live a quality life.

To help achieve this balance, the guidelines borrowed heavily from the contract-based approach to quality. These provisions rely on negotiated service plans and negotiated risk agreements to govern behaviors that residents choose against a provider's advice. The proposed guidelines offer substantial procedural details on consumer safeguards in this area. The Coalition felt these guidelines were necessary if these enhancements of consumer choice would enjoy any legitimacy.

Vigorous Testing

Minimum standards inevitably involve structural and process-oriented requirements. However, the NALQO's guidelines should make an effort to relate standards to desired outcomes as much as possible. The Coalition believes that giving to one independent body the responsibility

for developing and regularly updating guidelines for minimum standards, quality indicators and practice protocols helps to keep the focus on performance outcomes.

Practice Protocols and Intervention Strategies

Recommendation #4

The NALQO should develop model practice protocols and intervention strategies for commonly experienced problem areas.

The NALQO should develop model service delivery protocols and intervention strategies that are validated by outcome measures. Service delivery protocols and intervention strategies should:

- target commonly experienced areas of problematic performance;
- be reasonably easy to carry out working with the typical facility's technologies and staff capacity;
- be sustainable over the long term as a part of routine practice; and
- be accompanied by the development of outcomes measures.

Relationships Among Quality Indicators, Standards and Practice Protocols

Since they cover the same performance areas, the relationships among quality indicators, minimum standards and practice protocols require some explanation. Ideally, each approach should reinforce the others in meeting the goal of optimal (or at least acceptable) performance outcomes. However, each has a different and irreplaceable task to perform. The differences

among quality indicators, minimum standards and practice protocols are most noticeable in three distinct areas:

Doing the Right Thing

Quality indicators can give providers a tool to measure performance outcomes. However, quality indicators cannot tell a provider what he or she should do to produce adequate or outstanding performance. Minimum standards that are well-crafted and validated are necessary to provide defined practice processes and structured capacities that are most likely to achieve acceptable levels of performance. Unlike minimum standards, practice protocols and other intervention strategies that might be developed by the NALQO are not minimum requirements with the force of law. They are more like best practices that have stood the test of practical experience.

Checking Validity

Quality indicators should provide an important validity check on minimum standards. If a facility is complying with the minimum standards but its performance (as measured by quality indicators) is inadequate, then the minimum standards are not sufficient to produce acceptable results. If, on the other hand, a facility is not complying with minimum standards but its performance outcomes are more than adequate, then the minimum standards should be reexamined to see if they may be stifling innovation. The Coalition expects that the NALQO would use this feedback to validate and update its guidelines for minimum standards so that those guidelines will reflect industry innovations in service delivery practices. Similarly, research on practice protocols and intervention strategies may lead to changes in the NALQO guidelines to states for minimum standards, or to quality indicators.

Establishing the Norm

Minimum standards identify unacceptable practices in order to enforce corrective actions. In contrast, quality indicators compare assisted living settings to the industry's current performance midpoint and then aim at improving that midpoint. Quality indicators establish the norm in an industry. They give feedback to all providers on their individual performances so that the industry's aggregated performance norms will improve over time. Practice protocols and intervention strategies are designed to help settings deal with problems and improve performance, contributing to the improvement of industry norms.

IV. Redefining Relationships that Promote Quality

The National Assisted Living Quality Organization (NALQO) could be the catalyst for transforming the ways in which various actors in the assisted living industry think about and address quality. By providing ways to measure quality, the NALQO will help redefine the ways in which industry participants relate to one another to promote that quality. The following sections outline the contributions each party should make to a comprehensive system of quality improvement.

Giving Providers the Tools to Excel

Internal Quality Improvement Teams

Recommendation #5

Each assisted living setting should establish and effectively use its own internal quality improvement team to identify problem areas, develop action plans and monitor the results of actions taken.

The provider's commitment to quality is key to an outcomes-based approach. For this reason, the success of the Coalition's proposed quality improvement system hinges on the assumption that providers will create organizational structures that regularly monitor quality and take actions to promote quality outcomes. These structures are illustrated in Figure II.

Figure II. Quality of Performance



A vast literature has developed around “total quality management” and other organizational approaches to promoting quality. Various approaches, with varying degrees of formality, may be appropriate in different types or sizes of settings. Rather than endorsing a particular approach or one specific organizational structure, the Coalition urges experimentation with a variety of approaches.

At a minimum, each facility should have a quality-improvement process, overseen by a quality improvement team. That team's composition may vary from one setting to another. While some settings may choose to restrict participation to key management staff, the Coalition encourages providers to draw broadly from constituencies that could make valuable contributions to quality improvement discussions. These include: staff at all levels, residents, family members, local service providers and state monitors.

To be effective, the internal quality-improvement team must perform four functions. These include:

- **receiving feedback** on quality outcomes from a wide range of sources, including quality indicators, consumer suggestions and state monitoring results;¹
- **identifying problems** and determine which facility policies and procedures, if any, have created the problems;
- **devising action plans** to rectify addressable problems; and
- **monitoring** the impact that actions have on performance outcomes.

Recognizing Excellence

Recommendation #6

The NALQO should examine ways to recognize excellent performance.

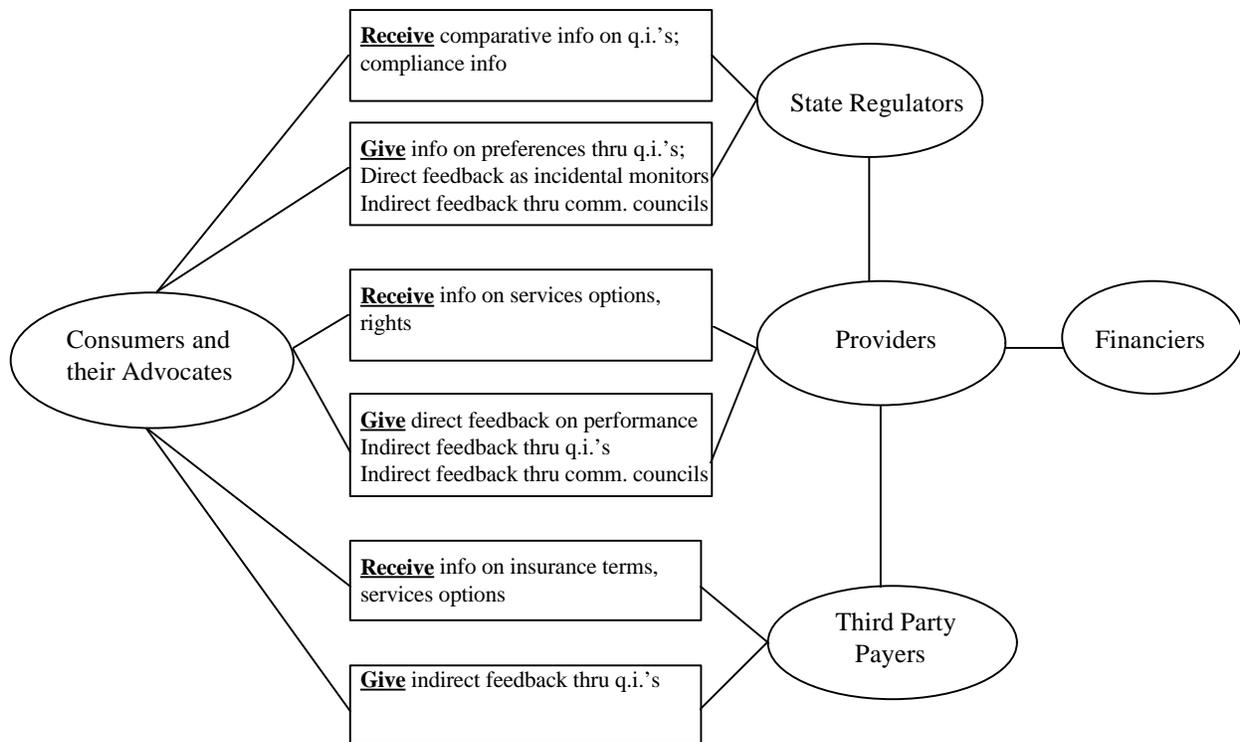
The Coalition hopes the NALQO will use the data it collects to identify and recognize outstanding performance. Recognizing excellence could be as simple as providing merit certificates to the top performers according to risk-adjusted scores on quality indicators. The NALQO could recognize superior performance in certain types of settings (e.g., special Alzheimer's and dementia services, affordable services, etc.) or performance categories (e.g., consumer satisfaction, clinical outcomes, etc.). It might recognize settings that have taken innovative approaches to services delivery, quality improvement, affordability or other characteristics.

¹ consumers, family members, and other nonprofessionals who sit on or advise the quality improvement team may require training to help them understand and effectively process outcomes information sources.

Empowering Consumers and Their Advocates

The critical roles that consumers and their advocates play in quality improvement systems should not be ignored. Consumers should not be viewed as the passive recipients of care rather than as active participants in planning and directing the services they receive. Figure III illustrates the more active voice the Coalition envisions for consumers and their advocates. First, though, consumers must receive more quality information that will enhance their decision-making capacity. In addition, the methods that allow consumers to communicate their own experiences -- the most critical information about quality -- must be improved.

Figure III.
The Consumer's View



Consumer Access to Information

Recommendation #7

The NALQO should promote consumer choice and a competitive assisted living market by ensuring that consumers and their advocates have access to appropriate setting-specific information necessary to do effective comparison shopping.

Any system based on promoting innovation, choice and quality must provide potential consumers with the information they need to make decisions. Having a competitive market is an important factor in promoting quality outcomes, and one of the critical factors in achieving a competitive market is adequate consumer information. Any system based on promoting innovation, choice and quality will have to make a major effort to provide potential consumers the information they need in a form they can use to make the right decisions for them.

An essential function of the NALQO will be ensuring that consumers, providers, third party payers, state regulators and financiers are able to use collected performance information to assist them in their respective decision-making and/or quality monitoring activities. The organization will have to make further decisions about the appropriate content, frequency and recipients of different types of information, depending on the needs of the interested parties. For example, providers, third party payers and state regulators may have very different information needs in terms of level of detail and frequency in order to monitor performance and quality improvement within settings. Consumers and their advocates who are shopping for a setting are likely to be more interested in aggregated annual reports that focus more on comparisons of performance among assisted living providers and settings in a given market area. Decisions about the form and type of information will have to be made with great care to assure full, accurate, and fair disclosure to all interested parties in a way that will be most helpful in making decisions.

Tapping Consumer Experiences

Recommendation #8

The experiences of consumers and their advocates should be tapped by each setting's internal quality improvement team.

Tapping the opinions and experiences of consumers and their families and friends should be a very important part of each setting's internal quality improvement system. The NALQO's consumer satisfaction measures can provide some of this information. However, settings are encouraged to actively seek more direct input from consumers and their advocates. Some suggestions:

1. Organizational policies should create an atmosphere that encourages -- and even welcomes -- consumers and their advocates to raise complaints or make suggestions without fear of retaliation.
2. More formal feedback should be solicited through resident councils or by recruiting consumers and their advocates to serve on the internal quality improvement team or on an advisory board to the team.

Incidental Monitors

Recommendation #9

States should enlist the input of consumers, their advocates, setting staff, and other parties who have contact with assisted living settings as incidental monitors of performance.

State monitoring staff cannot observe the daily operations of every assisted living setting. Quality indicators, while valuable, may mask specific problems. To experience the "real world" of daily operations, states should actively enlist the help of consumers, their advocates, setting staff, and others who could serve as "incidental monitors."

An incidental monitor could be any individual whose professional or personal relations bring him or her into assisted living settings regularly. Incidental monitors -- including consumers, their families, setting staff, clergy and caregivers -- offer a unique perspective from which to observe service quality.

The relationship of incidental monitors to state monitoring agencies can be more or less formalized. In either case, states should develop materials that guide incidental monitors on what to observe and how to access information, read reports on quality indicators, report observed problems and work for quality improvement. States are encouraged to develop several communication channels to protect an incidental monitor's confidentiality on sensitive issues and solicit candid, direct feedback. These might include toll-free numbers, clearly posted addresses and state interviews of incidental monitors.

Ombudsmen and Community Councils

Recommendation #10

States should enlist the input of long-term care ombudsmen and other community resources.

As independent consumer watchdogs, ombudsmen are in a unique position. They are not part of the state's formal monitoring and enforcement agencies, but have a responsibility to observe settings as well as to investigate and resolve complaints. States should tap the knowledge and expertise of ombudsmen and build on their strengths. For example, professional ombudsmen could train incidental monitors on effective ways to address quality issues. Ombudsmen, including those who are acting as volunteers, should receive training specific to assisted living and the state's quality monitoring and improvement programs for this industry.

Community Councils -- local groups with broad community representation -- can be established to monitor quality in the assisted living setting. Community Councils would solicit

and receive feedback on quality from many sources, note problem areas, and suggest remedial actions. States can experiment with ways to use effective Community Councils in their monitoring efforts. The Councils could help states target their monitoring and enforcement efforts on serious setting problems. The NALQO could foster this experimentation by developing training materials to help states use the councils effectively. States and ombudsman programs could provide training and technical assistance to these groups.

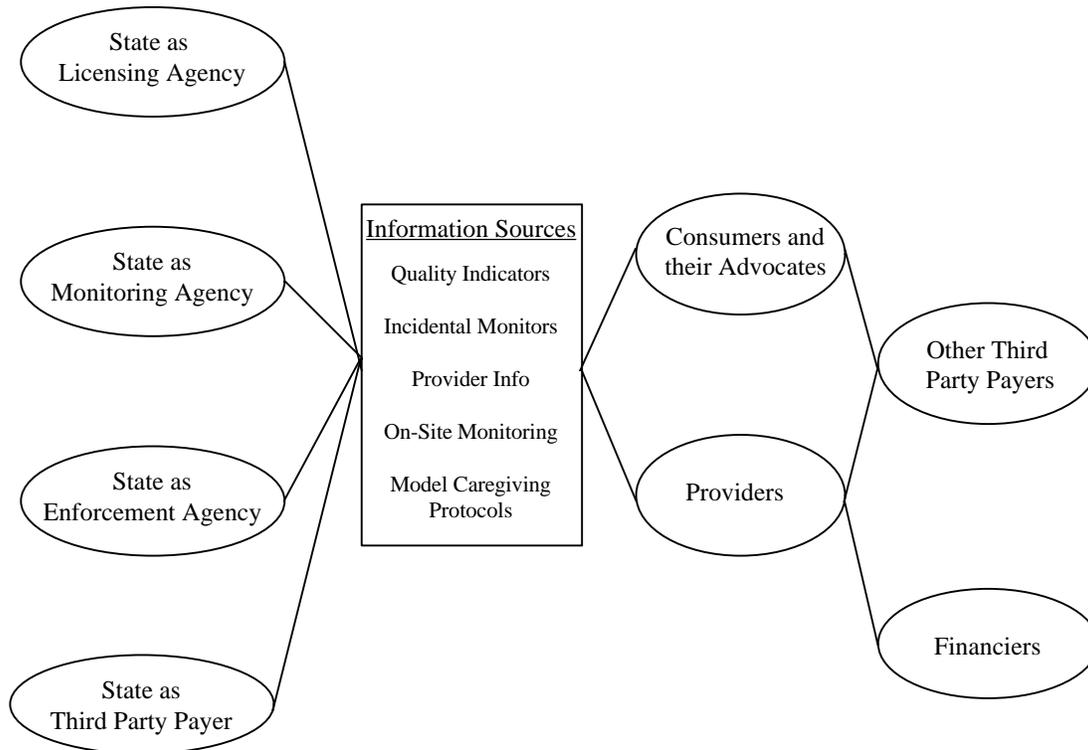
Reinventing the State Roles in Monitoring and Enforcement

Defining the relationship between the Assisted Living Quality Initiative and state efforts to regulate, monitor and enforce quality has raised some of the most complex issues encountered by the Coalition. Because the state must exercise enforcement authority to protect public safety and welfare, the relationship between states and providers is to some degree inherently adversarial. However, many of the state officials who participated in reviewing our efforts expressed frustration with an exclusively adversarial role in enforcing regulations and would prefer to have more positive options that emphasize quality improvement. These officials generally acknowledged a shortage of resources that would be needed to conduct a monitoring program with the level of thoroughness that is used in the nursing home industry. While reserving the right to adapt the Coalition's recommendations to their particular state circumstances, these state officials expressed openness to fresh ideas for a new way of accomplishing the essential roles of the state.

The Coalition agrees that only states have the power to control entry to the market through licensing procedures and only states can take certain types of enforcement actions, including delicensure, against providers who fail to achieve acceptable levels of performance. In the areas of establishing minimum standards and monitoring performance, however, states might make use of the work of other actors. Figure IV illustrates the ways in which the essential functions of the state – setting standards, licensing providers, monitoring performance, and taking

enforcement actions when necessary – might change under the quality initiative proposed by the Coalition.

Figure IV
The State's Perspective
on Quality Improvement



Adopting NALQO Guidelines

Recommendation #11

States should adopt any future guidelines established by the National Assisted Living Quality Organization as the basis for their minimum standards for regulating quality. In the interim, the Coalition encourages states to use the general guidelines in Appendix B in developing their regulations.

States could adopt all of the NALQO guidelines as their own standards or take a more selective approach. By adopting the guidelines, states would have the assurance that the

standards they develop have been thoroughly discussed and tested by the best experts in the field. However, the Coalition realizes that local market conditions and service delivery practices may make adopting a national standard politically or practically impossible. If states take a selective approach, the Coalition encourages them to adopt as many guidelines as possible.

As an interim measure, the Coalition urges states to use the preliminary guidelines in Appendix B as the basis of their regulatory efforts. These guidelines cannot be adopted as written because they lack the appropriate level of specificity and contain issues on which Coalition members could not agree. Despite these limitations, the Coalition believes the guidelines in Appendix B will serve as a useful interim tool for states seeking to develop assisted living standards. Note that the guidelines often represent a delicate balancing of varied interests. Selective use of only part of the guidelines could undermine the broad support that is important to establishing standards.

Improved Licensure Review

Recommendation #12

States should improve licensure review by focusing on both provider capacity and past performance. States should never use certificates of need, license moratoria, or any other means to artificially limit the supply of assisted living or other supportive housing settings.

Many quality problems in assisted living settings could be averted if states would effectively use licensing standards to predict performance and weed out poor performers. State licensure review should consist of two parts: a capacity review and a performance review.

The **capacity review** would determine the applicant's ability to meet minimum standards and assess its financial soundness. Financial soundness reviews should recognize the special circumstances of not-for-profit providers.

The **performance review** would focus on a provider's history of providing quality assisted living or similar services to consumers with disabilities in other settings. The performance review should include:

- any past complaints or problems with a provider's other settings;
- a record of the provider's previous performance on quality indicators; and
- the specific experience a provider brings to serving older persons and consumers with disabilities, especially older consumers.

The appropriate components of a licensure review process should be studied further by states. Among the issues to be resolved are: 1) how states will handle licensure for providers with a problematic history and those with no experience; 2) how an appeals process will be designed; and 3) the potential use of regulatory waivers to promote innovation and quality outcomes.

Since market competition is a very important part of improving quality, state licensure should never be used to artificially control the supply of assisted living. Certificates of need should not be required for licensure, nor should moratoria or processing delays be used to control supply. Because they reduce competition, such controls would drive up costs and diminish quality and innovation.

Monitoring Goals**Recommendation #13**

State monitoring efforts should evolve in the following directions:

- a. Greater focus on performance outcomes.**
- b. Greater focus on quality improvement through consultation.**
- c. Greater reliance on other actors who can demonstrate that they are better equipped to accomplish specific monitoring roles.**
- d. Greater reliance on ongoing communication and less reliance on annual survey approaches.**
- e. Greater targeting of monitoring efforts on settings that serve more disabled residents and settings that have histories of poor performance.**
- f. Greater focus on specific areas of problematic performance.**

A major focus of the Coalition's discussions has been finding a way to improve the monitoring process so that states can assure high (and improving) quality performance while dealing with some of the shortcomings of monitoring as it has often been done in the past [see pages 12-13 for a fuller discussion of the pros and cons of "traditional regulation"]. Each of the six goals of state monitoring included in Recommendation #13 requires a change in emphasis from the current process-oriented, annual survey approach to an outcomes-oriented, ongoing monitoring approach. The Coalition recognizes that this change will require experimentation with new methods of monitoring, the development of new tools for measuring outcomes, and new governmental approaches.

All of these changes may take years to fully implement, and states may experiment with different approaches. States will have to develop transition strategies that include effective monitoring until new approaches and measurement tools are proven to be effective. The NALQO could facilitate this transition process not only by developing the measurement tools but also by gathering information on the effectiveness of various approaches used by states. The following subsection discusses how each of the above recommendations could be implemented.

Greater Focus on Performance Outcomes

Rather than relying exclusively on process compliance surveys, the Coalition urges states to experiment with ways to focus the monitoring process on defined quality outcomes. States must develop ways to collect information on a provider's actual performance to gain a complete picture of a setting's performance. These enhanced information sources should include: a) better ways to use information from residents, family members, ombudsmen, and other persons who regularly visit a setting; b) quantifiable quality indicators that measure performance in clinical, functional, and quality-of-life areas; and c) site visits.

Greater Focus on Quality Improvement through Consultation

The Coalition believes that quality improvement would be best served by changing the nature of the routine monitoring process from an adversarial to a consultative model. By “routine,” the Coalition means regular, ongoing monitoring rather than monitoring done by the state’s enforcement agency in response to a reported complaint or as part of an enforcement action. The role of the monitor should be to identify performance problems and develop workable solutions, not simply to discover noncompliance with rules. To accomplish this change in focus, states must separate the routine monitoring they do as consultants from the monitoring they do as law enforcers. Neither role should be diluted nor distorted.

For example, state monitors who serve as consulting agents with a given facility should be distinguished from the agents who take enforcement action against that facility. A state may wish to assign the consulting and enforcement roles to two separate offices. Or, the state may wish to contract with other organizations to accomplish its consulting role, allowing the state to concentrate its efforts on the enforcement functions that only it can carry out.

The relationship between the monitor as consultant and the provider would hinge on the nature of the problems that emerge. The relationship would become more formal and directive as the problems become more serious. Specifically, the following three modes of operation would apply: 1) consultation as part of routine monitoring; 2) consultation when performance is

inadequate, but not creating actual harm or an immediate threat to health and safety; and 3) the transition to enforcement when consultation fails.

Consultation as a Part of Routine Monitoring

Under routine monitoring conditions, the consulting agent should be an information source to the facility's manager and the internal quality improvement team. Problems identified as needing improvement by the setting's internal quality improvement system need not be restricted to areas of regulatory noncompliance that could potentially lead to enforcement action. The consulting agent should reflect on the facility's performance and provide possible solutions to address quality issues. The consulting agent should keep abreast of innovative solutions through involvement in professional associations, training opportunities and research centers. The NALQO service delivery protocols and model intervention strategies (Recommendation #4) would be helpful resources for consulting agents.

Consulting When Performance is Inadequate

If the identified problem reflects unacceptable levels of performance, but does not present actual harm or an immediate threat to resident health and safety, then the consulting agent will negotiate an action plan to correct the problem with the internal quality-improvement team. The action plan should include performance goals and timetables. In most cases, an action plan should represent a consensus agreed upon by the internal quality-improvement team and the consulting agent. Differences should be negotiated to a mutually acceptable plan. Unless the setting's conduct has triggered an enforcement action, the setting has the option to implement its own action plan without the consulting agent's approval. If the setting can demonstrate that it can produce acceptable levels of performance, then no further action is necessary.

Until the consulting agent is satisfied with acceptable outcomes measures that indicate the problem has been corrected, the problematic areas of performance should be subjected to increased scrutiny by the internal quality-improvement team and the consulting agent. Violation

of standards and unfavorable outcomes information are problematic areas that should receive increased scrutiny.

When Consulting Fails

In the most serious of cases – when actual harm has occurred or the health and safety of the residents is at stake, when persistent problems fail to improve within an acceptable time frame, or when the consulting agent has evidence that the integrity of the performance data has been jeopardized by inaccurate reporting – the consulting agent has the responsibility to cease the consulting process and notify the state enforcement agency for immediate investigation and enforcement action. The state may, of course, launch enforcement-related monitoring whenever it receives information leading it to believe that any of the circumstances specified above have occurred (see the description of enforcement actions and procedures under Recommendation #14 below).

Greater Reliance on Other Actors Who Can Demonstrate that They are Better Equipped to Accomplish Specific Monitoring Roles

No private organization could completely replace the state's essential role in monitoring quality standards. For example, private organizations could not perform certain monitoring functions, such as life safety inspections by fire marshals or monitoring associated with enforcement actions. However, many functions traditionally performed by the state could be delegated to a private body that demonstrates it is better equipped to accomplish specific functions. Each state must identify the functions it wishes to retain and those it wishes to delegate to another entity that would act as its agent. The Coalition urges states to examine this option by evaluating their own capacity and the availability of other actors.

For example, many routine on-site monitoring functions might be well handled by properly-trained community councils. A research-based organization may be best suited to the task of monitoring the data collection required for quality indicators. Conceivably, the NALQO

could take on some of the state's monitoring functions, if it had staff capacity and funding, and if states were demanding these services.

Even if states contract with other parties to perform many of their traditional monitoring roles, they still have ultimate responsibility for protecting public health and welfare – meaning continuing responsibility for assuring the integrity of the monitoring process. State monitoring agencies would continue to collect ongoing reports on performance from whatever delegated monitoring agents it may employ. States will have to “monitor the monitors” to make certain that the reports they receive are accurate, fair and complete.

Greater Reliance on Ongoing Communication and Less Reliance on Annual Survey Approaches

The consulting role discussed above should encourage more routine interaction between the state's consulting agent and assisted living setting. The Coalition hopes that facility management will seek the consulting agent's advice as issues and potential problems arise. While the traditional onsite survey would not be eliminated, its frequency and intensity would significantly diminish for most providers if the quality-improvement process works as envisioned.

Greater Targeting of States' Monitoring Efforts

States could target their monitoring efforts more effectively. For example, settings that serve very frail residents should have more frequent and more in-depth oversight than those serving residents with light service needs. Similarly, settings at higher risk of having problems -- those with poor performance histories, or those owned by multi-setting owners with poor performance histories -- should receive more frequent and in-depth oversight than those with consistently outstanding performance. Settings that have experienced enforcement action would receive heightened scrutiny until the state is confident that the problem has been corrected and is unlikely to recur.

Greater Focus on Specific Areas of Problematic Performance

The most effective and efficient on-site inspections would focus on specific problem areas that quality indicators had identified as requiring more in-depth review. For example, a food service problem would not necessarily trigger a review of bathing or skin care services. Unless the monitoring process identified a serious problem requiring immediate enforcement action, its role would be to provide the basis for facility consultation.

When to Enforce Standards Vigorously

Recommendation #14

States should employ a consultative role when possible to correct problems, but vigorously enforce standards when:

- a. the consultative approach has failed to achieve acceptable results within a reasonable time frame;**
- b. the problems identified through monitoring are extensive or result in actual harm or an immediate threat to health and safety; or**
- c. outcomes data are inaccurate due to fraudulent or negligent behavior by provider staff with respect to their data-gathering responsibilities.**

Any effective quality initiative must have the option of enforcement. The Coalition hopes that states rarely need to take enforcement actions. Under its proposal, a setting would move immediately into the enforcement stage if any of three events, identified in Recommendation 14, takes place. If any of these events occur, the state's enforcement agency would have the power to issue a directed correction plan. It also could impose penalties, ranging from fines to receivership. In extreme cases, the state could take a setting's license away. By initiating the enforcement phase, the state recognizes that:

- the consultative process has failed in an important area of quality;

- the problem is too severe to wait for a consultation process; and
- more coercive measures are necessary.

A setting that had been negligent or had deliberately falsified its quality data report would also be referred immediately to the state enforcement agency for investigation and action. Since an outcomes-oriented system depends on the integrity of the raw data, deliberate data manipulation or inaccurate reporting must be regarded as a very serious offense bearing appropriate penalties.

We presume that most problems can be corrected through the consultative process and no further action would be needed. If, however, the consultative approach fails to produce acceptable results, the state's enforcement agency would have the power to issue a directed corrective plan or impose penalties ranging from fines to receivership, or in extreme cases to revoke a setting's license.

NALQO Assistance

Recommendation #15

The NALQO should assist states with the task of implementing new quality improvement systems.

All parts of the Coalition's quality initiative are interdependent, so optimal success requires implementing the whole system. Comprehensive implementation would involve a substantial transformation in the ways most states monitor performance and enforce standards. Working with states to make this transformation should be an important NALQO task.

For example, the NALQO could assist states in the monitoring and enforcement processes by developing service delivery protocols and model intervention strategies for common problem areas. (See Recommendation #4.) Up-to-date, experience-tested intervention strategies would

provide greater assurance that positive results are likely. They also would help to mitigate some provider concerns about the arbitrariness of state monitoring and enforcement. While not all problems are likely to be covered by such protocols and strategies, they could be very helpful tools for developing quality improvement plans.

The NALQO also could focus on developing strong two-way communication between itself and states. The NALQO can educate a state's political leadership, provide technical training to professional staff, and develop the tools that states can use in an outcomes-based monitoring system. States, on the other hand, will be crucial NALQO partners, providing feedback on how the quality initiative might be improved.

Reinforcing the Philosophy of Assisted Living Through Third Party Payers

Rewarding Settings that Subscribe to the Assisted Living Philosophy

Recommendation #16

In introducing assisted living coverage, third party payers, both public and private, should reward outcomes consistent with the philosophy of assisted living – especially those related to consumer satisfaction and quality of life. In particular, third party payers should reimburse services at a level that permits private rooms for all consumers who want them and assures adequate reimbursement for the services provided.

Currently, assisted living services generally are paid for directly by consumers in a private fee-for-service market. While a number of states finance some services through Medicaid waivers, very few do so on a wide scale. Similarly, many private long-term care insurance policies are beginning to add assisted living services. However, market penetration has been so slow that these payments have had little impact on the market.

Many observers believe that this situation will change rapidly in coming years as assisted living becomes an attractive option for states and private insurers. Its rapid growth, popularity

and potential cost savings for those who do not require substantial skilled nursing care, should encourage more interest from third party payers.

Past experience demonstrates the huge impact that third party reimbursements can have on service delivery and quality control. In the public sphere, Medicaid entitlements have shaped the nursing home industry for good and ill. Unfortunately, the conflicting roles that states play -- as overseers of quality and payers with fiscal constraints -- often makes services inaccessible, expensive, and unresponsive to consumer preferences.

Concerns are growing about how private insurance will affect assisted living's distinctive character. Consumer advocates and providers worry that health plans will be most interested in cutting costs, a goal that could reduce quality. Some advocates also fear that the growth of integrated service models could lead to the medicalization of assisted living where clinical outcomes may be emphasized to the detriment of quality of life dimensions such as the independence, autonomy and privacy of the individual consumer.

NALQO should work with public and private third party payers to:

- foster a competitive, consumer-driven and consumer-responsive market for assisted living services. The Coalition's proposed use of quality indicators should promote competition on quality as well as price. Third party payers should be intimately involved in developing quality indicators that will suit their needs for outcomes data.
- ensure that outcomes consistent with consumer choice, autonomy, privacy and independence are given adequate weight in reimbursement formulas.
- develop the means to evaluate quality of life and to establish industry norms for evaluating the relative importance of clinical, functional, and quality of life outcomes, a complicated set of issues from a technical and legal perspective.

- provide a forum for discussing these issues as a way of ensuring that third party payments also promote quality outcomes.

Third party payers, public and private, should provide adequate reimbursements to allow all consumers who want private rooms to have them. (See Appendix C.) Coalition members recognize that most consumers desire the greater privacy and independence that come with a private room. A principal concern about requiring private rooms is that such a requirement could price assisted living services out of reach for a segment of consumers under a system that currently relies largely on consumer out-of-pocket payments. Such policies should not, of course, preclude room sharing at the request of consumers.

Working With the Investment and Financial Communities

Recommendation #17

The NALQO should provide a forum for discussing risk factors that affect financial underwriting of projects in order to assure that the philosophy of assisted living is not jeopardized.

Growing interest on the part of the investment and financial communities has spurred a boom in the construction of assisted living settings. Efforts by the Coalition and the NALQO to establish a clearer product definition and develop performance measurements should stimulate even more growth by helping underwriters, investors and financiers evaluate current risks and potential rewards.

The NALQO could also provide a critical forum for discussing some important investment and financing issues.

- 1. Separating the financing of housing and services.** This approach has many potential advantages in promoting consumer choice and market competition. However, a potential downside would occur if the pressure to keep construction costs (and rents) low were to

shortchange the upfront investments needed to assure that a setting can fulfill the assisted living philosophy.

- 2. Developing underwriting criteria.** NALQO has a valuable role to play in helping the investment and financial communities develop underwriting criteria for financing settings. These criteria should reflect the philosophy of assisted living and the economics of capital versus operating costs.

Additional Recommendations

The Coalition also makes the following recommendations:

#18

Nurse practice acts should be amended to allow delegation of nursing services with appropriate professional oversight within assisted living settings.

#19

Accessibility standards set under the Americans with Disabilities Act should be modified to give greater flexibility in dealing with different types of disabilities – especially those most common among the frail elderly.

#20

Guardianship laws should ensure that guardianship occurs only when the individual is unable to make decisions, and then only on a limited basis in order to maximize the independence and autonomy of the individual.

#21

Building codes should be reviewed to ensure that assisted living services can be provided in buildings with residential scale and characteristics while assuring life safety and encouraging affordability.

V. Conclusion: Phasing in a System of Quality Improvement

Fully implementing the Assisted Living Quality Coalition's recommendations will require a sustained effort by all interested parties over several years. However, the Coalition believes that these recommendations outline a comprehensive and mutually reinforcing quality initiative that can help chart a new course for the assisted living industry. The following sections outline actions that can be taken immediately and those that should be anticipated for the future as such a quality improvement system is phased in over time.

The Assisted Living Quality Coalition

The Coalition's immediate task will be to examine the feasibility of a National Assisted Living Quality Organization, its potential tasks, and its potential impact on all stakeholders. After deliberations, the Coalition may decide that some of these tasks are outside the NALQO's capacity or would be better handled by other bodies. As the Coalition examines the feasibility of the NALQO, it will be looking toward expanding the participation of other interested parties to shape and finance its operations.

Whatever its final scope of work, the NALQO will have important responsibilities that, hopefully, it can begin to carry out in the next few years. As it is established, the NALQO rather than the Assisted Living Quality Coalition will become the forum for discussions on quality improvement issues, guidelines to states for minimum standards and related issues.

Providers

Provider organizations can begin immediately to prepare themselves for a new approach to quality improvement by establishing internal quality improvement teams and processes and by establishing means to solicit input from consumers and their advocates on quality issues. Indeed, many provider organizations have already been doing exemplary work in these areas. Some

provider organizations and trade associations are also moving ahead with the development and testing of instruments to measure quality outcomes and consumer satisfaction. These efforts will enormously facilitate the eventual development and validation of such instruments by the NALQO.

Eventually, providers will need to develop the capacity to gather and report outcomes information. This transition will require widely available computer technology and yet-to-be-developed staff training. Providers will also need to develop the management skills necessary to effectively use the valuable performance information they will be receiving in the future.

Consumers

The recommendations of the Coalition are premised on the assumption that consumers and their advocates will be active and informed participants in the decision-making that affects them. They can begin now by using the Coalition's guidelines to states on minimum standards as a guide for evaluating the services, philosophy, and consumer rights protections offered by providers. They can inquire about the availability of resident and community councils and participate as they are able. When necessary, they should use ombudsmen or state hotline numbers to deal with problems they experience.

As quality measurement tools become available, consumers and their advocates will need to become more informed on how to use these tools to help select settings as well as to promote quality improvement once the resident has relocated. Special training materials may need to be developed by the NALQO, the states, and consumer advocacy organizations to promote the fullest participation of consumers and their advocates.

States

The Coalition encourages states to use the guidelines included in this document as they review and revise their assisted living regulations. States could also begin immediately to review

their licensing, monitoring, and enforcement procedures in anticipation of implementing the quality improvement system recommended by the Coalition.

Other components of the quality improvement system will require a longer transition time for states. The quality indicators, practice protocols and intervention strategies have yet to be developed and validated. Effective consultation and intervention strategies will require some experimentation. While continuing to assure quality during the transition, states should begin to phase in these aspects of the quality improvement system as they prove effective.

Third Party Payers

Third party payers, public and private, will play a critical role in fostering a competitive, consumer-driven, and consumer-responsive market for assisted living services. As the Coalition works on the feasibility study for the recommendations in this report, we especially solicit the input of third party payers on ways to develop measurement instruments that will promote competition on quality outcomes as well as on price. The Coalition especially looks for guidance on ways to establish industry norms for evaluating and reimbursing consumer quality of life outcomes.

Investment and Financial Communities

The investment and financial communities should also be vital partners in the implementation of the Coalition's recommendations. The Coalition solicits input that would be helpful to the investment and financial communities as they develop standards for evaluating potential risks and rewards in this market.

A Final Note

Reaching the level of consensus reflected in this document has involved two years of intense discussions. The Coalition is grateful to the many individuals and organizations who have contributed to our understanding of the many issues addressed here. We look forward to the ongoing work of implementing this innovative approach to serving our nation's older and disabled consumers.

Appendix A: Overview of Participant Roles

Overview of the NALOO's Role

- Develop, validate and regularly update or approve quality measurement instruments (such as consumer satisfaction measures and quality indicators of clinical and functional performance outcomes in assisted living settings).
- Establish, regularly review and update as needed guidelines that states can use to develop minimum standards for the assisted living industry.
- Develop model practice protocols and intervention strategies for commonly experienced problem areas.
- Identify ways to recognize excellent performance.
- Ensure that consumers and their advocates have access to appropriate setting-specific information necessary to do effective comparison shopping.
- Help states implement new quality improvement systems.
- Work with public and private third party payers to foster a competitive, consumer-driven and consumer-responsive market for assisted living services.
- Work with third party payers to assure that outcomes consistent with consumer choice, autonomy, privacy and independence are given adequate weight when choosing which service costs to reimburse.
- Provide a forum for discussing risk factors that affect financial underwriting of projects in order to assure that the philosophy of assisted living is not jeopardized.

- Develop appropriate training materials in consultation with various stakeholders.

Overview of the Provider's Role

- Establish provider's internal quality improvement team and process.
- Tap the experiences of consumers and their advocates in efforts to improve quality.
- Use instruments approved by the NALQO to measure performance outcomes.
- Enlist the state and other appropriate parties to serve in a consultative role to correct problems and improve quality.
- Provide training to appropriate staff responsible for the collection and interpretation of data.

Overview of the Roles of Consumers and their Advocates

- Serve on resident or community councils as they are able.
- Give feedback on performance to providers, either formally through participation on a quality improvement team or informally through direct communications.
- Work with family members and other incidental monitors to give feedback on performance to provider or to state regulators.
- Submit problems as necessary to the ombudsman.
- Become informed on using quality performance measures through the use of consumer-oriented training materials that may be developed by advocacy organizations, states, or the NALQO.

Overview of the State's Role

- Use NALQO Guidelines to develop minimum standards for regulating quality in assisted living settings.

- Improve licensure review so it can be used to predict good performers and weed out poor performers.
- Work closely with the NALQO to transform how the state monitors performance and enforces standards.
 - Enlist the input of consumers, their advocates and other parties who have contact with assisted living settings, as "incidental monitors" of performance.
 - Establish a monitoring process that focuses on consultation to help assisted living settings correct problems and improve quality.
 - Examine delegation of monitoring functions to appropriate bodies, such as the NALQO, research-based organizations, and community councils.
 - Measure facility performance through the use of quality indicators
- Be prepared to take enforcement action when the consultative approach fails or problems are considered too serious or extensive for consultation.
- Enlist ombudsmen to monitor quality, investigate and resolve complaints, and report unresolved problems to the appropriate authorities.
- Enlist "incidental monitors" whose professional or personal relationships bring them into regular contact with assisted living settings to report on quality in specific settings.
- Diminish and target formal on-site monitoring as quality indicators demonstrate their utility in monitoring performance.
- Assure appropriate training for those with consultative, monitoring or enforcement responsibilities.

Overview of the Role of Investors and the Financial Community

- Develop underwriting criteria that reflect the philosophy of assisted living.
- Develop financing mechanisms that promote consumer choice by separating the choice of services from the settings in which those services are received.

Appendix B: Guidelines to States on Setting Minimum Standards for Providers of Assisted Living

Guidelines to States on Setting Minimum Standards for Providers of Assisted Living

*Developed by:
The Assisted Living Quality Coalition*

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I. PURPOSE

This document proposes consensus guidelines to states on setting minimum standards for assisted living providers developed by the Assisted Living Quality Coalition (the Coalition) as part of an overall quality initiative for the industry. Minimum standards serve as the foundation (i.e., minimum standards for quality-improvement and participation) of the quality-improvement system contained in the quality initiative. The quality-improvement process includes the integration of outcome-based measures centered on quality indicators and customer satisfaction.

The goal of the quality initiative is to provide an innovative and efficient monitoring and improvement system focused on achieving outcomes designed to meet individual resident's^{2,3} needs and preferences. In keeping with the resident-centered philosophy of assisted living, this document assumes that resident preferences and needs will be paramount in decisions about services, contracts, etc. To encourage continued innovation in assisted living, these guidelines and the quality-improvement process will be designed to change as the industry and quality-improvement techniques advance.

² Residents without cognitive impairments may elect to name a "legal representative." If a resident names a "legal representative", the "legal representative" only acts on the resident's behalf when authorized by the resident to do so. A competent resident always has the right not to name a "legal representative", to change the person so designated, to modify the responsibilities of the "legal representative," or to discontinue the arrangement altogether. Residents who are incompetent will have a "legal representative" named to represent them only in the areas required. "Legal representatives" for incompetent residents will be named in accordance with state law or guidelines. In the event of an emergency when a resident is incapable of authorizing a "legal representative" to act on his or her behalf, a "legal representative" is allowed, consistent with state law, to make decisions on that resident's behalf.

³ It should be understood that the references to "resident" or "residents" in the text usually mean "resident, to the extent that cognitive impairment permits, and with the responsible person and family, as appropriate or when requested by the resident." To remind readers of this entire phrase, an asterisk appears at each use of the word "resident" when this meaning is intended.

II. ASSISTED LIVING DEFINITION

Coalition's Intention: The Coalition believes that, more than any other type of long-term care service, assisted living must be driven by a philosophy of service that emphasizes personal dignity, autonomy, independence and privacy in the least restrictive environment. Further, it should enhance a person's ability to "age in place" in a home like setting while services intensify or diminish according to the individual's changing needs. The next two sections of these guidelines, detailing our definition and philosophy of assisted living, form the foundation for the provisions that follow.

An assisted living setting is:

- a congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services;
- designed to minimize the need to move;
- designed to accommodate individual residents' changing needs and preferences;
- designed to maximize residents' dignity, autonomy, privacy, independence., and safety;
and
- designed to encourage family and community involvement.

III. PHILOSOPHY

The philosophy of assisted living includes these principles and is reflected in the setting's mission statement, policies, and procedures:

1. Offer cost-effective quality supportive services that are personalized for each individual and delivered in a safe residential environment.
2. Maximize the independence of each resident.
3. Treat each resident with dignity and respect.
4. Promote the individuality of each resident.
5. Protect each resident's right to privacy.
6. Provide each resident* the choice of services and lifestyles and the right to negotiate risk associated with his or her choices.
7. Involve residents and include family and friends in service planning and implementation when requested by a competent resident or when appropriate for incompetent residents.
8. Provide opportunity for the resident to develop and maintain relationships in the broader community.
9. Minimize the need to move.
10. Involve residents* in policy decisions affecting resident life.
11. Make full consumer disclosure before move in.
12. Ensure that potential consumers are fully informed both verbally and in writing regarding the setting's approach and capacity to serve individuals with cognitive and physical impairments.
13. Ensure that specialized programs (e.g. for residents with dementia) have a written statement of philosophy and mission reflecting how the setting can meet the specialized needs of the consumer.
14. Ensure that residents can receive health-related services provided as they would be within their own home.

15. Ensure that assisted living, while health-care related, focuses primarily on a supportive environment designed to maintain an individual's ability to function independently for as long as possible.
16. Ensure that assisted living, with its residential emphasis, avoids the visual and procedural characteristics of an "institutional" setting.
17. Ensure that assisted living, with its focus on the customer, lends itself to personalized services with an emphasis on the particular needs of the individual and his/her choice of lifestyle. The watchwords should be "creativity", "variety", and "innovation".

IV. SERVICES

Coalition's Intention: Consistent with the Guidelines' definition and philosophy of assisted living, the Coalition's guidelines for standards governing services stress individual choice and the ability to age in place. As a consequence, much specificity that is usually included in standards for long-term care settings is left to negotiation between residents and providers in the services plan. Because of the emphasis on the services plan, this section provides some detail on how those plans should be negotiated and updated. The guidelines for services capacity seek to be flexible enough to recognize the varying levels of need in different settings while supporting the ability of residents to age in place with adequate support.

A. Assessment, Monitoring, and Service Coordination

1. Prior to move-in and/or the execution of a resident agreement, the setting:
 - a) provides the prospective resident* a description of services provided by the facility;
 - b) provides the prospective resident* a copy of all tenancy rules, including rights and obligations of the resident*;
 - c) conducts an initial screening of the applicant to determine the setting's ability to meet the resident's* anticipated health and service needs and preferences.
2. After execution of a contract and within a reasonable time after move-in, the setting conducts a more complete assessment of the resident* by an appropriately qualified person to verify the needs and preferences of the resident determined through the initial screening and/or to update the initial screening, that at a minimum includes:
 - a) review of physical health, psychosocial status and cognitive status and determination of services necessary to meet those needs;
 - b) information from professionals with responsibility for the resident's physical or emotional health;
 - c) meeting with resident*; and
 - d) obtaining any additional information or documents pertinent to the resident's* service planning such as guardianship papers, power of attorney, living wills, do-not-resuscitate (DNR) orders, or other relevant medical documents.
3. Following completion of the post-move-in assessment, the setting, using an appropriately trained person, develops a written service plan using information from the assessment, consistent with the services provided by the facility. The service plan is developed by the

setting with the resident* as a full partner. The service plan is signed by the resident* and the setting's representative.

4. The resident* retains a copy of this service plan, and a copy is kept on file in the setting.
5. The service plan:
 - a) includes the scope, frequency and duration of services and monitoring;
 - b) is responsive to the resident's* needs and preferences (including flexibility in scheduling, delivery method, activities, etc.); and
 - c) is discussed with as well as reviewed, revised and signed by the resident* and setting's representative as needs or desires change, but no less than annually (the resident's* and the staff's assessment of the resident's needs and/or preferences may change substantially after the resident has settled into the assisted living setting; it is recommended that the setting review the resident's service plan soon after the resident has adjusted to life in the setting, generally after the first 30 to 60 days and regularly thereafter to be sure that the plan is being carried out).
6. The setting establishes written policies regarding third-party providers that address applicable charges, notification procedures, provider selection, and monitoring of service provision.
7. The setting coordinates and monitors the quality of services provided by all third parties contracted by the setting.

B. Personal and Supportive Services (Activities of Daily Living [ADLs] and Instrumental Activities of Daily Living [IADLs] and Oversight

1. To meet the scheduled and unscheduled service needs of residents, the setting provides or coordinates some assistance with all activities of daily living (ADLs - dressing, eating, bathing, toileting, transferring) and all instrumental activities of daily living (IADLs - preparing meals, taking medications, walking outside, using the telephone, managing money, shopping, housecleaning). ("Some assistance" is defined as a modest level of assistance with any ADL or IADL. This supports assisted living's philosophy of minimizing a resident's need to move by assuring that a resident who requires a minor amount of assistance with any ADL or IADL will not be forced to move out to obtain assistance.)

2. The setting is able to provide adequate assistance and oversight/supervision around the clock as needed for any resident.

C. Health-Related Services

1. The setting monitors and has a reporting procedure in place for notifying appropriate individuals of observed or reported changes in a resident's condition.
2. The setting provides or assists in arranging for healthcare services as needed, to the extent that they do not conflict with occupancy criteria established by regulation or exceed the stipulations of the service contract.
3. If the provider serves residents with health-related needs, the setting makes consultation with licensed healthcare professionals available (in person or by phone) to staff at all times. ("Making licensed healthcare professionals available to staff at all times" should in no way be construed as a requirement that RNs or LPNs must be on site 24 hours a day.)
4. Residents* may choose or maintain their own physicians.
5. Medication assistance:
 - a) Residents who self-medicate may keep and use prescription and non-prescription medications in their unit as long as they keep them secured from other residents. The setting encourages residents who self-medicate (with prescription or non-prescription drugs) to have their medications regularly reviewed;
 - b) The setting assists residents in the administration of prescription and non-prescription medications as allowed by state statute/regulations and will maintain records of such assistance; and ⁴
 - c) The setting maintains clear written policies and procedures on medication assistance. The setting provides for ongoing training to ensure competence of medications staff.

D. Meals

1. The setting provides or arranges three varied, appetizing meals a day, seven days a week.
2. The setting makes reasonable accommodations to:
 - a) meet dietary requirements;

⁴ This recommendation is not meant to require the presence of licensed professionals if state law currently only allows licensed professionals to assist with the administration of prescription medications.

- b) meet reasonable religious, ethnic, and personal preferences;
 - c) meet the temporary need for meals delivered to the resident's room;
 - d) meet residents' reasonable temporary schedule changes as well as residents'* preferences (e.g., to skip a meal or prepare a simple late breakfast); and
 - e) make snacks, fruits, and beverages available to residents when reasonably requested.
3. All food preparation areas (excluding areas in residents' units) are maintained in accordance with state and local sanitation and safe food handling standards.

E. Housekeeping

Housekeeping services are provided to meet the reasonable needs of residents'*

F. Activities & Transportation

1. The setting provides activities programs that are appropriate to the abilities of the residents being served.
2. The setting provides and/or coordinates scheduled transportation to community-based activities, and to other services to meet the reasonable needs and preferences of residents*.

V. ENVIRONMENT

Coalition's Intention: The Coalition recognizes that the physical environment in assisted living settings can be as important as the services in fostering the goals of dignity, independence, privacy, and aging in place. The Coalition is also keenly aware of the need to keep assisted living as affordable as possible. The provisions relating to residents' units adapt generally accepted standards for housing units in order to enhance independence privacy and dignity. While specifying that units should be shared only when agreed by the residents involved and that units include private bathrooms and individual cooking capacity and food storage, the provisions do not set specific space or appliances requirements so that providers can seek innovative and cost-effective ways to ensure that the philosophy of assisted living is reflected in the residents' units and common spaces. The Coalition strongly urges that Medicaid and other public reimbursement programs recognize and adequately fund the residential enhancements of assisted living. Currently operating facilities without some of the residential enhancements could be grandfather under these guidelines because of the potential costs involved in retrofitting buildings.

A. General

1. The physical environment should provide freedom of movement for residents to common areas and their personal space. Settings should not lock residents out of or inside their rooms. Residents should be encouraged and assisted to decorate and furnish their rooms with personal items, consistent with local fire safety regulation.
2. The setting is designed to provide residential atmosphere.
3. The setting is designed throughout to meet the accessibility needs of the residents.
4. If more than one story, the setting provides an elevator. At the discretion of the appropriate official and as allowed by code, a mechanical alternative may be substituted for an elevator.

B. Construction/Life Safety Standards

1. Assisted living facilities meet any and all state or local codes specifically applicable to residential care.
2. A setting serving residents with dementia or other special needs has appropriately secured/designed doors and windows to ensure resident safety.
3. Facilities will have a disaster emergency plan, and staff must be knowledgeable about the plan.

4. Facilities will have a plan in place to minimize wandering by residents with dementia from the facility and will have a process in place to respond to such.

C. Heating, Ventilating, and Air Conditioning (HVAC)

The setting ensures comfortable temperatures in all areas in all seasons. In newly constructed facilities, HVAC in unit shall be individually controlled by the resident*, with a locking mechanism provided if required to prevent harm to a resident.

D. Illumination

The setting provides illumination that is sufficient and appropriate to the use of the area and sufficient for residents whose vision is diminished. Among other issues, this requires that settings design illumination to reduce glare.

E. Residents' Units

Introduction: The Coalition did not reach consensus on whether all assisted living should be private or whether shared units should be permitted. Please see Appendix C on page 86 for further clarification.

1. Resident units include:
 - a) a food storage area and counter space. The unit should be designed to accommodate such items as mini-refrigerators and microwaves; and
 - b) an operating emergency call system (installed or radio-controlled) that is easily accessible to the resident in the event of an emergency;
 - c) a locking front door. Residents* may request removal or disabling of lock; and
 - d) at least one telephone jack.
2. A setting serving residents with dementia provides units designed to meet their special needs and challenges of caring for residents with dementia within a residential environment.

F. Common Areas

1. The setting provides common areas that are sufficient to allow residents the opportunity for socialization.
2. Common areas are accessible and designed to accommodate safe wandering and provide freedom of movement for residents.

3. Setting provides public restrooms of sufficient number and location to serve residents and visitors. (Public restrooms are located close enough to activity hubs to allow residents with incontinence to participate comfortably in activities and social opportunities.)

G. Dining Room

The setting has a dining room(s) that can accommodate residents, including those residents who use wheelchair or other assistive devices for mobility, in an appropriate dining environment. Dining room(s) may be sized to accommodate residents in one or two seatings.

H. Kitchen

1. The setting has a central or a warming kitchen.
2. The setting has sufficient capacity to prepare, deliver and/or arrange for appropriate food to residents in an appetizing, sanitary, and safe manner and at an appropriate temperature.

I. Laundry

The setting has a laundry service, either on-site or off-site, that is adequate to handle the needs of residents, including those with incontinence.

J. Grounds

The setting provides, or arranges for, outside activities and/or an activity space suitable for the frail elderly and those who wander.

VI. CONSUMER PROTECTION

Coalition's Intention: In the following section, the Coalition makes the distinction between "basic rights," which are inherent to all human beings and, therefore, not enumerated and "rights specific to residents of assisted living". This section is more specific than many of the others for two reasons: 1) rights and consumer protections are less measurable in outcomes measures; and 2) the rights of persons with disabilities is an area where the law is rapidly developing. Since our approach relies heavily on negotiated agreements between the resident and the provider, we have provided particular detail on the issues of contracts and negotiated risk agreements. Discharge policy has also been a critical issue because of the philosophy of aging in place and the development of Fair Housing case law on requiring people to move because of their level of disability.

The Coalition could not reach agreement on how to address consumers pursuing judicial enforcement of the state minimum standards that they believe have been violated.

A. Basic Rights

1. The fundamental rights of individuals are not diminished by virtue of residence in an assisted living setting. The assisted living provider must respect all rights recognized by law with respect to discrimination, service decisions (including the right to refuse services), freedom from abuse and neglect, privacy, association, and other areas of fundamental rights.
2. Assisted living settings, as with all residential care setting, must accord their residents the basic rights enjoyed by all Americans. Some of the basic rights that are at issue for frail older persons are:
 - a) to be free from verbal, sexual, physical, emotional and mental abuse;
 - b) to be free from a physical or chemical restraints for the purposes of discipline or convenience, and not required to treat the resident's medical symptoms. No chemical or physical restraints will be used except on order of a physician;
 - c) to have records kept confidential and released only with a resident's* consent consistent with state law; and
 - d) to have a service animal, consistent with the "reasonable accommodations" clause of the Fair Housing Act.

B. Rights Specific to Residents of Assisted Living

1. In addition to the basic rights enjoyed by other adults, the residents of assisted living also have the right to:
 - a) be treated as individuals and with dignity, be assured choice and privacy and the opportunity to act autonomously, take risks to enhance independence, and share responsibility for decisions;
 - b) have access to their records immediately in emergency situations and in a timely fashion, generally within the next business day;
 - c) arrange for third-party services not available through the setting at their own expense as long as the resident* remains in compliance with the conditions of residency;
 - d) be fully informed of all resident rights and all rules governing resident conduct and responsibilities;
 - e) remain in current setting, foregoing a recommended transfer to obtain additional services as long as the resident* contracts for or secures the needed additional services in a nature acceptable to the facility and engages in a risk agreement with the setting which is acceptable to resident* and the setting and does not violate any applicable law;
 - f) remain in their unit unless a change in units is related to resident preference or to transfer conditions stipulated in their contract;
 - g) furnish their own rooms and maintain personal clothing and possessions as space permits, consistent with applicable life safety, fire or similar laws, regulations and ordinances;
 - h) be encouraged and assisted to exercise rights as a citizen; to voice grievances and suggest changes in policies and services to either staff or outside representatives without fear or restraint, interference, coercion, discrimination, or reprisal;
 - i) have visitors of their choice without restrictions so long as those visitors do not pose a health or safety risk to other residents, staff, or visitors, or a risk to property;" and
 - j) have private telephone and mail communication.

2. Setting provides a copy of resident rights in the resident contract.
3. Setting advises residents* of changes in rights in writing prior to implementing the revised changes.
4. Setting provides a copy of residents' rights to anyone requesting a copy.
5. Setting posts a copy of the address and telephone number of the local or state ombudsman program.

C. Resident Councils

1. Setting assists in establishing and facilitating resident* councils, which meet regularly to provide a forum for suggestions, comments and input regarding the setting's services and to provide interaction with the management and to discuss grievances.
2. Setting arranges for staff and allows for outside representatives to attend the council meeting upon the council's request

D. Grievance Procedures

1. Setting has a formal and timely appeals process for grievances.
2. Setting responds in writing to resident council requests and written grievances in a timely manner.

E. Resident Application, Contracts, and Agreements

1. All information provided by the setting is accurate, precise, understandable by a reasonable person, and readable by the resident and complies with all applicable laws.
2. The setting has a written application process and provides clear reasons if an applicant is rejected.
3. The setting allows and recommends review of the contract by an attorney or other representative chosen by the resident*.
4. The setting's contract:
 - a) is a clear and complete reflection of all commitments and of actual practice;
 - b) is signed by a representative of setting and by the resident*;
 - c) includes the availability of a service plan specific to each resident; and
 - d) covers the following topics:

- 1) clear and specific occupancy criteria and procedures (admission, intra-setting transfers, and discharge);
 - 2) rate structure and payment provisions that are clear on:
 - 3) covered and non-covered services;
 - 4) service packages and “A la carte” services;
 - 5) criteria for determining level of service and for triggering
 - 6) additional charges;
 - 7) fees and payment arrangements for any third-party providers;
 - 8) the provision of at least 45 days’ notice of any setting-wide rate increases or fee changes;
 - 9) the minimum notification a resident* must furnish when he or she plans to move out of the setting for reasons other than health emergencies (notification requirements may not exceed 45 days);
 - 10) the provisions regarding payment during unavoidable or optional absences (e.g., hospitalization, recuperation in a nursing home, or a vacation);
 - 11) an explanation of the setting’s billing, payment, and credit policies; and
 - 12) the facility’s policies regarding-residents* who can no longer pay for services.
 - 13) rules regarding third-party providers arranged for by resident* and by setting;
 - 14) division of responsibility between the setting, the resident*, family, or others (e.g., arranging for or overseeing medical care, purchases of essential or desired supplies, emergencies, monitoring of health, handling of finances); residents’ rights, including an explanation of grievance procedure and appeals process, and information on outside agencies to which appeals may be made; and policy on holding resident units if resident is hospitalized or otherwise absent from the facility; and
 - 15) The setting’s risk negotiation policy and process.
5. Following a prospective resident’s initial screening and execution of a contract, a resident may cancel his or her contract without complying with the notice period described above if the resident’s first complete assessment following execution of the agreement indicates that the setting will not be able to meet the resident’s needs, and

either the facility or the resident determine that this is the case. In such cases, the setting and the resident will work together to establish a move-out date and facilitate an orderly move-out. A facility's statement of resident rights shall include this right and its policies must indicate how residents who take advantage of this right are to be charged for services rendered between the time of move-in and cancellation of the contract under this section.

F. Financial Solvency

Settings requiring an entrance fee or a deposit in excess of three months of a resident's* minimum fees will maintain a bond or restricted account that guarantees the return of the resident's* entrance fees and/or the unused portion of his or her deposit if the setting ceases operation.

G. Admission/Retention

1. The setting accepts or retains only residents for whom it can provide appropriate services, unless the setting arranges for third-party services or the resident* does so with the agreement of the setting.
2. The setting encourages residents with impairments that impact their decision-making to arrange to have a guardian or other legal representative to represent their interests, in accordance with state laws or guidelines.

H. Discharge Criteria and Procedures

1. The setting can discharge a resident only for the following reasons and within the following guidelines:
 - a) except in life-threatening emergencies and for nonpayment of fees and costs, the setting gives 45 days' advance written notice of discharge in writing with a statement containing the reason, the effective date of termination, and the resident's* right to an appeal under state law;
 - b) if resident does not meet the requirements for tenancy criteria stated in the residency agreement or requirements of state or local laws or regulations;
 - c) if resident is a danger to self or the welfare of others; and the setting has attempted to make a reasonable accommodation without success to address resident behavior

- in ways that would make move-out or change unnecessary, which should be documented in the resident's records;
- d) for failure to pay all fees and costs stated in the contract, resulting in bills more than 30 days outstanding. A resident* who has been given notice to vacate for nonpayment of rent has the right to retain possession of the premises, up to any time prior to eviction from the premises, by tendering to the provider the entire amount of fees for services, rent, interest and costs then due. The provider may impose reasonable late fees for overdue payment. Chronic and repeated failure to pay rent is a violation of the lease covenant. (The setting makes reasonable efforts to accommodate temporary financial hardship and provides information on government or private subsidies available that may be available to help with costs.); and
 - e) the setting makes a good faith effort to counsel the resident* if the resident shows indications of no longer meeting residence criteria or if service with a termination notice is anticipated.
2. The setting provides for a safe and orderly move-out, including assistance with identifying a resource to help locate another setting, regardless of reason for move-out.
 3. The setting returns deposits, on a pro-rated basis, for instances of emergency discharge, if the resident is current in all payments.

I. Implementing Resident Autonomy through Risk Agreements

1. Providers recognize an individual resident's autonomy by respecting his/her right to make individual decisions regarding lifestyle, personal actions/ behaviors and service plans. In some cases a resident's* decision(s)/action(s) may involve an increased risk of personal harm and therefore potentially increase the risk of liability by the provider absent an agreement between the provider and the resident concerning such decisions/actions. In this situation, the provider will:
 - a) explain why the decision(s)/action(s) may pose a risk(s) and suggest alternatives for the resident's* consideration;
 - b) discuss how the provider might assist the resident* in mitigating the potential risks; and

- c) encourage, but not require, a competent resident to discuss his/her decision(s)/action(s) with his/her family.
2. If, after consultation with the provider, a resident* decides to pursue an action(s) or refuse service(s) (including healthcare services) that may involve increased risk of personal harm and conflict with a provider's usual responsibilities, the provider will:
 - a) describe the action or range of actions subject to negotiation;
 - b) negotiate a "risk agreement" acceptable to the resident* and the provider that meets all reasonable standards for the safety and comfort of the community as well as any statutory and regulatory requirements implicated;
 - c) follow a resident's preferences over his/her family's preferences unless the family has been granted legal powers of decision-making, consistent with applicable laws;
 - d) record the agreement, signed between the resident* and the provider;
 - e) implement any mitigation efforts to which the provider agreed;
 - f) review the decision(s) documented in the risk agreement with the resident* if the resident's mental or physical condition changes substantially from the time when he/she signed the agreement, renegotiating and re-signing the agreement as applicable laws permit; and
 - g) resident is required to engage in a risk agreement and to secure needed additional services in a manner acceptable to the facility that does not violate any other applicable laws to remain in the current setting when a transfer has been recommended to obtain additional services.
3. The setting will respond within 10 working days to the resident's* request to engage in behavior that could involve an increased risk of personal harm. If the resident then requests a risk agreement, the process of negotiation and documentation will be completed within a reasonable time period after the resident's* request.
4. The setting makes no attempt to use a risk agreement to abridge a resident's rights. Harm arising from a resident's actions after the execution of a risk agreement will not be presumed to be the fault of the provider, absent evidence of the provider's negligence.

J. Regulatory Issues

The setting meets applicable state and local licensing requirements and complies with all regulations.

VII. MANAGEMENT RESPONSIBILITIES

Coalition's Intention: Since the monitoring of quality under the system we have outlined above relies on an internal quality-improvement process, the establishing of such a process must be a core management responsibility. Rather than have specific requirements for staffing ratios and training, the following guidelines stress outcomes—i.e., that staffing be adequate in numbers and training. Since the delegation of nursing tasks is used by many assisted living facilities, this section also include guidelines for such delegation.

A. Quality-Improvement Program

The setting has a documented, ongoing quality-improvement program. To the extent a setting's quality improvement program includes the use of a quality assurance committee, a state may not require disclosure of the records of such committee.

B. Personnel Policies

1. Administration maintains written personnel policies and procedures.
2. The setting will request a criminal record check (and a check of any aide registry that may be available) 3 days prior to employment for all new staff, and keep the results in their confidential personnel file.
3. Staff are not to be retained if they have been convicted of a felony or any crime involving the abuse, neglect, or exploitation of others.

C. Staffing

1. The setting employs an administrator who:
 - a) is a minimum of 21 years of age;
 - b) has a minimum of a high school diploma or GED;
 - c) has adequate education, demonstrated experience, and ongoing training to meet the health and psychosocial needs of the residents; and
 - d) has demonstrated management or administrative ability to maintain the overall operations of the setting.
2. A competent substitute is designated to act on the administrator's behalf when the administrator is not readily available.
3. Staff are sufficient in number and qualifications to meet the 24-hour scheduled and unscheduled needs of the residents and services provided. The number and qualifications

of staff depend on a variety of factors, including the size of the setting and the skills required to provide for the specific needs of the residents. A minimum of one awake staff will be on-site at all times when one person, with cognitive impairments that prevent him/her from safely evacuating the facility independently, is present.

4. Staff have adequate skills, education, experience, and ongoing training to serve the resident population in a manner consistent with the philosophy of assisted living. “Ongoing training” means a regular program of staff training designed by a setting to assure that all staff with resident contact have the skills necessary to provide high-quality services in a manner appropriate to the philosophy of assisted living and includes staff training on how to monitor changes in resident’s conditions, including physical, cognitive, and psychosocial status.
5. In settings serving residents with dementia, staff who have contact with such residents have a minimum of 12 hours of dementia-specific training per year, conducted by a qualified trainer (or facilitated by a trained staff member) in order to meet the needs/preferences of cognitively impaired residents effectively and to gain understanding of the current standards of care for people with dementia.

D. Nurse Delegation

(Note: Applies only if the state statutes or regulations, as well as setting policy, permit nurse delegation.)

1. Staffing policies and procedures comply with any and all relevant state nurse delegation requirements.
2. The setting has a documented protocol for nurse delegation, including:
 - a) supervision, training and educational requirements for delegator and delegates. (Setting requirements must follow state requirements when available.); and
 - b) criteria for when and which tasks may be delegated (which follow state requirements when available and explicit).
3. The setting relies on the judgment of a medical professional to identify which tasks may be delegated.
4. The setting maintains in the files of the affected resident a record of any nursing tasks delegated.

Appendix C: Should Private Units Be Required in Assisted Living Settings?

The Assisted Living Quality Coalition was unable to reach agreement on whether or not private units should be required in assisted living settings as part of state minimum standards. Despite this disagreement, the members of the Coalition agree that most consumers have a strong preference for private apartments; indeed, a recent survey by the Assisted Living Federation of America found that 85 percent of units in assisted living are private. To further discussion on this important issue, the Coalition agrees with the following statements related to private units:

1. The philosophical principles of independence, dignity, autonomy and privacy enshrined in this document should also be applied to other long-term care services such as residential care.
2. Public benefit programs, especially Medicaid, should provide adequate reimbursements for private units and allow consumers much greater choice in the types and settings for the services they receive.
3. Research on the following topics would help inform future discussions of the private room issue: a) the benefits and problems associated with sharing rooms with persons with dementia and other cognitive disabilities; b) the relative costs associated with private versus shared units, including costs associated with construction or retrofitting, staffing, management, maintenance, resident turnover, unit vacancies, and marketing; and c) ways to maximize privacy in shared rooms through innovative design features and operating policies.

The Coalition recognizes that changing benefits or doing research will not fully resolve the private unit issue. The research projects will help inform future decision-makers at the state level as well as with the envisioned National Assisted Living Quality Organization, but they will obviously not determine the outcome. The Coalition members will continue to seek innovative solutions and information to help future decision-makers. In the meantime, the differing approaches to the private unit issue are described in the sections below.

WHY REGULATIONS SHOULD ASSURE PRIVATE UNITS FOR ASSISTED LIVING CONSUMERS WHO WANT THEM

I. Consumer Issues: Having to share a unit with a stranger is incompatible with the philosophy that is the hallmark of assisted living.

The assisted living philosophy of “privacy”, “independence”, “dignity” and “choice” is difficult to reconcile with housing residents in units with strangers they had no voice in choosing. Given the losses that many residents in assisted living have had to endure – loss of health, of spouse, and of home – sharing a room with a stranger is often experienced as a further loss of privacy, independence, dignity and choice.

Consumers overwhelmingly prefer private units.

A 1996 AARP poll found that Americans aged 50 and over would prefer a private living unit over a shared room by a margin of 20 to 1 (82% to 4%) if they or a loved one were to move into an assisted living setting. Other research has found that residents with private rooms experience less loneliness and have more socialization than residents who must share rooms. Private bathrooms are highly desired because of the access, privacy and cleanliness issues related to sharing a bathroom with a roommate.

Consumer choice is too often limited by the circumstances under which the decision to relocate to assisted living are made.

The decision to move to assisted living is often made under crisis circumstances where choices are limited by what is immediately available. Once relocated, moving the older person again is particularly difficult even if the living arrangements are less than optimal. Having a private unit minimizes one of the most problematic transition issues.

II. Market Issues: Private units are a defining characteristic of assisted living.

Permitting shared rooms and bathrooms weakens the distinctive features that make assisted living attractive. Diluting the marketing advantage of the term “assisted living” will only create market confusion and undermine ALQC efforts to define a consumer-driven approach to promoting quality. According to an industry survey done in 1996 for the Assisted Living Federation of

America (ALFA), only 14 percent of the nearly 15,000 units in 268 assisted living settings surveyed involved shared living units. Units almost always include private toilets (95.2%), private showers (79.8%) and/or bathtubs (33.8%), and refrigerators (67.4%).

Letting the market decide the private unit issue will not be adequate for the future.

In the absence of a requirement for private units, third party payers (especially public payers like the Medicaid program) will replicate the mistake made in the nursing home industry by reimbursing only shared rooms. The increasing participation of these third party payers makes the case for a strong standard for private living units more imperative.

“Not so hidden” costs in operating shared units offset much if not all of the increased cost of building private units.

Many providers report significantly higher operating costs with shared units due to increased staff requirements for conflict mediation, maintenance costs, and higher turnover and vacancy rates. An ALFA survey found an occupancy rate of 86.5% in semi-private units versus 95.1% in private units even with lower daily rates in the semi-private units – a very costly difference in the bottom line.

III. Regulatory Issues: Occupancy standards for reimbursements for assisted living should draw from those used in housing programs not from health care facilities.

The occupancy standards for subsidized housing programs require private units with bathrooms and kitchens that are shared only by resident preference. The fact that assisted living residents have higher levels of frailty does not mean that they are less deserving of standards of decency afforded other older people.

Permitting shared rooms blurs the distinction with nursing homes.

Occupancy standards in states permitting shared rooms often resemble those used in nursing homes, inviting regulators to view these facilities as re-creations of the intermediate care facilities eliminated by OBRA '87.

Requiring private units for assisted living would not preclude offering supportive services in settings with shared units that are regulated under other names.

Group homes, board and care facilities and nursing homes will continue to offer services with shared rooms even if assisted living regulations require private units. As long as each type of service is clearly defined and third party payers offer real choice, consumer choice should decide the market share controlled by different care settings. For example, in Oregon where private units are required in assisted living but the state also reimburses care in residential care facilities with shared rooms, the “market” for residential care has flourished – especially in dementia care. Oregon’s policy has promoted market diversification and innovation without diluting the distinctive qualities of assisted living.

States that permit shared units in assisted living settings should develop and enforce standards that adequately safeguard privacy.

Though we hope that states will require private units, those states that permit shared rooms should assure that acceptable levels of privacy is maintained by developing and enforcing standards in the following areas: visual barriers; auditory barriers; private possessions and furnishings; places for private conversations; access to windows and natural lighting; and procedures to deal with incompatible roommates.

WHY THE MARKET SHOULD DETERMINE WHETHER UNITS ARE SHARED OR PRIVATE

I. Regulatory Issues: Regulatory language that requires private units unless the resident chooses otherwise does not allow providers to build rooms to be shared and, therefore, does not give residents the right to choose.

Coalition members agreed that residents should have the right to choose whether to share a room or not. That choice is eliminated with regulatory language that requires private units. In effect, such language requires providers to build all private units in case no potential residents choose to share a room. Regulatory language needs to state that shared units are permissible in order to give providers the flexibility to build shared units. The popularity and continued growth of assisted living can be attributed to the ability of providers to create a variety of settings that addresses the varied needs and preferences of consumers.

II. Consumer Issues: Not being able to choose is incompatible with the philosophy of assisted living.

Consumer choice is one of the basic tenets underlying the philosophy of assisted living. That choice should extend to the environment in which a resident resides. This choice should extend to the consumer's choice to live alone, share an unit, share a bathroom and/or other amenities.

Consumers must make choices based on a variety of factors that often weigh one against another.

While most consumers may prefer a single-occupancy unit, a variety of personal factors will determine this choice. While one consumer may be adamant about living alone and is willing to sacrifice certain amenities to allow for this option, another may prefer to share a room because of the therapeutic benefits such as a decreased sense of isolation. For example, families and staff involved with caring for persons with Alzheimer's disease speak of the beneficial effects that sharing a room has on some persons with Alzheimer's disease. Cultural differences also play a role in determining whether an individual chooses to live alone.

Consumers may want to share a room because it makes assisted living an option they may not have otherwise.

Consumers may also choose to share a room for financial reasons. Current research shows that nearly 53 percent of assisted living residences have residents who receive financial assistance from

family/children, friends, churches, etc. Sharing a unit may allow some consumers to use their limited financial resources on necessary items or services and possibly extend the amount of time they will be able to afford to live in an assisted living setting. In the more extreme cases, sharing a room may be the only choice in making assisted living an actual option for a consumer who simply does not have the resources to afford a private unit in addition to any needed services.

III. Market Issues: The market needs to be able to continue to explore the development of affordable assisted living models.

Most providers are continually searching for ways to develop affordable models of assisted living. A current trend in assisted living development targets unique and affordable designs for the moderate to low income population. As the costs of the service component (personal care, ADL assistance, health monitoring, nursing/medical services) of assisted living continue to increase, it is imperative that providers be allowed to experiment with innovative designs that address resident preferences and decrease the overall development debt. For example, most assisted living residences allocate nearly 40 percent of a building's total square footage to common space. This allocation of space is consistent with the philosophy of many providers who promote the concept that the entire building is the "resident's home."*

One of the more costly building features is individual bathrooms. In developing an affordable product line, providers are experimenting with design, including two private units sharing a common, full bath. Some more innovative designs in facilities specializing in care for persons with Alzheimer's disease do not include private showers, while others have a ratio of six residents to one bathing/shower room.

IV. Public Reimbursement Issues: While public reimbursement for assisted living should be set to cover the costs of private rooms, this has not been providers' experience to date.

While Medicaid and other public reimbursement programs play a limited role in assisted living, this role should not go unrecognized. Ideally, governments should set rates at reasonable levels that include reimbursement for private units if desired by the consumer. In the experience of providers, however, this is not usually the case. The major concern of providers and developers, in fact, is that a requirement for private rooms will be met with reimbursement at a level that supports only shared space, making it financially untenable to responsibly manage a facility and ensure quality services.

Assisted living design continues to evolve especially in the ongoing development of affordable models. Providers must be given the flexibility in residential unit configuration and design to explore ways to deliver cost effective, personalized services in an affordable residential model available to consumers of all income levels. Consumers should be given the option of choosing from a variety of models in order to live comfortably in a setting that best meets their personal needs and preferences. After all, it is consumers who ultimately will dictate the shape and nature of assisted living through their purchasing decisions.

* An Overview of the Assisted Living Industry. Coopers & Lybrand, 1996.