

Topic Group Recommendations

Definition and Core Principles

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

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

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

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

Definition of Assisted Living

Part A: Services and Regulation

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

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

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

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

Rationale

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

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

Voting Record for Part A

1) Organizations Supporting Part A Without Qualification

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

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

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

Part B: Private Units

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

Rationale

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

Voting Record for Part B

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

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

4) Organizations Supporting Part B Only With Parts A & C

National Academy of Elder Law Attorneys

5) Organizations Opposed to Part B

American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Association for Regulatory Administration, Catholic Health Association, National Hospice and Palliative Care Organization

6) Organizations Abstaining From Voting on Part B

Alzheimer's Association, American Assisted Living Nurses Association, American Occupational Therapy Association, Joint Commission on Accreditation of Health Care Organizations, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Multiple Sclerosis Association, Pioneer Network

Part C: Levels of Care

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

Rationale

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

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

Voting Record for Part C

1) Organizations Supporting Part C Without Qualification

American Academy of Home Care Physicians, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, Consultant Dietitians in Healthcare Facilities,

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

2) Organizations Supporting Part C Only With Part A

American Medical Directors Association

3) Organizations Supporting Part C Only With Part B

National Association of Local Long Term Care Ombudsman, National Association of State Ombudsman Programs

4) Organizations Supporting Part C Only With Parts A & B

National Academy of Elder Law Attorneys

5) Organizations Opposed to Part C

AARP, American Association of Homes and Services for the Aging, American Seniors Housing Association, American Society of Consultant Pharmacists, Assisted Living Federation of America, Catholic Health Association, Consumer Consortium on Assisted Living, NCB Coming Home Program, National Center for Assisted Living, National Multiple Sclerosis Association

6) Organizations Abstaining From Voting on Part C

Alzheimer's Association, American Assisted Living Nurses Association, American Occupational Therapy Association, Joint Commission on Accreditation of Health Care Organizations, National Adult Family Care Organization, National Association of Social Workers, National Hospice and Palliative Care Organization, Pioneer Network

Voting Summary for Definition of Assisted Living

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

Supplemental Position on Parts A, B, and C

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

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

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

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

Supplemental Positions on Part A

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

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

By contrast, Part A relies on a model in which a resident's right to services is defined almost exclusively by the facility's admission contract. We emphatically reject this model. In almost all instances, an admission contract is a form contract signed by the resident or the resident's representative. For many, entry to assisted living occurs during an unsettled and stressful time.

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

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

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

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

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

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

This philosophy embraces the need to:

- Foster resident independence,
- Promote the individuality of each resident, and

- Nurture each resident's spirit.

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

Assisted Living Federation of America, National Association for Home Care

Supplemental Positions on Part B

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

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

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

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

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

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

The rationale for the proposed language asserts that resident dignity, autonomy and independence will not be achievable without private personal space that is controlled by the resident. The proponents of the proposed language are making a statement concerning their knowledge of how a resident's quality of care and quality of life is

affected without the benefit of asking residents who currently share units as to whether they agree with the statements that are being made on their behalf.

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

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

Supplemental Position on Part C

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

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

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

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

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

Core Principles

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

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

Organizations Supporting the Core Principles

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

Organizations Opposed to the Core Principles

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

Organizations Abstaining from a Vote on the Core Principles

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

Supplemental Position on Core Principles

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

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

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

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

