

# ***Topic Group Recommendations Adopted by Two-Thirds Majority of the ALW***

## **Direct Care Services**

### **Purpose**

The Direct Care Services Topic Group focused its efforts on the wellness and healthcare needs of ALR residents.

### **Issues**

The main focus of the topic group was in the areas of assessment, resident move-in and transfers, end-of-life and palliative care, dementia care, and wellness.

### **Participants**

The topic group was co-chaired by Doug Pace of the American Association of Homes and Services for the Aging and Jonathan Musher of the American Medical Directors Association.

Topic group participants included Linda Aufderhaar, National Association of Professional Geriatric Care Managers; Fred Cowell, Paralyzed Veterans of America; Marianna Grachek, Joint Commission on Accreditation of Health Care Organizations; Marsha Greenfield, American Association of Homes and Services for the Aging; Meg LaPorte, American Medical Directors Association; Karen Love, Consumers Consortium on Assisted Living; Katie Maslow, Alzheimer's Association; Cherry Meier, National Hospice and Palliative Care Organization; Constance Rowe, National Association of Home Care Physicians; Shelley Sabo, National Center on Assisted Living; Beth Singley, Assisted Living Federation of America; Bradley Schurman, American Assoc. of Homes and Services for the Aging; Ed Sheehy, Assisted Living Federation of America; Lisa Yagoda, National Association of Social Workers.

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**D.01 Pre-Move In Screening Process**

**Recommendation**

Elements of the Pre-Move In Screening Process

This is to be completed by appropriately qualified and trained individuals with active participation of the prospective resident\*.

1. Information and discussion of assisted living residence contract including resident and family expectations and resident rights, responsibilities and move in/move out criteria.
  
2. Information and discussion regarding the assisted living residence rate structure with full disclosure of rate charges and changes and third party payer information (e.g., Medicaid, LTC Insurance, and other Subsidies).
  
3. Written information regarding Advance Directives (e.g. Living Will, Durable Power of Attorney, and/or DNR).
  
4. History and Physical (including diagnoses, a list of current medications, and a TB screen). [These elements should be completed by the prospective resident's primary licensed healthcare provider (M.D., D.O., P.A., N.P.) who has seen the individual within the last 60 days prior to move in. The assisted living residence should obtain a signed release form from the resident to authorize the ALR to access the medical records of the prospective resident.]
  
5. Evaluation of the prospective resident's ability to self-administer medications or need medication reminders, or medication administration.
  
6. Evaluation of ADL's, IADL's, and risk factors (e.g. – falls, weight loss, elopement, self-neglect, abuse, exploitation).
  
7. Assessment of cognitive abilities and behavioral issues unless included in the prospective residents medical history. When indicated, a structured evaluation should be conducted (e.g. Folstein mini-mental health exam).

**Implementation**

Guideline for State Regulation

**Rationale**

To best assure that an assisted living residence can meet a prospective resident's needs and expectations, the residence will initiate a pre-move in screening. This process is initiated once a prospective resident requests admission into an assisted living residence and is concluded prior to admission.

**Organizations Supporting This Recommendation**

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of

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Consultant Pharmacists, Catholic Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Adult Family Care Organization, National Center for Assisted Living, National Hospice and Palliative Care Organization, Pioneer Network

**Organizations Opposing This Recommendation**

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

**Organizations Abstaining From the Vote on This Recommendation**

National Network of Career Nursing Assistants

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**Supplemental Positions for D.01**

1) We dissent. Pre-admission screenings are extremely important in determining whether an individual's needs can be met in an assisted living residence. Unfortunately, however, this recommendation has little content. Although the recommendation lists topic areas to be addressed, it does not specify how those areas are to be addressed, and contains no indication as to when a facility employee would be considered "appropriately qualified and trained" to conduct the screening.

Existing state laws do more to assure that screenings are meaningful. Virginia, for example, requires use of a Uniform Assessment Instrument to determine the appropriate level of care, based on the state's two-tier licensing system. The Uniform Assessment Instrument must be completed by a physician, a case manager, or a facility employee "with documented training in the completion of the UAI and appropriate application of level of care criteria." (Virginia Administrative Code, Title 22, §§ 40-71-10, 40-71-170(A)(1))

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

2) We support this recommendation. States should retain the flexibility to decide how to meet the intent of an appropriate recommendation in equally effective alternative ways.

We note the following points:

- Prescreening of a potential is generally not the point at which to conduct what amounts to a full assessment. What should be monitored is whether accurate, complete, and easy to understand information has been given to the prospective resident for the purpose of making an informed decision.
- No reference in the recommendation is made to obtaining any information about the prospective resident's lifestyle, preferences or desires, or even inquiring as to the reason(s) prompting the

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decision to move into the ALR.

· The pre-move in screening process is triggered when a resident requests admission into an ALR. There is nothing intrinsic to a resident's request to move-in that would necessitate an immediate discussion of advance directives or DNR orders. Indeed, some residents may find the timing of such a discussion as insensitive when all parties are working to ensure the consumer's transition into the ALR setting is a positive and welcoming experience.

· No rationale is offered as to why states must require assessments to be completed within 14 days of admission as opposed to another interval already specified in state regulation.

· No rationale is offered as to why states must require the pre-move-in screening process and initial assessment to be conducted as a two-step process.

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

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**D.02 Initial Assessment**

**Recommendation**

Elements of the Initial Assessment

When applicable, information from the Pre-Move In Screening Process may be used to complete the Initial Assessment. Initial Assessment should be completed by appropriate qualified and trained individuals with active participation of the prospective resident\*.

1. Physical history/exam (to be completed by a M.D., D.O., P.A., N.P.)
2. A Mental Health assessment, if appropriate (to be completed by a qualified, licensed, and/or certified professional based on observation, history and physical, or upon request)
3. Functionality: a) Assessment of ADLs; b) Assessment of IADLs; c) Assessment of risk factors (e.g. – falls, weight loss, elopement, self-neglect, abuse, exploitation).
4. Social Environment Factors (may be completed by a licensed and/or certified social worker or a trained staff member): a) Identify social interaction network (e.g.- cultural, spiritual, activities); b) Identify support resources (family, friends, etc.) and special needs c) Identify lifestyle preferences.
5. Obtain Advance Directives from resident if applicable.

Time Frame for Assessment to be Completed

Assessing medication requirements and information regarding advance directives and risk factors shall be completed immediately upon admission. All other components of the initial assessment shall be completed within 14 days of admission.

**Implementation**

Guideline for State Regulation

**Rationale**

The process of understanding, defining and measuring a resident's needs to ensure capable, comprehensive services is an on-going process in assisted living. After the pre-move in screening process, a more complete assessment process takes place upon admission. The purpose is to identify the resident's current needs and areas where support services may be needed as the Assisted Living Residence develops the resident's service plan.

**Organizations Supporting This Recommendation**

AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Association of Homes and Services for the Aging, American Association of Home Care Physicians, American College of Health Care Administrators, Assisted Living Federation of America, American Medical Directors Association, American Seniors Housing Association, American Society of Consultant Pharmacists, Association of Health Facility Survey Agencies, Catholic Health Association of the United States, Center for Medicare Advocacy, Consultant Dietitians on Healthcare Facilities, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care

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Organizations, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Local Long Term Care Ombudsmen, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Center for Assisted Living, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Hospice and Palliative Care Organization, National Network of Career Nursing Assistants, National Adult Family Care Organization, National Senior Citizens Law Center, Pioneer Network

**Organizations Opposing This Recommendation**

None

**Organizations Abstaining From the Vote on This Recommendation**

None

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**Supplemental Positions for D.02**

1) We support this recommendation. Although the recommendation gives an adequate description of the medical, functional and social components of an assessment, it does not adequately discuss that the focus of the assessment should be on using or identifying triggers or indicators to pursue additional information from the resident or as a cue to provide the resident with more information in a certain area.

*American College of Health Care Administrators, Assisted Living Federation of America, National Association for Home Care, National Association for Regulatory Administration, Joint Commission on Accreditation of Health Care Organizations*

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**D.03 Service Plan**

**Recommendation**

1. The assisted living residence shall develop a service plan for each resident. The service plan shall be customized to the needs and preferences of the resident (including flexibility in scheduling, delivery method, social activities, etc.) The resident shall actively participate in the creation of the service plan if they are able to do so.
  
2. The service plan shall be developed by appropriately trained and qualified staff, with input of direct care staff, in partnership with the resident\*. When appropriate, the resident's physician and outside healthcare and service providers shall assist in the development of the service plan. The resident's family will be invited to participate at the request of the resident.
  
3. The service plan shall be developed using information from the pre-move in screening process, initial assessment, and ongoing assessments.
  
4. The initial service plan shall be completed within 30 days of admission and signed by the assisted living residence and the resident\*. The ALR shall review the service plan 30-60 days after the completion of the initial service plan. The resident\* shall receive a copy of the initial and all subsequent service plans upon completion.
  
5. The service plan shall include both the services provided by or contracted by the assisted living residence and identify services contracted by the resident from outside agencies and health care providers.
  
6. When services are provided, a service plan should include the following: scope of services; the frequency of services; monitoring of the services being delivered; a review of the resident's goals/outcomes; and who is responsible for the delivery of service, including coordination responsibility between on-site and 3rd party service providers.
  
7. The service plan shall be reviewed semi-annually, and/or on significant change, and/or revised as the resident's needs or desires change. There shall be a system in place to identify significant change. The service plan is available to, discussed with, and implemented by the appropriate ALR staff.
  
8. With respect to services provided by third parties, who are contracted by the ALR, the assisted living residence shall have written policies and procedures addressing their charges, notification procedures, provider and/or resident selection and the monitoring of the services provided. The assisted living residence shall coordinate and monitor the services provided by all third parties contracted by the assisted living residence.

**Implementation**

Guideline for State Regulation

**Rationale**

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Resident assessments and service plans are two of the cornerstones of assisted living that help assure quality service and care. The preparation of an accurate resident assessment and individualized service plan is the first step in providing quality care in an ALR. Ongoing assessment of each resident's service and care needs, along with updating each resident's service plan when service and care needs/preferences change, is essential to providing continuous care.

A service plan is a document developed that identifies the needs and preferences of the resident and outlines how they will be achieved. The plan is developed through an organized collaboration between the ALR and the resident\*. The goal of the service plan is to promote positive outcomes.

Staff providing resident personal care is assigned primary responsibility for carrying out the service plan and performs the majority of the tasks outlined.

Because the resident's needs and wishes may change, the service plan is monitored on an ongoing basis to ensure that the services being provided as specified in the plan and the plan is adequate to meet the resident's needs.

ALR staff is responsible for observing and reporting changes in the resident's condition, with significant changes reported immediately.

### **Organizations Supporting This Recommendation**

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

### **Organizations Opposing This Recommendation**

Assisted Living Federation of America

### **Organizations Abstaining From the Vote on This Recommendation**

National Center for Assisted Living

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### **Supplemental Positions for D.03**

- 1) We support this recommendation, although we note that states retain the flexibility to decide how

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it will meet the intent of an appropriate recommendation.

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

## Direct Care

### D.04 Reasons for Resident Transfer or Move-out from an Assisted Living Residence

#### Recommendation

The following reasons may be given for transfer or move-out by the resident or ALR:

1. The resident desires to move.
2. Following a documented assessment, ALR is no longer able to care for the resident due to his/her physical, or mental/cognitive status or behavioral issues based on the scope of services offered or coordinated by the ALR as disclosed to the resident upon move-in and as required by, state licensing requirements; and, wherever practical and except in an emergency, the ALR has attempted to work with the resident\* so that move-out or transfer would be unnecessary and this attempt has been unsuccessful.
3. The resident fails to pay or arrange payments for services rendered or other material breaches of contract, after reasonable and appropriate notice to the resident\* by the ALR of the nonpayment or material breach.
4. The resident's behavior or conditions presents a direct and serious threat to the well-being or safety of the resident or other residents or staff.
5. The ALR has the right to make a temporary emergency transfer of a resident in the event of imminent and serious danger to the life or safety of the resident or to other residents. In the event of an emergency, the ALR may conduct such transfer without advance notification, although the ALR should make a good faith effort to contact the family or responsible party at the earliest opportunity.
6. The ALR ceases to operate.

#### Implementation

Guideline for State Regulation

#### Rationale

When the Assisted Living Residence cannot meet the resident's needs, limitations of its scope of services, or according to law and regulation, the resident may need to move to another setting or a different level of care.

In all such cases, every effort is made to minimize the trauma associated with the move or transfer. The transfer or move-out should be conducted in a manner that is safe and dignified for the resident.

Move-out due to nonpayment should be reserved for instances when rent and/or fees have been unpaid for 30 days or more beyond the due date. The ALR should provide information on government or private subsidies that may be available to help the resident with costs.

The Assisted Living Workgroup recognizes that a resident has certain rights and protections under federal statutes, including the Americans with Disability Act, the Fair Housing Amendments Act, and the Rehabilitation Act of 1973. The applicable provisions of these statutes generally prohibit discrimination against individuals in protected categories and require reasonable accommodation and program accessibility.

In some instances, the ALR may not be required to make an accommodation if the

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modification would impose an undue financial or administrative burden or would require the ALR to fundamentally alter the nature of its program.

A full and complete examination of the circumstances under which these statutes may apply to a specific case involving an involuntary transfer or move-out is beyond the scope of this discussion. However, state agencies and providers should consider how these rights and protections apply to involuntary transfer or move-out requirements, as the federal statutes may take precedence over state regulations permitting an involuntary transfer or move-out.

In some states, involuntary transfer or move-out from an ALR is governed by the state's landlord-tenant laws. In these states, the state agency generally cannot force the resident to move and the resident will have the opportunity to raise any claims regarding the statutes cited above in a Housing Court proceeding.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

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

**Organizations Abstaining From the Vote on This Recommendation**

None

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**Supplemental Positions for D.04**

1) We dissent. This recommendation, in combination with other recommendations, gives an assisted living residence excessive authority to evict a resident when the resident's needs increase, rather than requiring a reasonable effort to accommodate those needs. The recommendation's reference to the scope of services "required by state licensing requirements" is disingenuous, because the recommendations themselves (including all of the "guidelines for state regulation") do not require assisted living residences to provide any particular level of service. Whenever this issue was raised in the Workgroup, provider representatives refused to adopt any required level of service, maintaining that assisted living residences had to retain the "flexibility" to evict residents.

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We recommend that states adopt levels of care within assisted living – for example, Idaho’s three-level system of Level I - Minimal Assistance, Level II - Moderate Assistance, and Level III - Extensive Assistance. (Idaho Administrative Code § 16.03.22.010) This type of system lets a resident know what needs can be met.

The majority’s recommendation admittedly obligates an assisted living residence to provide the services disclosed at admission. This disclosure is not an adequate safeguard, given that these disclosures can be written in a vague way and, at the time of admission, a resident choosing among assisted living residences has little ability to understand disclosures relating to services.

The rationale references a facility’s obligations under federal anti-discrimination law, but a resident should not have to file a federal lawsuit in order to obtain needed services. A level-of-care system would address this problem so that it could be remedied within a state’s regulatory system, in response to a resident’s complaint.

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

2) We dissent. Although we support this recommendation in principle, it goes beyond the mandate to the ALW to specifically address the issue of adequate notice upon discharge.

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

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**D.05 Protocols for Resident Transfer or Move-out from an Assisted Living Residence**

**Recommendation**

After the criteria to initiate a move-out of a resident have been met, subject to any appeal rights held by the resident the ALR transfers or moves a resident only after providing the resident with:

1. A meeting will be coordinated with the resident and ALR staff to review the conditions for transfer or move-out. The ALR will assist the resident\* in identifying other appropriate alternative settings.
2. Except in an emergency, advance written notice that includes the reason for the transfer or move-out and the approximate date when the transfer or move-out will occur. A simple and expeditious appeals process should be available to allow the resident and family the opportunity to dispute the transfer/move-out, but does not unduly prolong or exacerbate the situation that led to the ALR's or State's decision;
3. Information on the availability of assistance and support services to help the resident make the transfer or move-out to a setting which is adequate and appropriate for the resident.
4. The ALR shall prepare a move-out summary which includes pertinent information regarding the resident's physical and mental and cognitive status and a list of current medications.
5. A copy of all pertinent resident records, including when an emergency transfer occurs

**Implementation**

Guideline for State Regulation

**Rationale**

The protocols listed in this recommendation are triggered when the ALR initiates the process to transfer or move-out or at the resident\* request.

The protocols are intended to minimize the trauma to a resident as a result of a transfer or move out and to ensure the process is conducted in a manner that is safe and dignified for the resident, balanced with scope of services of the ALR and considers the needs and safety of the other residents and staff.

The Assisted Living Workgroup recognizes that a resident has certain rights and protections under federal statutes, including the Americans with Disability Act, the Fair Housing Amendments Act, and the Rehabilitation Act of 1973. The applicable provisions of these statutes generally prohibit discrimination against individuals in protected categories and require reasonable accommodation and program accessibility.

In some instances, the ALR may not be required to make an accommodation if the modification would impose an undue financial or administrative burden far exceeding what could have been reasonably anticipated upon admission or would require the ALR to fundamentally alter the nature of its program.

A full and complete examination of the circumstances under which these statutes may

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apply to a specific case involving an involuntary transfer or move-out is beyond the scope of this discussion. However, state agencies and providers should consider how these rights and protections apply to involuntary transfer or move-out requirements, as the federal statutes may take precedence over state regulations requiring an involuntary transfer or move-out.

In those states where transfer/move-out is governed by landlord-tenant or other applicable state law, the resident and family may have the opportunity to appeal the ALR's decision. The court or appropriate state agency may require, and the ALR should provide service and discharge planning and information on the availability of services as described above.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

None

**Organizations Abstaining From the Vote on This Recommendation**

None

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**Supplemental Positions for D.05**

1) We dissent. Although we support this recommendation in principle, in our view, it goes beyond the mandate to the Assisted Living Workgroup to provide guidance to the states on matters that will improve quality in assisted living.

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

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### D.06 Palliative Care

#### Recommendation

1. An ALR will provide, within its scope of services offered, care and support for each resident so that he/she may live as fully and as comfortably as possible within the context of the resident's values and symptoms. These outcomes are accomplished when:
  - The resident\* is provided with accurate and timely information to make treatment decisions.
  - The service plan supports the resident's choices that are consistent with the resident's advance directives, values, spiritual preferences, and life-long living patterns, even though these decisions may involve increased risk or personal harm to the resident.
2. Procedures are in place to assure that the resident receives timely attention to palliative care needs.
3. ALR staff report observations of discomfort, adverse reaction/behaviors to an ALR supervisor or qualified health care professional.
4. ALR staff assists the resident in maximizing independence as the resident's functional capacity changes.

#### Implementation

Guideline for Operations

#### Rationale

Palliative care includes any comfort measure that will prevent, relieve, reduce, or soothe the symptoms of disease or disorder without affecting a cure. As such, palliative care can be provided throughout an individual's life, although it is usually associated with the end-of-life or hospice.

Comfort care can become a controversial issue when a resident makes a decision to forego treatment that others judge to be of benefit. For example, a resident decides to stop further chemotherapy, refuses surgery, or decides to terminate dialysis. Quality of life can only be defined by the resident\*. The responsibility of the ALR staff is to direct the resident to resources regarding palliative care. Treatment decisions are driven by the values and preferences of the resident\*. Advance directives, if executed, are a primary source of information.

Studies conducted on end-of-life issues have found that individuals prefer to die at home, surrounded by their loved ones, without pain. The ALR is home and residents may not want to be taken to the hospital or transferred to a nursing facility when they are bedbound or near death. ALR staff may be uncomfortable with death in the facility and feel that they are not capable of meeting the resident's needs. These issues can only be resolved with open communication among the resident, family, and ALR staff. At this point, it may be necessary to consider additional services from outside providers, such as home health agency or hospice.

#### Organizations Supporting This Recommendation

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

**Organizations Opposing This Recommendation**

None

**Organizations Abstaining From the Vote on This Recommendation**

Assisted Living Federation of America

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**Supplemental Positions for D.06**

1) We dissent. Although we support this recommendation in principle, in our view, it goes beyond the mandate to the Assisted Living Workgroup to provide guidance to the states on matters that will improve quality in assisted living.

Further, it preempts state and ALR flexibility to decide how to will meet the intent of an appropriate recommendation to improve quality in equally effective ways.

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

## Direct Care

### D.07 Hospice Care

#### Recommendation

1. If the ALR is able to provide or arrange for the provision of hospice care, the ALR should inform terminally ill residents\* of the availability to receive hospice care at the ALR. The ALR should identify and make available to residents\* information about hospice services and the names and addresses of providers in the geographic vicinity.
2. When a terminally ill resident is receiving hospice care, transfer from the ALR may not be required, if the needs are being met.
3. The ALR and hospice communicate, establish, and agree upon a coordinated service plan that reflects the hospice philosophy and is consistent with regulatory requirements.
4. The service plan identifies the provider/caregiver/family member that is to be held responsible for implementing the service plan.
5. The ALR and hospice determine a process by which information from the hospice interdisciplinary team and the ALR interdisciplinary team will be exchanged when developing, and evaluating outcomes of care and updating the service plan.

#### Implementation

Guideline for Operations

#### Rationale

A person becomes eligible for Hospice Care when a physician certifies that they have a terminal illness. Individuals living over six months are not discharged from the program unless it is determined, by a physician, that the prognosis is greater than six months. The Hospice Benefit is covered under Medicare and Medicaid (in all but a few states). When an individual elects the Hospice Medicare/Medicaid benefit, they elect to receive palliative care. They may still receive curative care if it is unrelated to their terminal illness. At any time, an individual may revoke the Hospice Benefit and return to treatment under Medicare Part A/ Medicaid. The ALR should be aware of the hospice providers in the community and explore potential opportunities to collaborate.

The Conditions of Participation as a hospice provider stipulate that when a Medicare/Medicaid beneficiary elects to receive hospice care, the hospice assumes professional management and financial responsibility for care related to the terminal illness. This care extends across settings from the person's home, personal care home, assisted living residence, nursing facility, or hospital. For this care, the hospice is reimbursed a per diem rate that is all-inclusive of care, without any additional expense to the individual/family. Services included in the hospice benefit are:

- professional care from the interdisciplinary team;
- supplies;
- medications related to the terminal illness;
- durable medical equipment.

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Hospice providers are required to have contracts with hospitals so that if an individual requires more intense care, it can be provided. Hospice providers may also have available staff to provide continuous care at the person's bedside. The intensity and level of care is based on the needs of the individual/family and adjusted as necessary.

Hospice programs provide state-of-the-art palliative care and supportive services to individuals at the end of their lives, their family members and significant others. On-call support is available 24 hours a day, seven days a week, in both the home and facility base settings. Physical, social, spiritual, and emotional care is provided by a clinically-directed interdisciplinary team consisting of physicians, nurses, aides, social workers, clergy, and volunteers. The hospice physician provides guidance to the team and is available for consultation with the primary physician, or in some cases may assume the role as primary physician.

Hospice provides support and care for persons in the last phase of a terminal condition so that they may live as fully and as comfortably as possible. Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life. Hospice affirms life and neither hastens nor postpones death.

### **Organizations Supporting This Recommendation**

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

### **Organizations Opposing This Recommendation**

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

### **Organizations Abstaining From the Vote on This Recommendation**

None

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### **Supplemental Positions for D.07**

1) We dissent. There are no standards in this recommendation. Care for terminally-ill residents is possible "[i]f the ALR is able to provide or arrange for the provision of hospice care."

The recommendation suggests wrongly that the presence of a hospice agency is sufficient, regardless of the staffing and expertise of the assisted living residence. In fact, hospice care is supplemental

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care (generally funded by Medicare) for terminally ill persons. Hospice agency employees are visitors that generally see a patient for only a few hours each day.

This weak recommendation is a step backwards. In many states, an assisted living residence can accommodate a hospice care program only if the facility meets certain statutory or regulatory requirements. In California, for example, an assisted living residence can house terminally ill residents only after the facility has demonstrated its competence to the California Department of Social Services, received the appropriate approval from the Department, and then entered into an agreement with a hospice agency. (California Health & Safety Code § 1569.73)

Terminally-ill individuals often present significant health care problems, and need consistent emotional support. Visitation by a hospice agency is not a panacea and, in any case, a hospice agency may fail to carry out its responsibilities. By failing to even take into account the capabilities and responsibilities of an assisted living residence, this recommendation would jeopardize the quality of care provided to terminally ill residents.

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

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident- centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

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

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**D.08 Advance Directives**

**Recommendation**

Assisted Living providers shall complete the following tasks related to advance directives upon admission and when appropriate.

1. Inquire whether the resident has an advance directive and, if so, request a copy of the advance directive for the ALR's records. If a copy is not provided, the residence shall document whether the resident\* indicates he or she has an advance directive and, if a health care proxy has been appointed, the name and contact information of the proxy. The ALR shall update this information at least annually, again seeking to include a copy of the current directive in the facility's records.
2. Provide the resident\* with an explanation of one's rights under state law to make decisions about medical care, including the right to accept or refuse medical and surgical treatment, and the right to formulate advance medical directives, such as a living will or durable power of attorney for health care, or comfort care only order (DNR order). The explanation approved for hospitals, nursing facilities, hospices and home health agencies by the state's medical assistance program under the federal Patient Self-Determination Act may be used for this purpose.
3. Provide the resident\* with an explanation of ALR's policies regarding the delivery of end-of-life care in the residence, including the delivery of hospice and palliative care (pain management), and the use of comfort care only orders (i.e., do-not-resuscitate orders).
4. Take reasonable steps to ensure transfer of the resident's advance directive, or information regarding its existence, to the hospital or other facility.

**Implementation**

Guideline for Operations

**Rationale**

As part of the ALR's pre-move in screening process, the ALR is obtaining information from the resident\* concerning advance directives. In some instances, the resident\* may not have advance directives, nor understand the benefit/risks of having them. It would be beneficial for the residence to have copies of forms accepted by state law and be able to provide information to the resident\* to make an informed decision.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

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Assisted Living Federation of America, Center for Medicare Advocacy, National Association of Local Long Term Care Ombudsmen, National Association of State Ombudsman Programs, National Association for Regulatory Administration, National Citizens' Coalition on Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

**Organizations Abstaining From the Vote on This Recommendation**

Association of Health Facility Survey Agencies,

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**Supplemental Positions for D.08**

1) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident- centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

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

**Direct Care**

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**D.09 Do Not Resuscitate Orders (DNR)**

**Recommendation**

ALRs should clarify a resident's resuscitation status on admission and with subsequent changes in condition. If the State has regulations regarding out-of-hospital DNR, the ALI should provide the resident\* with information to help assure that their treatment decisions are followed. The ALR should contact the physician to obtain appropriate orders.

**Implementation**

Guideline for Operations

**Rationale**

To provide portability to a DNR order, some states have regulations regarding resuscitation outside the hospital setting. These regulations were developed to assist Emergency Medical Technicians, Emergency Room personnel, and anyone else responding to a code situation, that the individual does not want resuscitation. Some states have designated devices such as a necklace or bracelet; however, this varies among states. This allows the individual to carry on their normal routine without fear of receiving resuscitation.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

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

**Organizations Abstaining From the Vote on This Recommendation**

None

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**Supplemental Positions for D.09**

1) We dissent. This recommendation evades the central issue – can an assisted living residence honor a DNR order or, more specifically, what does an assisted living residence do when a resident with a DNR order needs resuscitation in order to live?

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Currently many assisted living residences do not have licensed health care professionals on staff. As a result, depending on state law, it often is unclear whether these facilities are allowed to honor DNR orders. In many instances, when a resident suffers a heart attack or similar event in a facility, CPR is initiated and/or the paramedics are called, even if the resident and the resident's physician specifically have requested a DNR order.

We recommend that a level of care system be adopted within assisted living, that the highest level require nurse staffing, and that assisted living residences licensed at the highest level be required to honor DNR orders. Such a system would allow residents' health care desires to be honored, and would guarantee that decisions to withhold CPR would be made by qualified health care professionals.

As is noted in other of our dissents, the majority consistently was unwilling to develop levels of care, or to draw distinctions based on a facility's capacity to provide health care services. As a result, this majority recommendation (particularly the rationale) leaves largely to paramedics the job of deciding whether and to what extent to honor a resident's DNR order. We dissent because we believe that residents deserves an assisted living residence that is qualified to do more than just call 9-1-1.

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

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident- centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

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

**Direct Care**

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**D.10 Identification of Cognitive Impairment/Dementia**

**Recommendation**

The assisted living residence shall have in place procedures to 1) increase staff awareness of signs and symptoms of cognitive impairment/dementia in a resident, 2) evaluate or obtain an evaluation of the resident's cognitive status as it relates to the resident's ability to manage his/her own affairs and direct his/her own care, and 3) adapt the resident's service plan to meet his/her needs, given the resident's cognitive status.

These procedures should include:

1. Training for all staff members shall include information about the signs and symptoms of cognitive impairment/dementia.
  
2. When cognitive impairment is identified, staff should strongly encourage the resident and his/her family to obtain a diagnostic assessment by an appropriately trained and qualified professional in order to determine the cause of the cognitive impairment.
  
3. When cognitive impairment is identified, whether or not the resident has received a formal diagnosis of Alzheimer's disease, another dementing disease or condition, or another condition that causes cognitive impairment, staff shall evaluate the impact of the cognitive impairment on the resident's ability to manage his/her own affairs and direct his/her own care; issues of physical safety, ability to manage medications, and need for a surrogate decisionmaker shall be addressed in this evaluation; the resident and his/her family should be included in this evaluation as much as possible.
  
4. The resident's service plan should be revised to incorporate any changes needed because of his/her cognitive impairment. Since many diseases and conditions that cause cognitive impairment in elderly people are progressive, the resident's service plan should include a timetable for reevaluation.

**Implementation**

Guideline for State Regulation

**Rationale**

Available data indicate that 27-64% of assisted living residents have cognitive impairment but the condition often is not recognized and may not be considered important by assisted living staff. Hawes and Phillip, in their study of assisted living residences, found that 88 percent of staff members who provided or supervised direct resident care believed that memory loss and confusion are part of normal aging. Even in the case of sudden onset of these conditions, 9 percent of staff members believed nothing should be done because the conditions are part of normal aging. These beliefs jeopardize resident safety, interfere with timely identification of serious medical conditions that can cause sudden onset of cognitive impairment, and deprive staff of information they need to provide appropriate care.

In the case of sudden onset of cognitive impairment, diagnosis of the condition causing the change is critical. In the case of more gradual onset and progression, diagnosis is also

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important; however, a diagnosis of Alzheimer's disease or another dementing disease or condition does not establish the level of cognitive impairment or the person's self-care capacity.; in this case, for the purposes of assisted living providers, diagnosis of the cause of cognitive impairment/dementia is less important than the evaluation of its impact on the person's self-care capacity and ability to manage their own affairs.

Some people will be admitted to the assisted living facility with cognitive impairment. Others will become cognitively impaired as time passes. Assisted living staff members can be trained to recognize common signs and symptoms of cognitive impairment in residents. All staff should receive this training, even if the assisted living facility has a special dementia care unit, since some residents who are not in that unit are very likely to have to develop cognitive impairment over time.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

None

**Organizations Abstaining From the Vote on This Recommendation**

Assisted Living Federation of America, American Seniors Housing Association

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**Supplemental Positions for D.10**

1) We respect the fact that many states have set additional requirements for ALRs that seek a special designation to serve people with cognitive impairments. However, we do not attempt to prescribe the specific procedures that a state must regulate.

Residents with mild to moderate dementia can still participate in care decisions and express life long values and wishes regarding the care they are currently receiving. Therefore, our recommended guidance to the states and ALRs is to consider a quality monitoring component that focuses on the perspective of the resident and other responsible parties to look beyond the procedures, and to see if the resident and other affected parties feel that their choices are being respected, their needs are being met, and their opinion is sought as to the quality of the services provided.

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Examples of suggested areas for quality monitoring could include:

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

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

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### **D.11 Care for People with Cognitive Impairment/Dementia and Dementia Special Care Units and Facilities**

#### **Recommendation**

##### Part 1: Care for People with Cognitive Impairment/Dementia

ALRs shall have in place procedures and services that 1) meet the needs of residents with cognitive impairment/dementia, 2) accommodate and balance concerns about safety and autonomy, 3) recognize and build on strengths, capacities, choices, and values of the resident, and 4) reflect the likelihood that the cognitive status of many of these people will change and deteriorate over time. Such procedures and services include:

1. Staff training about cognitive impairment, dementia, and dementia care;
2. Procedures for assessing and reassessing the resident's cognitive status, abilities, and related care needs;
3. Procedures, including supervision, to help direct care staff understand and respond effectively to residents' behavioral symptoms;
4. Specialized activities that are appropriate for residents with cognitive impairment/dementia;
5. Procedures for working with the resident and the resident's family to define and clarify responsibilities of the resident, the family, and the facility;
6. Procedures for designating and working with a surrogate decision maker, if the resident is not capable of making decisions for him/herself;
7. Policies and procedures to protect residents who wander and/or are at risk of physical harm;
8. Regular monitoring to assure resident safety and health care status, consistent with impairment; and
9. Policies and procedures for involving and supporting family members.

Resident needs related to cognitive impairment/dementia differ depending on the severity of the cognitive impairment. An ALR should have in place procedures and services that are appropriate for the severity of cognitive impairment of its residents.

##### Part 2: Dementia Special Care Units and Facilities

ALRs that choose to serve only individuals with cognitive impairment/dementia or to establish a special dementia unit or units(s) should define precisely the purpose of the unit(s) and develop admission and discharge criteria, staff training activity programs, and physical design features that are consistent with that purpose.

#### **Implementation**

Guideline for State Regulation; Operations

#### **Rationale**

##### Part 1: Care for People with Cognitive Impairment/Dementia

Diseases and conditions that cause cognitive impairment/dementia result in problems with memory, judgment, reasoning, communication, orientation, awareness, and other cognitive abilities. Assisted living residents with cognitive impairment/dementia generally need the same services and help as those who are cognitively intact and some additional services

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that are directly related to these problems. The list of needed services and procedures above is intended to include only those additional services.

Residents with cognitive impairment/dementia are likely to need help with decision making because of condition-related problems with memory, judgment, and reasoning. Some residents with cognitive impairment/dementia have a court-appointed guardian who can make decisions for them, but many do not. For those residents, state laws designate certain relatives and others who can function as surrogate decision makers for people who are not capable of their own decisions. ALRs should be aware of the relevant state laws. At the same time, it is important to note that many individuals with cognitive impairment/dementia are capable to make some or all of their own decisions.

### **Part 2: Dementia Special Care Units and Facilities**

Available data show that 27-64 percent of assisted living residents have cognitive impairment/dementia. Some assisted living residences serve only individuals with cognitive impairment/dementia; some have one or more physically separate, dementia special care units; and many do not have dementia special care units. In a 1997/98 study of 2,078 residents of a stratified random sample of 233 assisted living residences in four states, Zimmerman et al. found that 8 percent of small facilities (4-16 beds), 8 percent of large, traditional model facilities (16+ beds), and 25 percent of large, new model facilities (16+ beds and built after 1987) had physically separate care areas for residents with cognitive impairment/dementia. Of all residents with moderate or severe cognitive impairment/dementia in the 233 facilities, 11-32 percent were in these physically separate areas; thus 68-89 percent of residents with moderate or severe cognitive impairment/dementia were not in physically separate areas.<sup>1</sup>

Since it is likely that most assisted living residents with cognitive impairment/dementia will not be in a dementia special care unit or an ALR that serves only individuals with cognitive impairment/dementia, the existence of these units and facilities does not eliminate the need for appropriate procedures and services, as described in Part 1 above, for residents with cognitive impairment/dementia in other units and facilities. State regulations for dementia special care units and facilities generally do not apply to the care of residents with cognitive impairment/dementia who are not in dementia special care units and facilities.

ALRs that choose to serve only residents with cognitive impairment/dementia or to establish one or more dementia special care units should define precisely their policies, procedures, and services in the following areas:

1. Purpose of the unit(s): the ALR could, for example, establish a special care unit that provides special supervision or monitoring, a secured unit to deter elopement, or a unit intended to serve residents with particular behavioral symptoms;
2. Admission criteria: the ALR could, for example, create criteria that admit individuals at a particular stage or stages of a dementing illness, or anyone with a diagnosis of a dementing illness, or individuals with particular behavioral symptoms.
3. Discharge criteria: the ALR could, for example, create criteria that discharge individuals who reach a particular stage of their dementing illness, or individuals whose behavioral symptoms have mitigated sufficiently that they can return to a regular unit.

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4. Staffing ratios and staff training requirements: the ARL could, for example, provide more staff on all shifts or certain shifts in the special care unit; the ARL could also create training requirements that go beyond the dementia care training provided for all direct care staff or that focus on particular behavior management approaches.
5. Activities: the ARL could, for example, provide specialized group activity programs or special dining arrangements in the special care unit.
6. Physical design or environmental features: the ARL could, for example, create a special care unit with physical design features that assist residents to find their way and identify their own room and other rooms (such as the bathroom), and/or a protected area for wandering.

This recommendation applies to activities of the ALR that shall occur before disclosure. Once an ALR has defined the purpose of its special care unit and created policies and procedures that fit the purpose, then it should disclose the relevant information to prospective residents\*.

1. Sloane, P.D. Zimmerman, S, and Ory, M.G., "Care for Persons With Dementia," in *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, S. Zimmerman, P.D. Sloane, and K Eckert (eds.) (Baltimore, MD: Johns Hopkins University Press, 2001).

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

American Association of Homes and Services for the Aging, Assisted Living Federation of America, Association of Health Facility Survey Agencies, National Network of Career Nursing Assistants Center for Medicare Advocacy, National Association for Regulatory Administration, National Committee to Preserve Social Security and Medicare, National Senior Citizens Law Center

**Organizations Abstaining From the Vote on This Recommendation**

National Citizens' Coalition on Nursing Home Reform, National Academy of Elder Law Attorneys

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**Supplemental Positions for D.11**

- 1) We dissent. The gist of the recommendation is that a facility is required to develop policies related to dementia care, and those policies must address certain areas. We dissent because there is

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no specificity as to what those policies might be. What type of staff training is appropriate for assisted living residences caring for residents with dementia? To what extent is the participation of a physician or nurse required? The recommendation takes no position on these and many other important questions.

Part 2 of the recommendation, pertaining to “Dementia Special Care Units and Facilities,” is particularly without content. For example, according to the rationale, a unit could be considered “special care” if it had criteria that allowed for discharge of residents whose dementia reached a specific level. This anything-goes definition of “special care” is wholly unfair to consumers, who would assume reasonably – but mistakenly -- that “special care” would be some indication of quality or expertise.

Existing state law has done a better job of establishing meaningful standards for the care of residents with dementia. In Alabama, for example, a “Specialty Care Assisted Living Facility” provides specialized care for residents with dementia. A physician must act as a medical director, and a registered nurse must perform assessments. Regulatory minimums are set for staff training, staff levels, and other important matters. (Alabama Administrative Code r. 420-5-20-.04, 420-5-20-.06, 420-5-20-.08)

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

2) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW’s recommended “guidance” to the states does not, as the Senate Special Committee on Aging asked, define “what quality assisted living should look like.” Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident- centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident’s values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

While we support the intent of this recommendation, we believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation.

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

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**D.12 Senior Wellness Programs in ALRs**

**Recommendation**

The assisted living residence may design and provide a senior wellness program that fits the overall needs of its residents. If components of a senior wellness program are unable to be offered on-site, the assisted living residence may make available community contacts for residents who desire services.

Components of a Senior Wellness Program, beyond what is required under state regulations, may include:

- Mental Health/Psychosocial Programs and Screenings
- Health Screenings (e.g., blood pressure; cholesterol)
- Nutritional counseling
- Physical exercise programs (e.g., walking programs, weight training for seniors)
- Recreational/activity programs
- Spiritual Enrichment
- Health educational seminars
- Holistic Therapies (e.g., aromatherapy; massage therapy; music therapy)

**Implementation**

Guideline for Operations

**Rationale**

Wellness programs have the ability to improve the quality of life for ALR residents from a holistic approach. Providing residents with wellness programs that include educational resources, physical activity programs and community referral sources may result in greater understanding of certain conditions associated with aging and prevent issues and illnesses from occurring.

**Organizations Supporting This Recommendation**

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

**Organizations Opposing This Recommendation**

Assisted Living Federation of America

**Organizations Abstaining From the Vote on This Recommendation**

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Center for Medicare Advocacy

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**Supplemental Positions for D.12**

1) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW's recommended "guidance" to the states does not, as the Senate Special Committee on Aging asked, define "what quality assisted living should look like." Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident-centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident's values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

We believe it gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation. Further, the recommendation would likely have a disproportionate impact on small providers who lack the resources to put into place all of the recommended components beyond what is already required under existing state regulations.

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

## ***Topic Group Recommendations That Did Not Reach Two-Thirds Majority***

### **Direct Care Services**

*The following recommendations did not reach a two-thirds majority of the ALW. The recommendations showing a voting record were unable to reach two-thirds majority at the final vote. The recommendations that do not show a voting record were unable to reach two-thirds majority during the development process.*

## Direct Care

### D.13 Shared Responsibility Agreement

2/3 Maj. Not Reached

#### Recommendation

Shared Responsibility Agreements are a tool for communications. They may be exercised when the resident\* is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR. As an extension of the Service Plan, the ALR and the resident\* may enter into a Shared Responsibility Agreement. The Shared Responsibility Agreements should cover the exception not the rule.

Shared responsibility shall not be a waiver of liability. A shared responsibility agreement is simply a written agreement between both parties--the Assisted Living Residence and the resident\*--which memorializes the parties' discussions and agreements regarding the resident's preferences and how they will be accommodated in the community.

Shared Responsibility Agreements may be used when any or all of the following are true:

- There is a deviance from an accepted standard.
- There is a lack of consensus on a course of action.
- The risk of an adverse outcome is high.

The goals of the Shared Responsibility Agreement are:

- Empower the resident to exercise choice regarding service delivery (within established boundaries).
- Identify resident preferences
- Perform a realistic assessment of potential harm due to resident preferences.
- Identify potential outcomes
- Seek consensus around decision.
- Document process of negotiation and decision.
- Provide acknowledgement of the discussion

A Shared Responsibility Agreement should:

- Identify the cause for concern.
- Identify the probable consequences of the resident's choice.
- Make clear what the resident wants.
- Describe possible alternatives.
- Set forth the final agreement.
- Decide what staff will be notified of the agreement and how often follow-up is necessary
- Agreement is signed by the ALR and the resident\*.

#### Implementation

Guideline for Operations

#### Rationale

The agreement itself is an extension of the service plan and the end product of a process in which the Assisted Living Residence, or the ALR and the resident together, identify a resident preference (e.g., to engage in or avoid certain activities or behaviors) which the ALR normally would not recommend or allow, or would remove, because they involve unacceptable risk to the health and safety of the resident or others in the ALR.

**Direct Care**

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Ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident.

Recognition of the need for a shared responsibility agreement normally arises in one of three ways. In some cases, a resident will verbally express to ALR staff a desire to engage in certain activities or behaviors that normally would be prohibited. In other cases, ALR staff may raise the issue where a resident repeatedly engages in behaviors which normally would not be allowed for that resident. Occasionally, third parties such as family members, or ombudsman or other resident advocates may suggest a shared responsibility agreement to resolve complaints or concerns raised by a resident or family.

**Organizations Supporting This Recommendation**

No Vote Recorded

**Organizations Opposing This Recommendation**

**Organizations Abstaining From the Vote on This Recommendation**

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**Supplemental Positions for D.13**

1) Many states are requiring shared responsibility or negotiated risk agreements as a part of the management of services in assisted living residences. Recommendation D.13 does an excellent job of describing the legitimate uses of such agreements, they are “a tool for communication” between residents and providers where residents are empowered to exercise choices in activities and expect services according to their preferences.

The recommendation also makes it very clear what are not legitimate uses of such agreements: “Shared responsibility shall not be a waiver of liability.” While providers may reasonably use such agreements as part of their risk management policy, nothing in such agreements absolves providers from responsibility for negligent actions.

Perhaps the most useful part of the recommendation is its detailed outline of a process for negotiating such agreements. Many states require negotiated risk or shared responsibility agreements without providing guidance on how they should and should not be developed. The process recognizes that the provider has a responsibility to identify the consumer’s preferences as well as potential risks that may be associated with certain behaviors. The process also recognizes that not all courses of action are possible or reasonable, but that resident preferences should be honored even when the provider does not believe them to be in the resident’s best interest.

The undersigned organizations believe that this recommendation strikes the right balance between the resident’s preferences and the provider’s responsibility to provide services within a safe environment. It provides much needed guidance to states as they move into this relatively uncharted area of the law.

*AARP, American Association of Homes and Services for the Aging, American Seniors Housing Association, Catholic Health Association of the United States, Consumer Consortium on Assisted Living, NCB Development Corporation, Association of*

**Direct Care**

*Professional Geriatric Care Managers, National Center for Assisted Living, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network*

2) We oppose this failed recommendation. This recommendation is confusing and unnecessary, and seems to reduce a resident's right to make choices.

It is unclear what type of real-world fact pattern would require the use of a "shared responsibility agreement," particularly given the availability and general acceptance of the care planning process. Although "shared responsibility agreements" purportedly are designed to advance resident choice, they actually diminish resident choice, as shown by the fact that they are to be employed when the resident "is not complying with the goals and outcomes listed in the Service Plan or the Policies and Procedures of the ALR," or there is "a deviance from an accepted standard" or "a lack of consensus on a course of action."

The rationale emphasizes that the "shared responsibility" process is to be employed when the assisted living residence disagrees with decisions made by the resident, even if the only person affected is the resident himself or herself. This raises the inference, confirmed by the debate within the Workgroup, that shared responsibility agreements are designed almost exclusively to protect the facility from regulatory requirements and legal action.

There is no need for this confusing and self-contradictory recommendation. Resident/facility disputes are currently being addressed through care planning in assisted living residences around the country.

*American Geriatrics Society, Association of Health Facility Survey Agencies, Center for Medicare Advocacy, National Association for Regulatory Administration, National Association of Local Long Term Care Ombudsmen, National Association of Social Workers, National Association of State Ombudsman Programs, National Citizens Coalition for Nursing Home Reform, National Committee to Preserve Social Security and Medicare, National Conference of Gerontological Nurse Practitioners, National Network of Career Nursing Assistants, National Senior Citizens Law Center*

3) We support the recommendation. Negotiated risk agreements are becoming recognized as one of the primary tools through which assisted living providers can operationalize and preserve the values of independence, autonomy, and choice upon which the assisted living model rests so directly. Statutory and/or regulatory mandates in virtually every state direct both regulators and providers to further and nourish resident independence and autonomy in assisted living communities. The negotiated risk process focuses the attentions of resident, community staff, resident families, resident advocates, and regulators via a systematized process on one central issue – what are the wishes and preferences of the resident as balanced against the resident's health and safety needs. By so doing, the negotiated risk process responds to the legislative and regulatory directive to foster and promote these resident values and helps deliver the promise of assisted living.

The negotiated risk process is an individualized planning process designed to maximize a resident's ability to make his or her own decisions by facilitating discussions and analysis of a resident's stated choices where those choices create a normally unacceptable level of risk for the resident.

Negotiated risk is not a waiver of liability on the part of the provider of its obligations under governing regulations.

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

**Direct Care**

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## Direct Care

### D.14 Access to ALR's for Individuals with Personal Healthcare Needs

2/3 Maj. Not Reached

#### Recommendation

The personal healthcare needs of individuals should not be a barrier to admission or an automatic trigger for discharge by providers or in state regulation for Assisted Living Residences when the resident\* or ALR chooses to provide or arrange care for the condition.

When a person with healthcare care needs wishes to or currently resides in an ALR, and care for the healthcare need is provided by the resident, caregiver (family or contracted), appropriately qualified and trained staff (if the ALR chooses to make those services available), the existence of the healthcare needs should not be a barrier to admission or a trigger for discharge. This recommendation does not permit ALRs to reduce services below those required by regulation, nor does it require that they provide additional services.

Examples of personal healthcare needs may include but are not limited to:

- Catheter use
- Oxygen
- Medical ostomy, i.e. colostomy, ileostomy, urostomy
- Temporary medical conditions that require bed rest, i.e. severe colds, grade I & II pressure ulcers
- Mobility impairments that require use of a wheelchair, walker, cane or scooter.

#### Implementation

Guideline for State Regulation

#### Rationale

Many individuals with personal healthcare needs are capable to manage their care. Others have the ability to self-direct their care with occasional assistance from qualified caregivers or trained staff. These conditions can be easily managed in a home environment, and therefore are manageable in an ALR. It would be discriminatory to exclude individuals with personal healthcare needs from living in an ALR.

#### Organizations Supporting This Recommendation

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

#### Organizations Opposing This Recommendation

**Direct Care**

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

**Organizations Abstaining From the Vote on This Recommendation**

American Bar Association

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**Supplemental Positions for D.14**

1) The failure of Recommendation D.14, by one vote, on March 4, 2003, represents a major setback for people with disabilities and other older Americans who may develop personal healthcare needs and wish to choose assisted living as an alternative to nursing home care.

Current state assisted living regulations prohibit many individuals with disabilities and other aging individuals who may acquire conditions later in life from admission to assisted living because these individuals require the use of a catheter, require oxygen, or have some form of medical ostomy. Additionally, current state assisted living regulations can also require a person with a disability to leave their assisted living home when they develop a temporary medical condition that requires bed rest, i.e., severe colds or Grade I or II pressure ulcers.

People with disabilities who have personal healthcare needs have been living independent lives in their own homes for years and are capable to self-manage or self-direct the personal care they need through a spouse, caregiver, or paid personal assistant. Therefore, these personal care needs should not be a barrier to admission or a trigger for discharge from an assisted living residence.

Assisted living providers may choose to provide these services or not, but must allow an individual resident to choose the most appropriate assistant for her or his personal healthcare needs. Assisted living residents should have the option to select between provider services, when available, or choose the private caregiver of their choice to assist with their personal healthcare needs.

The failure of D.14 only serves to reinforce existing negative stereotypes regarding the abilities of individuals with disabilities and forces these individuals or the organizations that represent them to consider taking expensive legal action to protect their civil rights. Recommendation D.14 was consistent with the U.S. Supreme Court's Olmstead decision and President Bush's New Freedom Initiative which are both designed to provide services in the "most integrated setting" according to the Americans with Disabilities Act.

Recommendation D.14's intent was to correct state assisted living regulations that discriminate against people with disabilities and other aging Americans by unjustly forcing them into severely restricted institutional care environments.

*AARP, Alzheimer's Association, Consumer Consortium on Assisted Living, American Assisted Living Nurses Association, American Society of Consultant Pharmacists, NCB Development Corporation, National Association of Professional Geriatric Care Managers, National Hospice and Palliative Care Organization, National Multiple Sclerosis Society, Paralyzed Veterans of America, Pioneer Network*

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2) We oppose this failed recommendation. This recommendation would jeopardize residents' health and safety, because there is no assurance that assisted living residences would be capable of providing care for the residents with healthcare needs. The state licensing agency would be powerless to prevent an assisted living residence from admitting or retaining a resident, even if that assisted living residence was not capable of meeting the resident's needs.

As discussed in other dissents, the majority's recommendations require little health care expertise among assisted living residences. This recommendation establishes no quality of care standards whatsoever. Regardless, this recommendation defines "personal healthcare needs" to include colostomies, ileostomies, and urostomies. Also, the listed personal healthcare needs are just examples, so there is no real limit on the healthcare needs that could be cited by assisted living residences under this recommendation.

Also, this recommendation is completely one-sided. Although the state would be prohibited from citing a "personal healthcare need" as disqualification for assisted living, an assisted living residence could refuse admission or force discharge simply by refusing to provide necessary services.

As an alternative to this recommendation, we recommend a system that would establish levels of care within assisted living -- for example, the Florida system that licenses assisted living residences for either Limited Nursing Services or the more-extensive Extended Congregate Services. (Florida Administrative Code Ann. r. 58A-5.030- 5.031) Such a system would help assure that an assisted living residence would be prepared to meet the needs of a resident with a significant health care condition.

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

3) We believe there should be agreement between the resident and the facility about the care being provided to a resident who wants to move into an ALR or who currently resides in the facility. To make a blanket statement that healthcare needs should not be a barrier or trigger encourages the provision of higher levels of care that may exceed the ALRs care capabilities. States must have the flexibility to determine what is best for their individual state with regard to admission and discharge criteria in ALRs.

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

4) We dissent. The recommendation states that it would be discriminatory to exclude individuals with specified personal health care needs from living in an ALR.

This statement is in conflict with the ALW's recommendation for Transfer and Discharge which states that while residents enjoy certain rights and protections regarding reasonable accommodation under federal statutes including the ADA, FHAA, and the Rehabilitation Act of 1973, there may also be instances where the ALR may not be required to make an accommodation, if the modification would impose an undue financial or administrative burden or would require the ALR to fundamentally alter the nature of its program.

Absent a full set of facts regarding a specific case under which a resident was involuntarily

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discharged, the ALW has no basis on which to declare when a discharge for specified health care conditions would categorically violate the ADA, FHAA or the Rehabilitation Act of 1973 and therefore constitute discrimination.

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

## Direct Care

### D.15 External Professional Consultant

2/3 Maj. Not Reached

#### Recommendation

##### Consultant Role and Responsibility

To adequately provide for the needs of residents, each ALR should assess whether an agreement with certain consultants, including, but not limited to, physicians, consultant pharmacists, social workers, and registered dietitians with geriatric experience and an understanding of ALR philosophy to assist the ALR with their particular healthcare and wellness services. The consultants would have the following responsibilities based on the specific needs of the residents\* and the ALR, including:

- Assist the ALR in ensuring the provision and monitoring of those specific services;
- Assist the ALR in developing policies and procedures related to those specific services;
- Assist the ALR in developing performance expectations;
- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of care, and other health-related services and provide appropriate feedback;
- Participate in the ALR's quality improvement process; and
- Assist the ALR in developing healthcare and wellness information and communication systems with staff, residents, families and others.

#### Implementation

##### Guideline for Operations

#### Rationale

The types of individuals moving into assisted living are changing. Residents of ALR on average are older and frailer and have more healthcare and cognitive problems. The need of these individuals span the spectrum from medical/ healthcare to nutritional and psychosocial services.

Because of these needs it is important to consider having an agreement with consultants who have specific knowledge of the healthcare/wellness issues that face this population and the training to help the ALR set up the systems needed to meet the needs of the residents.

##### A. Physician Consultant Role

##### Physician Coverage and Performance

- Assist the ALR in ensuring that residents have appropriate physician coverage and ensure the provision of physician and health care practitioner services;
- Assist the ALR in developing a process for reviewing physician and health care practitioner credentials;
- Provide specific guidance for physician and health care practitioner performance expectations;
- Assist the ALR in ensuring that a system is in place for monitoring the performance of health care practitioners;
- Facilitate feedback to physicians and other health care practitioners on performance and practices.

## **Direct Care**

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- Assist ALR with resident assessment and development of the clinical component of the service plan, when necessary

### **Clinical Care**

- Participate in administrative decision-making and the development of policies and procedures related to resident care and medication management;
- Participate in administrative decision-making on staffing levels, coverage, licensing and training requirements for resident-care staff.
- Assist in developing, approving, and implementing specific clinical practices for the ALR to incorporate into its care-related policies and procedures, including areas required by laws and regulations;
- Review, respond to and participate in federal, state, local and other external inspections and
- Assist in reviewing policies and procedures regarding the adequate protection of residents' rights, advance care planning, and other ethical issues.

### **Quality of Care**

- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of clinical care, medication management and other health-related services and provide appropriate feedback;
- Participate in the ALR's quality improvement process;
- Advise on infection control issues and approve specific infection control policies to be incorporated into ALR policies and procedures;
- Assist the facility in providing a safe and caring environment with optimal levels of family and community involvement;
- Assist in the promotion of employee health and safety; and
- Assist in the development and implementation of employee health policies and program

### **Education, Information, and Communication**

- Promote a learning culture within the facility by educating, informing, and communicating;
- Assist the ALR in developing medical information and communication systems with staff, residents, families and others
- Assist in establishing appropriate relationships with other healthcare professionals.

### **B. Social Work Consultant Role**

#### **Access to Professional Social Work Services**

- Assist the ALR staff in ensuring that residents have access to appropriate social work services and ensure the provision of social work and mental health practitioner services;
- Assist the ALR in developing social work staff qualifications and guidelines for practice;
- Assist the ALR in developing a process for reviewing social work practitioner credentials
- Assist the ALR in developing a system for monitoring performance of social work practitioners;
- Assist the ALR with resident biopsychosocial assessment and development of the clinical component of the service plan, when appropriate.

### **Clinical Care**

## **Direct Care**

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- Provide direct services to residents, families, and other involved in a resident's care;
- Assist residents, families and others in receiving the maximum benefit of the ALW and community-based social resources throughout the stay of each resident from preadmission to discharge;
- Assist in discharge planning, advocacy, and serve as a community liaison;
- Participate in administrative decision making and the development of policies related to resident biopsychosocial functioning and well being;
- Provide clinical supervision to staff or consulting social workers hired by the ALR as needed;
- Participate in administrative decision making and the development of policies related to resident access to community resources as necessary;
- Participate in administrative decision making on social work staffing levels, coverage, licensing and training requirements;
- Assist in developing, approving, and implementing clinical social work practices for the ALR to incorporate into its care plan related policies and procedures, including areas required by laws and regulations;
- Review, respond to and participate in federal, state, local and other external inspections;
- Assist in reviewing policies and procedures regarding resident's rights, advance care planning and other ethical issues.

### **Quality of Care**

- Assist the ALR in establishing systems and protocols for revising the quality and appropriateness of social work services, both inside and outside of the ALR;
- Participate in the ALR's quality improvement process;
- Advise the ALR in providing a caring environment and promote the highest level of family and community involvement as possible;
- Assist with establishing employee assistance programs to reduce employee stress and promote employee retention and well being.

### **Education, Information and Referral, Interdisciplinary Communication**

- Assist the ALR to achieve and maintain a therapeutic environment essential to the optimal quality of life and independent functioning of each resident.
- Assist the ALR in developing information about community resources and entitlements programs for residents, families and others involved with the resident's care;
- Assist in establishing appropriate relationships with other care providers, public and private community agencies, and other services as appropriate;
- Promote ALR-community interaction through encouraging community involvement in the ALR and resident and staff involvement in the community;
- Assist in developing linkages with a wide range of community resources;
- Strengthen and promote communications between residents, their families, and others, and the program or facility staff.

For more information contact:

The National Association of Social Workers, 750 First Street, NE Suite 700, Washington, DC 20002; (202) 408-8600

### **C. Assisted Living Dietitian Consultant**

**Direct Care**

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**Consultant Role and Responsibility**

- Assist the ALR in assessing the kitchen and food service personnel by reviewing and providing consultation in the following areas.
  - Safe food handling procedures
  - HACCP guidelines
  - Sanitation and safety standards/policies throughout the kitchen
  - Disaster preparedness per local regulations, that food, water, disposable items and utensils are stocked appropriately.
  - Proper techniques for equipment use. (i.e. slicers, ovens, etc.)
  - Nutritional care of residents
- Assist the ALR in developing policies and procedures related to food service and nutritional care.
- Review and approve all menus for nutritional adequacy and variety
- Assist with developing policies and procedures that will be implemented to achieve safe food handling that food is received, stored, prepared, transported and served in a safe and sanitary manner.
- Assist the ALR with meeting State regulations in kitchen, dining rooms and meal service areas.
- Review, participate in, and respond to federal, state, local and other external inspection
- Assist FSD with any budgetary needs (i.e. food cost control, recommending products appropriate for special resident populations, etc.)
- Monitor compliance of special diet orders.
- Monitor resident weights quarterly for weight trends
- Assist the ALR in developing performance expectations
- Assist the ALR in hiring FSD or other kitchen personnel
- Assist in training FSD if needed
- Assist in providing inservice training to FSD and staff at least monthly or as needed
- Assist the ALR in establishing systems and methods for reviewing the quality and appropriateness of care, and other health-related services and provide appropriate feedback
- Assist ALR with developing a process for screening residents regarding nutritional status.
- Assist ALR with resident assessment and development of the nutritional clinical component of the service plan.
- Assess any person with nutritional risk and make recommendations to PMD and other health care practitioners on areas of nutritional care.
- Assist the ALR in establishing criteria for requiring additional dietitian services for high risk nutritional needs.
- Assist the FSD and ALR in providing "food council committee."

**D. Assisted Living Activity Consultant**

- Assist the ALR in recruiting, interviewing, checking references and hiring of activity staff
- Assist in developing and explaining models of operations, staffing, programming, documentation and volunteers
- Assist the ALR in writing mission and philosophy statements, goals, objectives, policies and procedures
- Assist in developing forms and systems for documentation
- Assist in scheduling staff, participants, programs and resources

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- Assist the ALR in developing, implementing and evaluating budgets
- Assist in purchasing supplies, equipment, furniture, outdoor furniture and equipment
- Assist the ALR in adapting activities, supplies and equipment to meet residents functional needs and interests
- Monitor staff and participants in action and provide feedback
- Assist in developing and implementation of quality assurance programs
- Assist the ALR with resident assessments and development of an activity service plan
- Assist in developing community resources
- Develop and provide activity in services for all staff
- Assist the ALR with meeting local/state/federal regulations
- Coordinate transportation services

For More Information contact:

National Association of Activity Professionals (NAAP), P.O. Box 5530, Sevierville, TN 37864-5530; (865) 429-0717

National Certification Council of Activity Professionals (NCCAP), P.O. Box 62589, Virginia Beach, VA. 23466-2589; (757) 552-0653

The book, *The Professional Activity Manager and Consultant* was developed and supported by both the National Association of Activity Professionals (NAAP) and the National Certification Council of Activity Professionals (NCCAP). In 1996 it was copyrighted by the National Association of Activity Professionals and Idyll Arbor Inc. For more information contact Idyll Arbor Inc., P.O. Box 720, Ravensdale, WA., 98051. ISBN 882883-24-1

The agreement itself is an extension of the service plan and the end product of a process in which the Assisted Living Residence, or the ALR and the resident together, identify a resident preference (e.g., to engage in or avoid certain activities or behaviors) which the ALR normally would not recommend or allow, or would remove, because they involve unacceptable risk to the health and safety of the resident or others in the ALR. Ultimately, the shared responsibility agreement process is simply a systemized method of accommodating individual resident choices, or finding acceptable alternatives to those choices, and the propriety of its use depends upon the unique facts and circumstances pertaining to each resident.

Recognition of the need for a shared responsibility agreement normally arises in one of three ways. In some cases, a resident will verbally express to ALR staff a desire to engage in certain activities or behaviors that normally would be prohibited. In other cases, ALR staff may raise the issue where a resident repeatedly engages in behaviors which normally would not be allowed for that resident. Occasionally, third parties such as family members, or ombudsman or other resident advocates may suggest a shared responsibility agreement to resolve complaints or concerns raised by a resident or family.

**Organizations Supporting This Recommendation**

AARP, Alzheimer's Association, American Association of Homes and Services for the Aging, American Assisted Living Nurses Association, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Catholic

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Health Association of the United States, Consultant Dieticians on Healthcare Facilities, Consumer Consortium on Assisted Living, National Multiple Sclerosis Society, NCB Development Corporation, National Association of Activity Professionals, National Association of Social Workers, National Hospice and Palliative Care Organization, National Association of Professional Geriatric Care Managers, National Conference of Gerontological Nurse Practicioners, Paralyzed Veterans of America, Pioneer Network

**Organizations Opposing This Recommendation**

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

**Organizations Abstaining From the Vote on This Recommendation**

Joint Commission on Accreditation of Health Care Organizations

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**Supplemental Positions for D.15**

1) Statement in support of the recommendation with modifications. As stated in the rationale section of the recommendation, the types of individuals moving into assisted living are changing. Residents of ALRs on average are older and frailer and have more healthcare and cognitive problems. The needs of these individuals span the spectrum from medical/healthcare to nutritional and psychosocial services.

Because of these needs, it is important for ALRs to consider having an agreement with certain consultants, including but not limited to, physicians, consultant pharmacists, social workers, registered dietitians, and activity consultants with geriatric experience and an understanding of ALR philosophy to assist the ALR with their particular healthcare and wellness services.

The External Professional Consultant recommendation is intended to assist ALRs in providing the highest quality service to its residents and to clarify and define the role of clinician consultants in assisted living.

We suggest that Recommendation D.15 should be a guideline for state regulation rather than an operational model but feel that the decision to contract with professional consultants such as a physician consultant be left up to the individual facilities and not mandated across the board to all ALFs.

As reported in the National Academy for State Health Policy State Assisted Living Policy: 2002, “the trend over that past five to ten years has been for states to offer flexibility [in their ALR requirements] in order to accommodate aging-in-place, which allows people with higher levels of impairment to remain in assisted living and allowing health related services to be provided.”

*American Academy of Home Care Physicians, American College of Health Care Administrators, American Medical Directors Association, American Society of Consultant Pharmacists, Consumer Consortium on Assisted Living, Joint Commission on Accreditation of Health Care Organizations, National Association of Professional Geriatric Care Managers, National Association of Activity Professionals,*

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*National Association of Social Workers, National Multiple Sclerosis Society,  
Paralyzed Veterans of America*

2) We oppose this failed recommendation because it does not go far enough. The recommendation does no more than require an assisted living residence to “assess” whether it would be appropriate to consult with a physician, pharmacist, social worker, dietician, or other professional. By contrast, we believe that under certain circumstances an assisted living residence should be required to employ or consult with an appropriate professional.

Existing state law already recognizes that it is sometimes appropriate to require that an assisted living residence employ or consult with a professional. For example, Alabama requires that a physician act as medical director in an assisted living residence providing dementia special care. (Alabama Administrative Code r. 420-5-20-.04, 420-5-20-.06, 420-5-20-.08) Arkansas and Oklahoma require under certain circumstances that an assisted living residence contract with and use a consultant pharmacist. (Code Arkansas Rules 016 06 002, § 702.2.1 (Level II assisted living facilities); Oklahoma Administrative Code § 310:663-9-2(a))

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

3) We dissent. There are recommendations within the ALW report that we, as individual organizations, helped to develop and continue to support. However, we have come to the conclusion that fundamental differences of principle exist between ALFA and the Assisted Living Workgroup (ALW) in its overall approach to developing recommendations as to how the states might best regulate assisted living. In our view, the bulk of the ALW’s recommended “guidance” to the states does not, as the Senate Special Committee on Aging asked, define “what quality assisted living should look like.” Rather, it is devoted to prescribing, in detail, the processes that a state should require of its assisted living residences (ALRs), not the quality goals that the good ALR should strive to achieve.

Any regulatory guidance to the states should recognize, reflect, and even foster resident- centered care--the unique characteristic that distinguishes assisted living from other forms of long-term care. Resident-centered care involves incorporating the resident’s values and experiences, as well as the individual preferences into the definition and evaluation of quality of care and quality of life. At the same time, state governments should be granted regulatory flexibility so as not to just promote basic resident safety, but to actually improve quality of care.

We believe this recommendation gives insufficient attention to defining quality standards from the perspective of the consumer, and fails to acknowledge that states and/or ALRs should consider equally effective alternative approaches to meet the intent of an appropriate recommendation. Further, the recommendation would likely have a disproportionate impact on small providers who lack the resources to have all of the specified consultant relationships.

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

4) We are opposed to this recommendation due to its potential cost implications for residents. Many assisted living residents are on limited incomes. Assisted living providers are capable of

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determining when outside consultants are needed and for what issues.

*National Center for Assisted Living, American Seniors Housing Association*

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