



January 25, 2008

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Dear Colleagues:

The Women's City Club of New York appreciates the opportunity to comment on the proposed licensure of Assisted Living Residences Chapter X, Part 1001 Public Health Law, and Section 4662.

The Women's City Club of New York, founded in 1915, is a nonpartisan, non-profit 501(c)(3) organization that shapes public policy through education, advocacy and citizen participation. Over the years, our issues have varied depending on contemporary needs. One of our current areas of concern is the provision of and access to services for our aging population. We have and will continue to advocate for the elderly and work cooperatively with community organizations and governmental agencies to develop quality programs that encourage dignified and productive lives for our elderly population. The progress made in the development of regulations for Assisted Living Residences is commendable. We think that people who go into assisted living generally want to live out the remainder of their lives in relative stability, and to have additional needed services come to them as much as possible rather than being forced to move as their health deteriorates.

We are concerned about the State's creation of a three-tier system (ALR; EALR; and SNALR) that is also a new layer on top of existing Adult Home/Enriched Housing programs, with their own regulations. It will be difficult for consumers to navigate this complicated system which introduces a labyrinth of variables into their decision-making process, at a time when--all too often--people must make assessments and decisions on short notice, during periods of personal crisis. Such a complicated system also puts people who are attempting to choose a home in the awkward position of trying to guess all their possible future conditions, in an effort to avoid being forced to move within a facility, or to another facility, as their health needs change. We would ask that you consider consolidation of some of these levels to limit the number and type of changes an individual needs to make. For example Adult homes/Enriched housing, ALR and EALR might be structured in a way that they could be available to a resident within one facility and the more intense level beyond these may require transfer if they are not available in the same facility. This approach ensures limited change of placement and a more stable and comfortable life style for the individuals involved.

In the meantime the complicated system now being advanced makes it particularly important that consumers are provided regular, timely, thorough, and complete disclosure of a particular facility's limitations, constraints, and deficiencies so they may evaluate it in terms of their potential future needs.

It is the responsibility of the State to actively solicit and consider public comment-both in regard to applications for licensure, and to ongoing complaints and disputes. The State should publicize the availability of such information on its website (including linkages to consumer organizations), through the new POE program, and by any other manner that ensures consumers can access pertinent information on facilities and their operation.

In addition, these proposed regulations seem to have a limited evaluation program. It would appear that no criteria have been set for evaluating outcomes, and no mechanism has been instituted for requiring that information useful in assessing outcomes is gathered and reported, so that this ALR / EALR / SNALR program model can be evaluated in the future. We would suggest that the evaluation of this program be expanded to include funding for a longitudinal study that would be conducted by qualified independent researchers. The result of this evaluation should be submitted to an oversight committee to review and make appropriate recommendations to the legislature and state authorities.

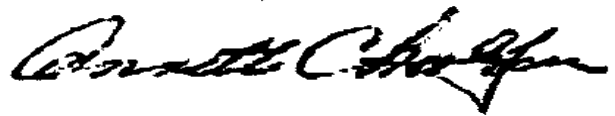
Our specific comments on the regulations are attached for your consideration.

Once again thank you for the opportunity to share our thoughts with you.

Sincerely,



Ruth E. Acker  
President



Annette Choolfaian  
Chair, Health Issues Committee

cc: Long Term Care Community Coalition

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**January 25, 2008**  
**COMMENTS ON THE PROPOSED LICENSURE OF**  
**ASSISTED LIVING RESIDENCES**  
**Chapter X, Part 1001**  
**Public Health Law, Section 4662**

**1001.5 Applications for Licensure....**

We are concerned that the proposed revised regulations, as currently written, state that "enhanced beds *may* 'float,'"--but further require Provider-applicants to justify such a configuration being employed by their facilities.

**Recommendation:**

While we do recognize that an ALR resident who comes to have Special Needs requirements may need to be moved to a more secure part of the building for his/her own protection, we firmly avow that "floating" EALR beds should be the norm, and that EALR beds that are separated from the general population should require Provider justification--perhaps even Waivers. We would argue: Separating people requiring EALR services from the general resident population is a violation of ADA and the Olmstead Decision, which require that people be housed in ways that are the least restrictive possible.

**Recommendation:**

The applicant should also be required to explain how it will address the accompanying increased demands on staff without removing resources currently in place for other residents.

A statement is made by the Provider that its shares of stock are "not traded on a national securities exchange and are not regularly quoted on a national over-the-counter market..."

**Recommendation:**

The WCC supports extending to assisted living facilities the same restrictions imposed on "Outside Entities" (publicly traded corporations) operating in New York State under Public Health Law, Article 28 which includes hospitals, nursing homes, adult homes, and enriched housing facilities. This law, in operation for 25 years, requires that the operator of such a facility must retain within New York State independent and ultimate power and authority over, and responsibility for, all aspects of the facility's staffing, finances, and administrative and operational policies.

Corporations have an inherent conflict between meeting the needs of the care recipient and the needs of the stockholders. Thus, the often vulnerable elderly or disabled population admitted to assisted living facilities cannot be fully protected by these corporate interests.

Corporations are frequently headquartered out of state, and far from the local community which they serve. Therefore, residents or their families do not have ready access to the real decision-makers, and even the State may not be able to hold such operatives in the state accountable for poor care or other issues such as fraud or mismanagement.

## **1001.7 Admission and Retention Standards**

We are aware that the wording of the original legislation appeared to allow Providers to cherry-pick among the five categories that are generally considered to comprise enhanced needs: difficulty transferring, walking, negotiating stairs, need of medical equipment, chronic incontinence. We do not believe this was the intent of the legislation.

We note that the proposed revised regulations--reflecting this mistake--do not require that Providers seeking EALR certification provide services for all five categories of the disabilities people needing enhanced services may require. Thus, any shared definition of what constitutes Enhanced Assisted Living is lost.

### **Recommendations:**

Immediate efforts must be made to amend the legislation to correct this over-site so that all EALR-certified facilities are required to provide consistent core services to serve all five types of disability. In the interim, Provider documents must clearly disclose which disabilities the facility will accommodate--and which they will not accommodate. Such information should be a required part of the documents provided to potential residents as described in 1001.8, Consumer and Resident Protections.

## **1001.8 Consumer and Resident Protections**

The Women's City Club of New York has long advocated *full disclosure* in admissions contracts *and related documents* for prospective residents.

We request that the Consumer Information Guide developed by the commissioner -- which is among the documents required to be given to potential residents by Providers should advise consumers of the potential problems raised by a layered, multi-tier system. It should provide them with pertinent questions they need to have answered by a particular Residence in order to: 1.) compare and evaluate competing Provider offerings; 2.) ensure more realistic assessment of the risk of potential later disruption to their living accommodations.

The current outline of 1001.8 Consumer and Resident Protections does not include criteria for discharge decisions.

### **Recommendation:**

The Admission Agreement must include the criteria and process for discharge.

### **Recommendation:**

Discharge Planning: The admission agreement should include the rights of residents and their representatives to participate in the discharge planning process. Protocols for discharge planning should include providing the resident with information on appropriate options for residential settings and medical care.

We note that no section of these regulations details resident protections against involuntary discharge. In the nursing home field, abuses of the discharge process prompted the State, over time, to add important resident protections.

## **1001.8 cont.**

### **Recommendation:**

The WCC feels that the same safeguards should be provided to residents of ALRs, and urges that the nursing home discharge process be added to these regulations in a manner that addresses all levels of ALR.

Regulations should provide for the resident/resident representative to challenge the discharge decision through an independent hearing process in which the resident or representative can be heard in person or by presenting a written response. The final decision made through this process should detail the reasons why the resident is no longer eligible to remain in the facility.

#### Issues to be addressed:

- a.) whether the individual has a home or appropriate setting to return to;
- b.) whether discharge is justified based on representations as to availability of now-needed services made by the Provider prior to the resident's admission;
- c.) whether the discharge is justified based on medical criteria;
- d.) whether the discharge is justified, if based on personal behavior the facility finds unacceptable.

It can be assumed that a resident's psychiatric history, if there is one, has been noted at the time the resident was accepted by the facility.

### **Recommendation:**

If a resident is sent to a hospital for psychiatric evaluation for disruptive behavior, assurance of his/her right to return to the facility at the completion of such evaluation must be assured if medically appropriate.

### **Recommendation:**

#### Special Needs Residents:

Regulatory protections are needed by Special Needs residents to ensure that facilities do not send them off to psychiatric facilities for "evaluations" when a). They have no history of psychiatric illness, and b.) The facility has not instituted current non-medical treatment for "disruptive or aggressive behavior."

### **Recommendation:**

Wording should be inserted to require that, upon admission, Residents should be informed of, and urged to sign, Health Care Directive documents. (They are included in the list in 1001.12 Records and Reports.)

### **Recommendation:**

We note that a requirement has been added that resident/resident council complaints/recommendations must receive a written reply in 21 days. This requirement should also be added to the requirements regarding individuals and family organizations.

## **1001.9 Resident funds and valuables**

### **Recommendation:**

The following should be added:

c.) The family or resident representative must be provided, on the death or discharge of the Resident, with a written account of all funds, personal belongings, and valuables left in the possession of the facility. All such items must be held and safeguarded for a period of two months to give the appropriate parties an opportunity to retrieve them.

## **1001.10 Resident Services**

### **Recommendation:**

We think it is vitally important that Providers be required to disclose clearly how a resident can appeal provider decisions within the facility as well as to the regulatory agency in their own materials.

The statement: "(f) Residents shall have the right to choose their health care providers, notwithstanding any other agreement to the contrary," is unclear.

### **Recommendation:**

Residents or a resident's representative must be assured of their right to select a regular physician/health care provider who will agree to attend them, and have the choice of selecting specialists, and physicians to provide second opinions, when appropriate. Residents should not be required to use a doctor selected by the facility if they have none, except if they so agree.

### **Recommendation:**

Residences should be required to provide or arrange for transportation to off-site medical appointments as part of their core services.

Regarding "(h) 3. food options: Food services that respect dietary needs and preferences should be required at all levels of care."

### **Recommendation:**

Add the following: Any limitations to the above must be *disclosed* before admission to give incoming residents an opportunity to withdraw an application.

The revised regulations, as currently written, are silent on requiring planned activities, (or even facilitating access to community activities), for any but SNALR residents. A lack of planned activities is inadequate for even well-elderly, who may need some direction in remaining involved and active. It is completely inadequate for people eligible for enhanced services, and for special needs residents who are, of necessity, more home-bound. Appropriate and regular/frequent activities must be considered an essential aspect of a healthy life style and, while voluntary for individual residents, provisions must be required for people at all levels of ability. (Watching TV should never be considered an "activity.")

### **Recommendation:**

Minimum requirements for the offering of organized, scheduled activities must be incorporated into the Regulations.

### **Recommendation:**

Facilities should be required to make available some form of daily exercise program/s commensurate with the abilities of Residents.

**Recommendation:**

It is the intent of the law that ALRs are non-institutional and integrated into the local community. Facilities should be required to schedule/coordinate activities in the general community: i.e., local shopping, church events, movies, theatre, public library, political events, etc.

**Recommendation:**

Facilities should be equipped to provide special transportation to such activities, if necessary.

Regarding the use of prescription PRN medications for persons with dementia (see page 59, Section (7) and Special Needs Residents, page 62 Section (6): The experience in many nursing homes currently caring for these categories of residents shows that medications tend to be over-prescribed to "constrain" behavior, and that anti-psychotic medications are prescribed even though their efficacy for these conditions is medically questionable. (We note that residents with forms of dementia who act out their frustrations frequently need non-medication solutions: staff attention to help distract them, and appropriate activities.)

**Recommendation:**

WCC supports regulatory language which calls for requiring close and regular (48 hour) review of medications (particularly anti-psychotic medications), and a "second opinion" if necessary. Also (in Section (6) page 62), wording as follows: "a care plan drawn up with the assistance of the health care agent or designated representative to include non medical interventions to promote the highest level of resident function."

**1001.13 Structural and Environmental Standards****Recommendation:**

Elderly people are particularly vulnerable to heat-related medical problems. Air conditioning must be provided in all rooms of all facilities-existing or new.

**Existing Structures**

WCC recognizes that it is impractical to require existing facilities currently operating under other licenses to reconstruct themselves to comply with the requirements listed below (under New Structures), however:

**Recommendation:**

Facilities that do not include the amenities described below (under New Structures) must be prepared to incorporate them when the State approves any structural remodeling of the facility.

**New Structures**

WCC is not conversant with all requirements currently in place for the construction of Adult Homes and Enriched Housing, so we recognize that some of our additional suggestions may be redundant.

**Recommendation:**

New ALRs should be designed to have a mix of decentralized dining, living, and common areas to provide residents with a range of options for privacy and socialization.

**Recommendation:**

All new ALRS must be designed to include some safe, secure outdoor space--such as a roof-top garden, patio, open yard--with appropriate seating, adequate lighting, and railings or grab-bars. Urban facilities with building limitations which restrict the availability of such space should be required to provide alternative options to enable and encourage residents' use of a secure outdoor area.

The regulations are silent regarding the matter of residents' access to cooking facilities for their personal use. WCC notes that, in some states, a chief difference between ALR and EALR/SNALR-type residences/resident areas is whether or not residents have--or are allowed--unrestricted/unsupervised access to cooking facilities. We understand that resident access to cooking facilities may be rightfully constrained by the disabilities of some residents, which could cause fire and safety hazards. Notwithstanding this difficulty, the ability to, at least occasionally, prepare one's own meal/snack is important to anyone's feeling of independence and autonomy, and should be enabled for as long as possible.

**Recommendation:**

Facilities should be constructed in ways that enable residents (in keeping with their level of ability) to do some of their own meal/snack preparation, if they desire to do so. At minimum, facilities must provide a refrigerator in each resident's unit.

**Recommendation:**

(In addition to the "additional standards" currently outlined in 1001.13/(e) on page 76), the following should also be added:

- Each bedroom or resident unit shall have its own full bathroom or, at the minimum, its own lavatory (i.e., sink and toilet) with separate bathing facilities.
- It may be necessary to provide special separate bathing facilities for residents who require special assistance in transporting, or for other safety reasons.
- Laundry facilities for residents to do their personal laundry should be available.

## **1001.14 Disaster and Emergency Planning**

(WCC recognizes that this may already be included in 18NYCRR 487.12 and/or 488.12 but additional language may be needed for EALR and SNALR facilities.)

**Recommendation:**

Staff and residents must have fire, evacuation and other disaster drills for both daytime and evening periods.