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INDEPENDENT REGULATORY REVIEW COMMISSION

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Consumer Health Coalition

September 10, 2008

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REFER TO

Ms. Gail Weidman
Department of Public Welfare
Office of Long-Term Care Living
P.O. Box 2675
Harrisburg, PA 17105

Mr. Arthur Coccodrilli, Chair
Independent Regulatory Review Commission
333 Market St., 14th Floor
Harrisburg, PA 17101

Dear Ms. Weidman and Chairman Coccodrilli:

The Consumer Health Coalition hereby submits comments to the Proposed Assisted Living Regulations #14-514.

We write on behalf of the Consumer Health Coalition's Health Committee for People with Disabilities, a group of consumers with all types of disabilities (physical, mental, sensory, and developmental), family members, advocates, providers, and other interested parties that work on issues of importance to people with disabilities. Specifically, the committee currently has the following two advocacy priorities:

- Assure the consideration of both physical and mental health issues in all care; and
- Collaborate with and support other organizations in furthering home and community-based services.

Recognizing that individuals with disabilities primarily wish to remain living in their community with supports to ensure their independence, health and safety, we understand that Assisted Living Residences will be an option for some people who need supportive services. In light of our advocacy priorities, we are submitting comments to the proposed regulations for Assisted Living Residences. We are pleased that Pennsylvania has created a licensure status for Assisted Living Residences; however, we are concerned that the proposed assisted living regulations #14-514 do not ensure that Pennsylvania's persons with disabilities can be safely served in a home-like setting.

The proposed assisted living regulations build on the current personal care home rules and do include some positive changes to account for some of the differences between

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personal care homes and assisted living residences and the difference in the population that will be served in assisted living residences. At the end of our comment letter, we list all the positive changes made thus far that we view as critical and must be, by all means, preserved in the final regulations. However, these changes alone are not sufficient enough to deliver on the promise of safely serving our friends, family members, colleagues, and consumers in assisted living residences.

Many more changes must be made to ensure that assisted living residences are equipped, enabled, and accountable for providing all residents with quality care, provided by sufficient numbers of adequately trained staff, in a home-like setting that is safe, accessible, and stimulating.

Some ways in which the proposed regulations must be changed before becoming final rules for assisted living facilities include:

- **Freedom to Choose Providers. Residents have a right to choose all their healthcare providers and must not be required to use the providers the Assisted Living Residence (ALR) picks for them.** The proposed regulations give the facility total control over where residents get all medical care and supportive services. The proposed regulations contain no articulation of any ability to choose and to use outside providers. In fact, the regulations articulate that a facility can force a resident to use providers of its choosing despite Medicare, Medicaid and other freedom of choice rules. The allowance for consumers to use their own physicians and pharmacies that exist in the personal care home system has been eliminated. Consumers want to be able to use their own providers. It provides a check and balance against poor care, conflict of interest, and complete isolation. And, if nothing else, it allows the consumer to use the marketplace when quality care is not provided in their supportive, apartment-like assisted living setting.

  2800.142 – Assistance with health care and supplemental healthcare services – We find it unthinkable that the consumer could be made to forfeit choice of all doctors, specialists, psychiatrists, and supplemental healthcare providers by virtue of moving in to an assisted living facility. While this section attempts to guide the facility's determination of who provides residents with care, it must more strongly prohibit facilities from interfering with access to providers whose services are paid for by Medicare, Medicaid, and private health and long term care insurance. This needs to be changed in the final regulations to ensure that residents have a choice of healthcare providers and not be forced to use the providers the residence picks for them.

- **Applicant and Residents Rights. All persons applying to and residing in Assisted Living Residences (ALR) should have certain fundamental rights such as:**

  - Applicants have the right to an initial interview and tour of the ALR prior to admission.

- Applicants have the right to a written decision regarding acceptance into an ALR including a reason for denial of admission.
- Residents have the right to reasonable accommodations of their disabilities (physical, mental, sensory, and developmental) to enable them to be afforded the same amenities as other residents.
- Residents have the right to receive all written and oral communication in a format that is accessible to them (including but not limited to American Sign Language interpreter, oral interpreter, large print, audio recording, Braille or computer disk) and to request information in an accessible format for their representative payee or legal representative if necessary.
- Residents have the right to NOT be forced to share a room

The proposed regulations do not guarantee that all consumers have meaningful rights, are aware of these rights, and are free to exercise their rights. It is critical that applicants for residency have enumerated rights and that the rights for applicants and residents all be articulated in one regulatory section on rights. The proposed regulations make no enhancements or additions to the rights provided personal care home residents, despite the differences in the models and the greater care dependence of the population being served in assisted living residences.

There is no consolidated statement of all the rights the resident has when living in an assisted living residence. There is a residents' rights section in the proposed regulations (2800.42), yet rights such as the right to view your records or to be notified of egregious incidents or violations that occurred within the ALR are not included in this section and are included in other sections of the proposed regulations. Because the various rights are scattered in various sections of the proposed regulations and do not appear in the official statement of "rights", most consumers never know about these other rights or how to exercise them. **All** resident rights must be contained in a single section of the regulations to which consumers and their families can turn to understand their rights and protections. Furthermore, consumers must be provided meaningful rights and protections beyond what are already in the personal care home regulations.

The proposed regulations contain NO resident or applicant appeal rights or appeal process. While the providers have a place to turn should they need to challenge a licensing decision or a penalty imposed, the resident has no ability to challenge the facility's unilateral determination that her needs can no longer be met and that she must be discharged. There are no articulated rights 1) to appeal a discharge to the Department's Bureau of Hearings and Appeals or 2) to continue to reside in the facility pending the outcome of the appeal. These must be provided to residents and must be included in the final regulations.

We urge the addition of a section **2800.40** on **Applicants** rights so that applicants can know, across all facilities, what to expect in the application process. We agree with the specific comments made by the Pennsylvania Assisted Living Consumer Alliance regarding applicant rights and urge you to adopt their suggested additions for this section.

2800.42 – Specific Rights. The proposed regulations fall short in that they fail to include many fundamental consumer rights. Residents should have, and be unequivocally aware that they have, certain rights. In addition to the rights we listed above, we urge you to adopt the rights suggested by the Pennsylvania Assisted Living Consumer Alliance (PALCA) in their comments and include those rights in the final regulations.

We urge the addition of a section **2800.42a** on Rights upon Transfer or Discharge as suggested by PALCA in their comments.

- **Living Units/Accessibility. Assisted Living Residences, including those that exist as of the day the regulations take effect, should be required to meet the best available standards or practices for safety and accessibility**. Facilities must adhere to the requirements of the Federal Americans with Disabilities Act Standards for Accessible Design. The accessibility requirements are most important for bathing/showering and toileting. Residents' rooms, common areas, and hallways must be large enough for wheelchairs to enter and move around with ease. Residences should be required to accept service animals.

  As proposed, facilities that exist as of the day the regulations take effect would not have to meet the best available standards or practices for fire safety or even wheelchair accessibility. The regulations do not address the issues of older construction that do not meet current fire or life safety building codes or, perhaps, that were grandfathered years back and never had to come up to even past best practice standards for safety and accessibility. Similarly, ALRs are not required to admit service animals for residents who need them.

  As proposed, newly constructed living units must have 250 square feet of living space. This is in line with the state housing agencies' recommendations. Existing construction, however, need only have 175 square feet of living space and this is unacceptable as it is too small and not accessible to a wheelchair user.

2800.14 – Fire Safety Approval – This section needs to be revised to indicate the impact to the facility's license if fire safety approval is withdrawn by the appropriate fire safety agency. The facility should be put on a provisional license and should be required to remedy fire safety problems immediately or residents should be relocated until the facility is safe again.

2800.18 – Applicable Laws. To the extent that the state expects to permit old existing buildings to be converted to assisted living use, it is critical that the regulations require facilities to satisfy applicable fire safety and life safety laws as if they were new construction. This would ensure that the best practices for keeping residents safe are applied and not the outdated methods that were in place when the many year old structure was built.

2800.19 – Waivers. These are brand new regulations for a brand new licensure category. No exceptions or waivers to these requirements should be granted to a

facility when first seeking to become an assisted living facility. At a later date, a facility that complied with the requirements that wants to try to do something a little differently could potentially be granted a waiver of the regulations, but only if the request goes through a process that includes public input. This section needs to say this.

2800.96 – First Aid Kit – It is not appropriate for the facility to have only one first aid kit for the whole facility. The requirement should be that the facility has enough first aid kits in accessible locations throughout the facility to ensure that the staff can swiftly administer first aid treatments.

2800.86 – We'd like to see the facilities use carbon monoxide detectors.

2800.88 – Surfaces – We'd like to see that any asbestos on site that is found be appropriately remediated.

2800.90 – Telephones – The facilities should have at least one phone on each floor and they must be accessible to all residents.

2800.98 – Indoor Activity Space – All indoor activity space needs to be accessible to all residents. All hallways and common areas must be accessible to wheelchair users.

2800.101 – Living Units - The proposed regulations authorize grandfathering of bedrooms that are only 175 square feet. This is not accessible to a wheelchair and is not acceptable. We likewise do not believe that having a ceiling height at an average of 7 feet is accessible to chair lifts and other assistive devices nor is it safe in the event of a fire. Ceiling height should be no less than 8 feet, throughout the 250 square feet of living space. If there is a dormer or other low ceiling area in a portion of the living unit that does not get counted towards the living space, that would be permissible.

2800.109. Facilities are not required to accept service animals. This must be changed in the final regulations.

2800.129 – Chimneys that are used must be regularly cleaned.

2800.130 – Smoke Detectors need to be located throughout the facility and not just in living units.

- **Assessments/Supports Plans. A person should be assessed and have a support plan created before they move into an ALR to make sure the residence can meet their needs.** The assessment and support plan should be completed with involvement of an interdisciplinary team including a nurse or someone with similar qualifications to a nurse. Residents should be re-assessed every quarter and their support plan revised as necessary following the

assessments. Support plans must be developed with the resident and any family member or other representative(s) the resident chooses.

The regulations do not ensure that facilities can and will meet Residents' Care Needs. As proposed, a consumer would have to move in, sign a contract for residency and services, and begin payment to the facility weeks before the facility would be required to identify the consumer's care needs and explain to the consumer and her family whether the facility can meet her needs, how it proposes to meet those needs or even how much the consumer's care would actually cost. Although there is a short-form, pre-screening checklist to determine whether the consumer has conditions that would require exclusion from the facility, the ALR is given 15 days after a person is admitted to the residence to conduct a real consumer needs assessment. The actual care plan need not be completed until 30 days after admission to the facility. As proposed, the regulations put consumers in the untenable position of having to move into a facility without knowing for certain if the facility can meet their needs and if they will be able to remain there. With the possible exception of an immediate discharge to the Assisted Living facility from a hospital, a comprehensive assessment should be completed prior to admission and should determine whether the applicant can live in the facility successfully, what are her care needs, whether they can be met (and whether they can be met in a way that comports with the consumer's choice around how and when to receive care), and what are the costs associated with her care in that facility.

As written, the proposed regulations provide no sufficiently clear statement as to what services a consumer should actually expect to be able to access within an ALR and the regulations articulate no core package of benefits that must be uniformly available within **any** ALR. If consumers are not assured that each facility will universally provide a minimum core benefit package with the admission price, consumers cannot realistically compare ALRs. Without a minimum core benefit, consumers cannot understand the a la carte items for which they might be charged nor the value added by purchasing an "enhanced" benefit package. Not only will it be impossible to understand how facilities differ in what they offer and cost, but it will be impossible to tell exactly what care will regularly cost in the chosen facility, as consumers may end up being nickeled and dimed at every turn.

2800.22 – Application and Admission – The regulations would allow medical evaluations, needs assessments, and support plans to all be completed after admission – even after the contract is signed and the consumer has lived in the facility for weeks. These must all be completed **prior to** admission, except in the event of an urgent discharge to a facility from a hospital.

2800.25 – Resident-Residence Contract. The contract must make reference to a core package of benefits that is included in the base price of admission. The core package of benefits must be uniform from facility to facility. This is not currently in the proposed regulations and must be added.

2800.220 – Services – The regulations need to be clear on 1) what assisted living services all facilities must be equipped to provide and 2) the minimum core package of benefits that each consumer can expect to receive as part of their monthly fee. Each residence must provide a base core package of services that residents must purchase and can trust they will receive.

2800.225 – Assessments – Under the proposed regulations, assessments of individual resident needs are not required to be completed by the facility until after 15 days of residence. These are not required to be completed by a nurse, and are only required to be completed annually. It is imperative that assessments be completed prior to admission, that they be done by or with a nurse (at present the proposed regulations do not require an assessor to have any training in assessing care needs), and that they be done quarterly, not annually, as well as after a change in condition or hospitalization.

2800.227 – Support Plans. Under the proposed regulations, support plans are not required to be completed by the facility until after 30 days of residence. These are only required to be completed annually or upon change in condition. It is imperative that these be completed prior to admission, by a nurse, and quarterly as well as after a change in condition or hospitalization.

- **Public Funding. Assisted Living Residences (ALRs) cannot discriminate against individuals who receive public funding.** This includes not allowing residences to deny admission or transfer or discharge an individual because of her payment source. Individuals who receive public funding and who live in an ALR have the right to NOT have the residence (or an employee of the residence) act as their Representative Payee, Power of Attorney, or Guardian.

  2800.20 – Financial Mgmt – The regulations must prohibit the administrator or any other employee of the facility from being required to be representative payee for any resident's Social Security payments.

- **Staffing and Training. Assisted Living Residences must have enough staff to meet residents' needs. Staff must be adequately trained.** Staff must meet specific training requirements to ensure safe, quality care for residents such as:
  - All staff must be trained in first aid and CPR;
  - Administrators and direct care staff must be trained on the philosophy of choice and aging in place;
  - Administrators and direct care staff must be trained on caring for individuals with dementia, mental illness, mental retardation and other special needs;
  - Training requirements must include a minimum number of hours for direct care staff training; and
  - Supervisors must meet, at minimum, the training requirements imposed on direct care staff.

The proposed regulations do not ensure that care is provided by appropriate amounts of adequately trained staff. As written, the proposed regulations rely on the archaic labels of "mobile" and "immobile" residents and rely on those terms alone to determine whether a resident needs 1 versus 2 hours of direct care by staff. Instead, a floor should be set of at least 2 hours of care per resident per day with the actual care hours determined based on the assessed needs of residents. The proposed regulations for assisted living include no enhancements or additions to direct care staff qualifications or training from the minimal training required of personal care home staff. As proposed, direct care staff are not required to complete a minimum amount of training hours and direct care staff are not all required to be trained in first aid and CPR. No minimum training or qualifications are articulated for third party contractors serving as direct care staff, and supervisory staff are not required to meet at least the direct care staff training requirements. ALL staff and ALL administrators are not required to be trained in cognitive support services and care for cognitively-impaired residents. In addition, there is no affirmative statement ensuring that training requirements will not be waived. These issues must be addressed in the final regulations.

We urge the creation of a **2800.54a** – Qualifications and training for ancillary staff, other staff or volunteers to address minimum training and qualifications for food service, housekeeping, administrative or supervisory staff, medical directors, service planners/care managers, and third party contractors. All supervisory staff should meet at least the direct care staff training requirements.

2800.57 – Direct Care Staffing - The proposed regulations label consumers as either "mobile" and "immobile" and key staff levels at 1 or 2 hours accordingly, regardless of actual resident needs. Staffing levels should allow for at least 2 hours per day per resident with actual care hours determined based on assessed needs of residents. The regulations do not do this.

2800.60 – Additional staffing. The proposed regulations do not require that a facility have a nurse on staff or under contract to participate in all initial or ongoing needs assessments. The final regulations need to include this requirement.

2800.63 – First Aid and CPR. The proposed regulations fail to require that all staff be trained in first aid and CPR. This is essential and must be remedied.

2800.64 – Administrator training and orientation. Administrators should have 150 hours of training and this training should include training in numerous additional areas than are listed in the 100 hour personal care home administrator training, including how to care for residents with cognitive impairments, how to control infection, prevention of decubitus ulcers, malnutrition and dehydration, and hazard prevention. The regulations should also clearly state that the training requirements must be met without grandfathering of any kind.

2800.65 – Direct Care Staff person training and orientation. The proposed regulations would require no additional training for direct care workers in an assisted living facility than in a personal care home, despite the different needs of the populations intended to

be served. The regulations include no minimum number of training hours. The final regulations must at least adopt the minimum 77 hour core competency training crafted by stakeholders for the Department of Labor and Industry. The regulations should also clearly state that the training requirements must be met without grandfathering of any kind.

We urge the addition of a **2800.70** on Third Party Care Providers that states that all those employed by the facility must meet the direct care worker requirements of the regulations or their licensure requirements (if they are separately licensed in the state).

Despite the problems with the proposed regulations as just discussed, the proposed regulations contain some crucial improvements that the Department made to what exists in the personal care home system. These improvements must, at all costs, be retained. It is crucial that the Assisted Living regulations improve upon the regulations for personal care home, and we are sincerely pleased that the proposed assisted living regulations:

1) Establish licensure fees that are meaningful and potentially sufficient to fund the licensure and oversight and relocation efforts of the Department, as required by Act 56. (2800.11)

2) Require fire safety approval to be renewed every 3 years. (2800.14)

3) Limit the number of regulatory provisions that a facility could seek to have waived so that they not have to comply. (2800.19)

4) Add a few critical pre-admission disclosures that facilities will have to make to potential residents. (2800.22(b))

5) Standardize that the resident-residence contracts should all run month to month with 14 day advance notice by the resident required for termination. (2800.25(b))

6) Add a requirement that the person who manages and controls the operations of the facility have prior experience in the health or human services field. (2800.53)

7) Require the facility to – at all times – be under the supervision of a person who is trained in how to operate and manage the facility. This is a massive improvement over the personal care home system where the only person with training and knowledge in how to manage, operate, and supervise need only be present in the facility 20 of the 168 hours in a week. (2800.56)

8) Require a nurse to be on call 24 hours a day and a dietician to be involved in meal planning for residents' whose support plans call for special diets. (2800.60)

9) Call for air conditioning for the entire facility, whereas personal care homes have never been required to have air conditioning, despite the care needs or health conditions of their residents. (2800.83)

10) Require all stairs and steps to have strips to help ensure evacuation for those with vision impairments. (2800.94)

11) Require facilities to have larger rooms than in personal care homes, with 250 square feet of living space for new construction. However, we disagree with the exception allowing 175 square feet of living space for existing facilities because 175 square feet is too small and it is not wheelchair accessible. (2800.101)

12) Require living units to have kitchenettes with counter space, cabinet, microwave, fridge, and access to a sink. (2800.101)

13) Require facilities to disclose their policies about pets and whether pets are already in the facility. (2800.109)

14) Require smoke detectors in each living unit. (2800.129)

15) Require access to all exits required to be marked with readily visible signs indicating the direction to travel. (2800.133)

16) Prohibit unreasonable withholding of approval of providers of a resident's choice if the resident has insurance. We wholly oppose limits on resident choice of provider. Such limits do not exist in the personal care home system. We are only minimally comforted by the provision that a facility cannot unreasonably limit resident choice where health insurance or long term care insurance may only pay for specific providers. Please note, however, that "unreasonable withholding" is not defined and there are no appeals processes or rights for consumers to challenge an ALR decision to withhold approval of a provider. (2800.142(a))

17) Require assistance with meals and cueing for meals for residents who require this in order to make it to or through a meal. (2800.162)

18) Require vehicles for transportation to be accessible to residents with wheelchairs and other devices. (1800.171)

19) Require facilities to obtain medications prescribed for resident and to maintain an adequate amount of the residents' medications on site. (2800.181

20) Require all residences to provide cognitive support services. (2800.119)

21) Require a written decision if an application for residency is denied including the basis for the denial. However, the problem remains that the potential resident is provided no means for challenging a denial. (2800.224)

22) Requires a nurse to review and approve the support plan, whereas in the current personal care home system, there are neither qualifications nor specific training requirements for the individual who conducts assessments or trainings. (2800.227)

23) Mandate that a facility must ensure that residents that are discharged have a safe and orderly discharge and that the resident's medications, durable medical equipment, and personal belongings go with the resident. (2800.228)

24) Improve upon the termination notice that consumers must receive, providing them more information on why they are being discharged and what limited steps they may take about the discharge. (2800.228)

25) Require tracking of admissions and discharges and transfers by the facility – including those involving excludable conditions. (2800.228 and 2800.229).

26) Adopt a good standard for when an exception to the excludable conditions prohibitions would/should be granted. (2800.229).

We appreciate the opportunity to comment on this important matter and thank you for considering our comments.

Sincerely,

Sally Jo Snyder, Community Organizer
Health Committee for People with Disabilities

Jessica Seabury Larochelle, Executive Director
Consumer Health Coalition