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Enclosed please find:

1) A copy of the Testimony of Alissa Eden Halperin, Esq. who is leading the efforts of PALCA
2) A press release on the formation of PALCA;
3) A copy of our comment letter submitted on 9/10 to DPW;
4) Stories from consumers who have contacted PALCA to share the experiences of their loved ones
5) PALCA's position statements on
    a. choice of provider,
    b. size of the living unit, and
    c. public funding of assisted living.

Please visit the PALCA website at www.paassistedlivingconsumeralliance.org . In the left margin you will find links to access

1) Additional PALCA position statements on:
    a. grandfathering and waivers
    b. assessment and support plan
    c. core package of services
    d. dual licensure;
2) PALCA's full comment package that was submitted to DPW on the proposed regulations, include the letter that is enclosed and a line-by-line, tracked changes version of the proposed regulations reflecting our recommended changes; and
3) News stories around issues in assisted living.

Testimony of Alissa Eden Halperin
on Behalf of the Pennsylvania Assisted Living Consumer Alliance
Before the House Aging and Older Adult Services Committee
on the Department of Public Welfare's
Proposed Assisted Living Regulations
September 18, 2008

Good morning. Thank you Chairwoman Mundy, Chairman Hennessey, Representatives and staff of the House Aging and Older Adult Services Committee for giving me the opportunity to testify about the Department of Public Welfare's Proposed Assisted Living Regulations.

I am a Senior Attorney and the Deputy Director of Policy Advocacy at the Pennsylvania Health Law Project (PHLP). The Pennsylvania Health Law Project is a statewide public interest law firm that provides free legal services to lower income consumers, persons with disabilities, and the elderly who are having trouble accessing publicly funded healthcare and quality long term care services throughout the state of Pennsylvania. PHLP is the lead agency of the Pennsylvania Assisted Living Consumer Alliance (PALCA). The Pennsylvania Health Law Project is primarily using operating support from The Pew Charitable Trusts to fund the campaign.

I. About PALCA

PALCA was formed this year to make sure that new licensing rules will protect residents who are elderly or have disabilities. Consumers, family members, and advocacy organizations comprise our Alliance. Participating organizations of PALCA include:

- The Pennsylvania Health Law Project (www.phlp.org)

- The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) (http://www.carie.org)
- The Disability Rights Network of Pennsylvania (http://drnpa.org)
- Mental Health Association in Pennsylvania (MHAPA) (http://www.mhapa.org)
- Mental Health Association of Southeastern PA (http://www.mhasp.org)
- The National MS Society—PA chapters (http://pae.nationalmssociety.org)
- Liberty Resources (http://www.libertyresources.org)
- Pennsylvania Statewide Independent Living Council (http://www.pasilc.org)
- Pennsylvania Association of Area Agencies on Aging (http://www.p4a.org)
- SEIU Healthcare Pennsylvania (http://www.seiuhealthcarepa.org)
- Elder Law Section of the Pennsylvania Bar Association (http://www.pabar.org/public/sections/elderlaw)
- Community Legal Services Elderly Law Project (www.clsphila.org)
- PA Brain Injury Network (www.abin-pa.org)
- Pennsylvania Council on Independent Living (www.pcil.net)
- Pennsylvania HomeCare Association (www.pahomecare.org)
- PA Statewide Independent Living Council (www.pasilc.org)
- United Cerebral Palsy (www.ucp.org)
- Speaking for Ourselves (www.speaking.org)
- Southwestern Pennsylvania Partnership for Aging (www.swppa.org)
- Vision for Equality (www.visionforequality.org)
- AIDS Law Project (www.aidslawpa.org)
- SeniorLAW Center (www.seniorlawcenter.org)
- Eldernet of Narberth and Lower Merion (www.eldernetonline.org)
- Pennsylvania Jewish Coalition (www.pajewishcoalition.org)
- Mental Health America Allegheny County (www.mhaac.net)

II. Strong Support for Regulation of Assisted Living

The Pennsylvania Assisted Living Consumer Alliance strongly supports the need for passage of good assisted living regulations to ensure that Pennsylvania's older adults and persons with disabilities are provided with adequate care. The Department of Public Welfare has gotten off to a good start with the proposed regulations. As written, however, the proposed regulations simply do not do enough to protect the consumers that assisted living facilities will serve.

III. Opposition to Grandfathering

Currently, Pennsylvania licenses nursing homes and personal care homes. Personal care homes have been designed for consumers who need limited assistance with basic activities of daily living. By definition, the care needs are

minimal and, accordingly, the standards imposed in the personal care home regulations are minimal. Nursing homes, by contrast, are designed for consumers who need extensive assistance with activities of daily living as well as healthcare and supplemental health care services. Nursing homes must comply with detailed federal and state requirements to ensure that they can safely meet these complex care and healthcare needs.

We are all here today because we are creating a brand new care setting. And, while this new care setting may reflect some blending of the facets of personal care homes and of nursing homes, Assisted Living is a new model of care for Pennsylvania in concept, in care level, in construction.

There is no question that some lines may seem blurred. Presently, any facility that calls itself assisted living is currently licensed only as a personal care home. But this is by default, not by design. It is not the outcome of a planned process, such as we are undergoing in this very hearing, or any conscious decision that personal care home standards come close to being appropriate for what the public and the marketplace have defined as "assisted living".

The lines might also be blurred by the fact that the Department, in drafting the assisted living regulations, began with the personal care home regulations as its framework and overlaid changes to account for some of the differences between personal care homes and assisted living residences and some of the care needs of the residents they are intended to serve. **The changes made thus far are critical and must be, by all means, preserved in the final regulatory package; they alone, however, are not enough to deliver on the promise of safely serving our loved ones in assisted living facilities.** We believe the Department made a good decision in building off the personal care home regulations as it provides for 1) ease of drafting, 2) ease of public comparison or 3) ease of administration at the point at which the regulations would be applied. It also makes it easier to confirm that the Department is meeting its statutory obligation to craft regulations no less than what exists for personal care homes.

Assisted Living is a new licensure category and, as such, grandfathering of staff qualifications, physical site or other elements of the new regulations is not appropriate. Historically, "grandfathering" has a limited regulatory use where an existing licensed system is facing a hardship by an updating of standards, as happened in 2005 with the Personal Care Home regulations. This situation must be distinguished as the state is not updating an existing set of regulations but creating a new licensed entity to operate under a new regulatory system. Grandfathering is **not** appropriate as a regulatory construct when creating a brand new licensed entity, as is happening now. The hardship argument does not apply here as facilities that currently exist can continue to operate under the Personal Care Home licensure should it choose not to meet the new standards.

None of these facilities will be forced to become licensed as an assistive living facility; they would simply not be allowed to call themselves assisted living.

Assisted Living facilities are supposed to be home-like care settings that are designed, staffed, and equipped to meet significantly greater care needs than the personal care home regulations address. It is for this reason that we must ensure that the standards to which all assisted living facilities are held are good enough to meet the complex care needs of those we intend and expect to reside and to receive services therein.

IV. Overall Comments about the Regulations: The Good and The Bad

As written, the assisted living regulations do not go far enough towards meeting the ultimate objective of quality care provided by adequate amounts of appropriately trained staff in a safe, supportive, and stimulating apartment-like setting. Many more changes must be made to ensure that assisted living facilities are equipped, enabled, and accountable for providing all residents with quality care, provided by appropriate amounts of adequately trained staff, in a home-like setting that is safe, accessible, and stimulating.

PALCA has submitted extensive written comments to the proposed regulations detailing the critical issues that need to be addressed before the regulations are finalized and highlighting the positive changes made to what exists for personal care homes. These are critical and must be retained.

1. With fire as the leading cause of death in personal care homes, we must retain the requirements that a smoke detector be placed in each living unit and that fire safety approval is renewed every three years.
2. With more than 21% of all assisted living residents using wheelchairs and more than 44% of all assisted living residents using walkers, we strongly support the requirements for new construction and believe it must be applied to all applicants for assisted living licensure, that rooms be sized at no less than 250 square feet so as to be accessible for 2/3 of all residents. Likewise, we strongly support the requirement for facility vehicles to be accessible.
3. With so many critical decisions needing to be made and actions needing to be taken at all times of the day, it is essential that a person trained to supervise, oversee, and manage an assisted living facility be on site at all times, and thus we strongly support the requirement that the administrator's designee(s) satisfactorily complete the administrator training.
4. With so many consumers having conditions for which their medications lose efficacy if their body temperature is too hot, we must retain the requirement for all facilities to have air conditioning.

5. With the anticipation of a resident population that has complex care needs, we strongly support the need for a nurse to be involved in assessing resident care needs and developing their support plans, and for a nurse to be on call, if not on duty, at all times.

Beyond these essential changes, however, lie many critical issues that are not sufficiently addressed in the proposed regulations that need to be. Some ways in which the proposed regulations must yet be changed before becoming final rules for assisted living facilities include:

- By adding fundamental consumer protections that all Assisted Living residents and applicants deserve.
- By requiring consumers to have their needs assessed and a full picture of what the facility can or cannot do to meet the consumers' specific assessed needs - along with how much this will cost – prior to moving in to the facility and being made to sign a contract for residency and services.
- By mandating that all direct care staff complete a minimum amount of training hours (no less that the 77 hour core competency curriculum developed by the State Department of Labor and Industry) and be trained in first aid or CPR.
- By requiring all facilities (including buildings that exist as of the day the regulations take effect) to meet the current standards or practices for fire safety and accessibility.
- By requiring enough direct care staff to ensure that at least 2 hours of care can be delivered to each resident each day but that the actual amount of direct care staffing to be based on the individual needs of the residents.
- By requiring all living units to be wheelchair accessible with no less than 250 square feet of living space, with no exceptions.
- By providing consumers with a right and a process to challenge a facility's decision to kick them out.
- By assuring the resident has a right to continue to use or otherwise choose their own healthcare providers, such as their doctor or psychiatrist.
- By prohibiting the facilities from attempting to dictate who the resident must use as their doctor, psychiatrist, cardiologist and other healthcare providers and by limiting the ability of the facilities to limit resident choice of physical therapist, occupational therapist, durable medical provider, and other supplemental healthcare provider.

V. <u>Specific Points For Attention:</u>

Because time is limited, I would like to draw your attention to two of our concerns. **They are: How is the facility staffed? And, how is the facility staff trained?** As proposed, the regulations only require an Assisted Living Facility to

have 1) Administrator (or designee), 2) direct care workers, and 3) housekeeping, food preparation, food service, or maintenance staff. No nurse, doctor, medical director, care manager, activities coordinator, or dietician needs to be on staff, despite the increased care needs of the population generally and regardless of the actual care needs of each specific facility's resident population. The proposed regulations demand that administrators bear a tremendous scope of responsibility and that direct care workers deliver a tremendous array of services without adequate qualification, training, and staffing requirements to ensure that these can be accomplished.

1. **Training of Administrators and their Designees:**

With assisted living comes entirely new concepts and entirely new rules for Administrators to implement; rules around such things as HCBS waivers, interacting with resident health insurance (as potential payers for healthcare services residents require), implementing informed consent agreements, following excludable condition requirements, and enabling aging in place as well as providing, managing, and overseeing the kind of care that the greater care needs population will require. Despite all these additional components an administrator will be required to master and implement, the proposed regulations require no additional training hours nor additional training content beyond what is required to administer a personal care home. **For this reason, we strongly recommend a training curriculum that is enhanced to cover the necessary content as well as dementia care and is provided in no less than 150 hours prior to being employed as an administrator.**

2. **Qualifications of Administrators:**

To be an assisted living administrator, one must meet the administrator qualification requirements from the personal care home regulations plus have work experience in a health or human services related field. Many would suggest that individuals who were grandfathering out of having to meet the qualification requirements should again be grandfathering out of having to meet this qualification requirement for administering an assisted living facility simply because they call themselves assisted living facility administrators. **The qualifications for administrator in the proposed regulations are a bare minimum qualification that all assisted living administrators must be required to meet, with no exception or grandfathering.** *Please refer back to the earlier discussion around our outright objection to any grandfathering in this brand new licensure system.*

3. **Administrator Staffing:**

It has been a travesty in personal care homes that the administrator is barely present. There is no question that managing, supervising, and overseeing all the moving parts of a challenging 24 hour a day, 7 day a week business as an assisted living facility is a complex task. How could it be acceptable that the one and only person trained in how to manage, supervise, and oversee a facility could be only present 20 of the 168 hours in a week? Residents cannot confine their falls, their strokes, their fevers, their need for access to their funds, their desire to lodge a complaint about the quality of care, their need for reassessment, or other emergencies or reportable incidents to the 20 hours per week the administrator would be present were the personal care home standard to carry over to assisted living. **For this reason, PALCA strongly supports the proposed requirement that there be an administrator or a designee that has satisfactorily completed the administrator training on duty at the assisted living residence at all times.**

4. Direct Care Worker Training:

The direct care staff training is incomplete and insufficient. Under the proposed regulations, direct care staff need not complete any minimum amount of hours of training. Direct care staff need not have any training in first aid or CPR. Clearly, given the care needs of the anticipated residents, more training is needed. To put this regulatory flaw in context, we provide a comparison of training hours required for jobs in our Commonwealth that one can hold without having any formal education:

Current Pennsylvania training requirements for licensure				
Occupation	**Minimum Required hours of training for licensing**		**State board oversees licensure**	**State board requires Exam**
Nail technician[1]	200		Yes	Yes
Esthetician[2]	300		Yes	Yes
Cosmetologist[3]	1,250		Yes	Yes
Natural hair braider[4]	300		Yes	Yes
Barber[5]	1,250		Yes	Yes

[1] http://www.pacode.com/secure/data/049/chapter7/chap7toc.html
[2] http://www.pacode.com/secure/data/049/chapter7/chap7toc.html
[3] http://www.pacode.com/secure/data/049/chapter7/chap7toc.html
[4] http://www.dos.state.pa.us/bpoa/lib/bpoa/20/cosm_board/cosmetology_-_natural_hair_braider_application_w_out_exam.pdf
[5] http://www.pacode.com/secure/data/049/chapter3/chap3toc.html

Time Share Salesperson[6]	30 hours + 30 days onsite training		Yes	No
Auctioneer[7]	300		Yes	Yes
Dog Warden[8]	56		No	Yes
Certified Real Estate Appraiser[9]	120		Yes	Yes
Personal Care Home direct care staff person	0		No	No
Assisted living direct care staff person	0		No	No

One can also add to this list a recent legislative proposal to license all of the state's dog groomers that would have required no less than 300 hours of training for a basic dog groomer; surely caring for human lives calls for as much if not more training. **PALCA is urging the state to adopt minimum training hours, no less than the 77 hour core competency curriculum adopted by Workforce Taskforce of stakeholders under the Department of Labor and Industry, and to require all direct care staff to be trained in 1st Aid and CPR.**

5. Staffing Levels:

As written, the proposed regulations rely on the archaic labeling of residents as "mobile" or "immobile" and rely solely on those labels to determine whether the resident needs one versus two hours of direct care services. This old-school labeling was based on concerns about safe evacuation of the facility but it was woven into the calculus of how many direct care staff persons must be on duty to care for residents. This provision is another one that remains completely unchanged from what exists in personal care home regulations, once again, despite the increased acuity for which assisted living facilities are being licensed to serve. **Instead of leaving the personal care home calculus as is, the regulations should establish a floor of at least 2 hours of care per resident per day with the actual care hours above that being determined based on the assessed needs of each resident. The care needs should be identified by a standardized, mandated assessment tool that calculates staff time required to meet each identified care need.**

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[6] http://www.pacode.com/secure/data/049/chapter35/s35.229.html
[7] http://www.pacode.com/secure/data/049/chapter1/s1.11.html
[8] http://www.agriculture.state.pa.us/agriculture/lib/agriculture/legalreference/doglaw.pdf
[9] http://www.pacode.com/secure/data/049/chapter36/chap36toc.html

Thank you for the opportunity to share our ideas with you today. Every one in this room cares very much about our loved ones. And every one supports standards to ensure that they are safely cared for in apartment-like settings that promote privacy, autonomy and most important, dignity.

Respectfully Submitted,

Alissa Eden Halperin, Esq.
Pennsylvania Assisted Living Consumer Alliance
A Project of the Pennsylvania Health Law Project

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PALCA Living Unit Position Statement

The PA Assisted Living Consumer Alliance believes that consumers must be provided with adequate living space in order to live comfortably and safely in an assisted living facility. We believe this means that a living unit must have at least 250 square feet of space, excluding the closets and bathroom. We base this recommendation on many factors:

1) Many states require at least 200 square feet per single bedroom living unit.
2) Most of the "marketplace" provide at least 250 square feet and up to 500 square feet for a single bedroom living unit.
3) And, the Pennsylvania Housing Finance Agency along with the Philadelphia Housing Authority recommends no less than 250 square feet, excluding bathroom and closets, per living unit.
4) Hotel rooms average 325 square feet.
5) Apartments (at least those built with financial support from the Pennsylvania Housing Finance Agency) are required to have at least 400 square feet per efficiency, 550 square feet per 1 bedroom, and 750 square feet per 2 bedroom.

There must be no less than 250 square feet of usable space in the living unit, not including the space occupied by the bathroom, kitchen area, closets, and storage spaces. All units must be accessible to potential residents who use wheelchairs. The most stringent level of construction and fire safety requirements must apply to these facilities and the living units, no matter whether a facility was physically in existence prior to the adoption of such requirements.

There must be a distinct kitchen space (visually and functionally distinct). The kitchenette must have a countertop, storage cabinet, sink, a GFI outlet, a mini fridge and a microwave (not just capacity and space

for these items). The sink must be separate and distinct from the bathroom sink.

Lockable doors to living units. On the topic of lockable doors, the ultimate issue for consumers is privacy and respect. There must be a presumption that the consumer gets to choose locked or not. Uniform assessment criteria for determining ability to have a lockable door must be established so that there is a standard process for making the determination across the facilities. The consumer's assessment and care plan must indicate whether consumer will have a lockable door. Whether a person has a lockable door or is assessed as unable to have a lockable door (for safety reasons), the person must be protected from intrusion into their private space by prohibitions of widespread use of a master key or of unscheduled and unannounced entry into the living unit. We support some exception for emergencies. Door and door locks must be of accessible design.

Lockable Bathroom Doors. Bathroom doors within a living unit need not have lockable doors within single living units. However, any double bedroom living unit must have a lockable bathroom door to ensure privacy of the residents in bathing. The same individualized assessment analysis described above should be followed in the event of a question as to whether lockable bathroom doors in a shared unit would be appropriate.

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PALCA Public Funding Position Statement

All Pennsylvanians can choose, if provided with the necessary supports and services, to remain in their own homes*. Sometimes the lack of accessible or available home and community based services, affordable housing and housing supports is the only reason a consumer moves to an institutional setting. PALCA wants to ensure that assisted living is an option and not a default position any consumer falls into when preferred options cannot be afforded.

In this position paper about public funding for assisted living, we note the critical nature of ensuring a fair and level public funding playing field across long term care settings. It is for this reason that we suggest that the Commonwealth must swiftly and simultaneously act to both create public funding options for assisted living consumers as well as enable consumers to be supported in their own homes, as this is where most consumers want to be.

Personal Care Services Must be Added to the State Plan:
Consumer directed, personal care services must be added to the state Medicaid plan to support consumers who need supportive services but whose level of acuity is lower than the current requirements for existing Medicaid waiver programs. These PCS services should be available through the Medicaid state plan for consumers in the community as well as for those living in assisted living.

Additional SSI Supplements Must be Available to ALR Residents and to Consumers Needing ADL assistance but living In the Community:
A housing supplement (like that available to PCH and DCH residents) must be created for assisted living consumers and must be adequate to cover costs of room and board.

This housing supplement must be available to consumers remaining in their own home to prevent the many inappropriate institutionalizations that result from lack of housing supports. The same supplements must also be available to residents of Personal Care Homes and Assisted Living Facilities who want to move out of the facility and into their own homes.

PA Must Apply for a Waiver for Assisted Living Residences, so as not to rob slots from existing home and community based waivers:

- Aside from the Assisted Living Waiver, no existing Medicaid HCBS Waivers shall be used in Personal Care Homes or Assisted Living Facilities except that Medicaid HCBS Waivers and other publicly funded programs serving individuals with brain-injury may be used in approved Personal Care Homes and Assisted Living Facilities as permitted by state and federal law.

- Any facility that seeks to accept Medicaid payment and use Medicaid HCBS Waiver funding must:
    - Admit individuals with day-one MA eligibility
    - Not deny admission to individuals who are MA-eligible
    - Not deny admission or discharge individuals who are converting to MA status
    - Be prohibited from creating a MA unit or section of the facility, transferring a resident to another part of the facility because of payment source, or segregating MA recipients to one area
    - Must receive approval from the Commonwealth that facility based capacity is needed in the given community

*The term "home" includes both privately owned and rental properties.

The state must zealously enforce the anti-discrimination provisions we propose.

Medicaid waiver dollars must not be permitted to be used only for those who privately paid and spent down their resources to the point of Medicaid eligibility. The state must commit to equal access which means prohibitions on discrimination and regular tracking of admissions to ensure that prohibitions are not violated. Enforcement actions must be taken when a facility has been found to deny admission or to transfer or discharge a resident due to payment source. Several members of PALCA believe it should even be a condition of participation in the Medicaid Waiver program that providers should be required to commit to a fixed percentage of residents funded by Medicaid.

There must be a public process to develop the Assisted Living Medicaid Waiver Application that the state would be submitting to the Centers for Medicare and Medicaid Services.

It is imperative that stakeholders be involved in developing the finer points of the Assisted Living Medicaid Waiver Application and that the broader public be provided an opportunity to submit input as well.

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PALCA Position Paper on Freedom of Choice of Providers

Act 56 Section 1057.3(a)(12) states that "To the extent prominently disclosed in a written admission agreement, an assisted living residence may require residents to use providers of supplemental health care services designated by the facility." Supplemental Healthcare services is defined as all healthcare services that are not required to be provided in a Health Care Facility (as defined under the Health Care Facilities Act – which relates to hospitals and nursing homes).

PALCA is opposed to any limitation on choice of provider, including a limitation relating to physician, psychiatrist, specialist, pharmacy, home health agency, nursing agency, DME provider, physical therapist, occupational therapist, and more. An assisted living facility is supposed to be a consumer's home, a home in which she retains her maximum independence and autonomy in such decision-making as from whom to receive healthcare services.

The Pennsylvania Assisted Living Consumer Alliance has many concerns.

1) This is bad public policy.
2) This is bad fiscal policy.
3) This is anti-consumer.
4) This is anti-free-market.

Why forced forfeiture of choice is bad public policy:

Assisted Living residents and those who would consider entering an assisted living facility want to retain their freedom, choice, and autonomy. This includes the ability to direct their own healthcare and select their own healthcare providers. If assisted living is truly intended to be a home like setting, consumer must retain the freedom to make choices that consumers daily exercise in their own homes. Notably, even in nursing facilities, consumers retain choice of pharmacy and doctors.

Why forced forfeiture of choice is bad fiscal policy:

Assisted Living residents may have a variety of health insurances between Medicare, Medicaid, or even private health insurance for covered healthcare services (such as doctor visits, nursing care, PT, OT, etc.). Assisted Living Facilities are not "provider types" that can bill the Medicare program and they are not "provider types" that can bill private health insurance. Under an AL Medicaid Waiver, ALFs will be able to bill Medicaid for waiver services but not necessarily all healthcare services that the recipients resulting Medicaid coverage would cover.

Requiring residents to use doctors, psychiatrists, physical therapists, pharmacies, etc. that do not participate in their insurance means that consumers forfeit not only choice of provider but also their right to use their health insurance to pay for needed healthcare services. Consumers will be forced to forego services to avoid paying out of pocket or will be forced to pay out of pocket for their healthcare services, more swiftly depleting financial resources than if they were permitted to use their health insurance. Expedited spend-down will lead to more impoverished consumers needing more public funding support to fund their healthcare and non-healthcare supportive services.

Why forced forfeiture of choice is anti-consumer?

Assisted living residents can quickly become isolated in their facility and the isolation is only hastened and worsened by denying the residents their choice of healthcare and other providers. When no outside eyes ever get to mark to progress or decline a consumer is making, avoidable outcomes cannot be averted. One would think facilities would be more at risk of negligence suits when such a forced closed-loop of care is mandated.

Similarly, ethical considerations rage when such a highly conflicted system is established.

Why forced forfeiture of choice is anti-free-market?

To those who have always argued that the marketplace can correct for its quality problems and consumers can use their feet and leave one provider if that provider's care is poor, the free-market argument gets turn on its head here. What better way to ensure to the public that ALFs provide good quality care than by permitting free choice of providers. When there is no guaranteed, captive audience for a provider's services and the provider must compete for the residents' business, quality services will be assured.

Recommendations:

Regulatory: Any regulations must qualify the provisions of 1057.3(a)(12) to ensure that its application is lawfully limited to ensure as much consumer choice, consumer protection, and ability to use one's own health insurance.

Statutory: This provision should be removed from Act 56 as bad public policy.

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September 10, 2008

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

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

Dear Ms. Weidman and Chairman Coccodrilli:

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

PALCA is a coalition of organizations and Pennsylvanians that formed in January of 2008 to ensure that the concerns of consumers are heard in the formation of Assisted Living licensure rules for Pennsylvania. Organizations participating in the Alliance include:

- The Pennsylvania Health Law Project (www.phlp.org)
- The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) (http://www.carie.org)
- The Disability Rights Network of Pennsylvania (http://drnpa.org)
- Mental Health Association in Pennsylvania (MHAPA) (http://www.mhapa.org)
- Mental Health Association of Southeastern PA (http://www.mhasp.org)
- The National MS Society—PA chapters (www.nationalmssociety.org)
- Liberty Resources (http://www.libertyresources.org)
- Pennsylvania Statewide Independent Living Council (http://www.pasilc.org)
- Pennsylvania Association of Area Agencies on Aging (http://www.p4a.org)

- SEIU Healthcare Pennsylvania (http://www.seiuhealthcarepa.org)
- Elder Law Section of the Pennsylvania Bar Association (http://www.pabar.org/public/sections/elderlaw)
- Community Legal Services Elderly Law Project (www.clsphila.org)
- Acquired Brain Injury Network of Pennsylvania (www.abin-pa.org)
- Pennsylvania Council on Independent Living (www.pcil.net)
- Pennsylvania HomeCare Association (www.pahomecare.org)
- Eldernet (www.eldernetonline.org)
- Vision for Equality (www.visionforequality.org)
- AIDS Law Project of Pennsylvania (www.aidslawpa.org)
- SeniorLAW Center (www.SeniorLAWCenter.org)
- Pennsylvania Jewish Coalition (www.pajewishcoalition.org)

Many of us have worked for years to see assisted living licensure come to pass. We are excited to see that licensure for assisted living is finally happening. We are excited because consumers need licensure for assisted living.

We emphasize the importance of having good assisted living regulations. Assisted living is a critical part of the continuum of long term care and is invaluable for rebalancing our long term care system towards providing care in more home-like settings than nursing facilities.

Everyone who has ever had to look for care for a loved one, care that can no longer be provided at home, knows that this search is painful and difficult. There is a delicate balance between the most home-like environment possible, and the institutional supports that must be provided. Although it may appear contradictory, promoting independence, dignity, privacy, and choice requires Pennsylvania to set clear standards in order for those in need of assisted living to find it in our Commonwealth.

Our Alliance formed earlier this year to give voice to consumers, family members, and their advocates who are all seeking to ensure that assisted living facilities are equipped, enabled, and accountable for providing all their loved ones with quality care, provided by appropriate amounts of adequately trained staff in a home-like setting that is safe, accessible, and stimulating.

We have analyzed these regulations and many of us reviewed preliminary drafts, as we participated in the Assisted Living Workgroup of the Department of Public Welfare. We applaud the many good things the Department did in the proposed assisted living regulations as these provide some hope of quality care. However, the regulations do not go far enough towards the promise of quality care.

The regulations for personal care homes served as the platform from which the state proposes to build assisted living licensure. Several of the proposed requirements represent crucial enhancements to the personal care home regulatory requirements. These are essential changes for meeting the care needs of the population that Assisted Living residences are intended to serve. These are changes of which we are wholly supportive and we list all of these herein. More provisions, however, were left exactly the same as in the personal care home system, even though changes are critical for ensuring that Assisted Living facilities are able to safely serve Pennsylvania's assisted living consumers.

While the personal care home regulations are the floor for the proposed regulations assisted living regulations, it is critical to remember that Assisted Living is a new licensure category and, thus, grandfathering of staff qualifications, physical site or other elements of the new regulations is not appropriate. Historically, "grandfathering" has a limited use where an existing licensed system is facing a hardship by an updating of standards, as happened in 2005 with the Personal Care Home regulations. This situation must be distinguished as the state is not updating an existing set of regulations but creating a new licensed entity to operate under a new regulatory system. Grandfathering is **not** appropriate as a regulatory construct when creating a brand new licensed entity. There is no hardship to the facility; it faces no harm by the new requirements as it can continue to operate exactly as it always has under the Personal Care Home licensure should it choose not to meet the new standards.

While the proposed regulations make small steps in the right direction, we do not believe that the proposed regulations make adequate strides towards 1) meeting residents' care needs, 2) guaranteeing that all consumers have meaningful rights of which they are aware and that they are free to exercise their rights, 3) assuring safe and accessible physical site, 4) ensuring care is provided by appropriate amounts of adequately trained staff, and 5) answering critical unanswered questions that the public needs answered. We urge the Department to take additional steps towards ensuring that consumers can be safely, happily, and healthily served in Pennsylvania's assisted living facilities.

Our comments are broken down as follows: **First, we offer our overarching concerns we have about the proposed regulations. We then outline the crucial improvements from what we have in the personal care home system, improvements which we feel must be retained in the final regulations. Third, we list by section the outstanding problems with the regulations. Finally, as an attachment, we offer line-by-line recommended edits to the entire set of proposed regulations to delineate how our comments could be implemented.**

I. Overarching concerns with the proposed regulations:

A. 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 the rules provide for a short-form, pre-screening checklist to determine whether the consumer could be safely admitted to an ALR or if he has conditions or needs that would require exclusion from the facility, an ALR is only required to perform a comprehensive assessment "within 15 days" after admission to the facility. In addition, the facility has until 30 days after admission to develop the resident's actual care plan. The result is that consumers are put in the untenable position of having to move into a facility without knowing for certain if the ALR can meet their needs and if they will be able to remain in the facility. With the possible exception of an immediate discharge to the Assisted Living facility from a hospital, an ALR should be required to perform a comprehensive assessment of a potential resident prior to admission in order to determine: whether she can live in the facility successfully; her care needs; whether her needs can be met in a way that comports with consumer choice around how and when to receive care; and the costs associated with meeting her care needs in that facility.

As written, the proposed regulations provide no sufficiently clear statement as to the specific assisted living services a consumer should expect to receive from an ALR, nor do they articulate a minimum, core package of benefits If consumers are not assured that every ALR must provide at least a uniform minimum core benefit package with the admission price, consumers cannot meaningfully compare and choose among facilities. Without a minimum core benefit, consumers cannot understand the differences in costs/ extra services from one facility to the next or the value added if they purchase 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. We are sure that the last thing the state wants to see is a consumer being forced to choose between three nutritious meals a day and having their care needs met in an ALR.

The proposed regulations give the facility total control over where residents get all medical care and supportive services. Consumers want to be able to choose and use their own trusted healthcare providers. The personal care home system recognizes this and allows consumers to use their own physicians and pharmacies. The proposed ALR regulations, however, do not provide residents with any ability to choose and to use outside providers. Instead, a facility can mandate that residents use providers of its choosing. This clearly flies in the face of consumer freedom of choice provisions found within Medicare, Medicaid and other insurance programs. The vague regulatory

language in the proposed rules that facilities not "unreasonably withhold approval of outside provider when consumers have insurance" does not fully redress this problem. Protecting residents' rights to choose and use their own providers provides a check and balance against poor care, conflicts of interest, and complete isolation within the facility. It also allows consumers to use the marketplace to meet their medical needs when quality care is not provided in their supportive, apartment- like assisted living setting.

The Informed Consent Process fails to adequately protect residents. The proposed regulations create an informed consent system that does not include adequate protections for residents. ALRS cannot be allowed to use the informed consent process on a regular basis as a means to get around their responsibility to provide good care and/or their liability when such care is not provided. Residents who are at the mercy of those who are caring for them must be assured they will not be forced to hastily release the facility from its responsibilities when that may not be in the resident's best interests. There must be an independent entity designated to help consumers determine and understand the merits and consequences of entering into an informed consent agreement. Ombudsmen are inappropriate to serve in this role.

Consumers are disadvantaged where the facility has total control over whether a consumer can stay or has to find a new place to call home. The proposed regulations suggest the **possibility** of consumers aging in place, yet at the same they set out a blanket list of excludable conditions that, if present, would warrant a facility to discharge the consumer without exception. The excludable conditions provisions in the proposed regulations draw black and white lines in areas where there are clearly shades of gray. For example, why should a resident be DISCHARGED for developing stage 3 or 4 decubitus ulcer? Why not transfer the resident to a hospital and readmit when she has healed if that is what the consumer wants? A tenant would never be evicted from a rental apartment for having to go to a hospital for a couple weeks, especially if she is continuing to pay the rent. The excludable conditions provisions must allow for exceptions and for fair and reasonable considerations so as to protect residents' ability to remain in the place the resident has come to call home. Additionally, there is a process for facilities to seek exceptions to the excludable conditions prohibitions. There is no mechanism for insuring that these exceptions are fairly sought and that facilities do not discriminate against two similar residents based on payment source or history of complaints against the facility, etc.

B. The proposed regulations do not guarantee that all consumers have meaningful rights of which they are aware and that they are free to exercise their rights.

It is critical that ALR applicants have enumerated rights and that the rights of applicants and residents are all set out in a regulatory section on rights. The proposed regulations simply provide ALR residents the same rights provided personal care home residents, despite the differences in the facilities and the greater frailty and dependence of the population being served in ALRs. Additionally, the "rights" section is what residents are provided as their list of "rights". It is also what is posted in the facility

as the residents' rights. Yet, the residents' rights section of the proposed regulations does not articulate **a consolidated statement of all the rights the resident has.** For example, the resident's rights to view their own records or to be notified of egregious incidents or serious regulatory violations within the ALR are embedded elsewhere in the regulations. Because these rights do not appear in the official statement of "rights" however, most consumers are unaware of these other rights and how to exercise them. **All** residents' rights must be contained in a distinct rights section of the regulations to which consumers and their families can turn to understand how or whether they are protected. Residents must also be provided additional rights and protections beyond what are already set out in the personal care home regulations. The proposed regulations set forth no ALR applicant rights. This must be addressed to assure applicants such important rights as the right to a written decision regarding their application, the right to reasons/the basis of the decision if their application is denied, and the right to receive a list of facility services and costs upon request and prior to signing an admission agreement.

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 state licensing decision or a penalty imposed, the proposed regulations give the resident **no** ability to challenge the facility's unilateral determination that her needs can no longer be met and that she must be discharged. The resident is provided no articulated rights 1) to appeal a discharge to the Department's Bureau of Hearings and Appeals and 2) to continue to reside in the facility pending the outcome of their appeal. These must be provided to residents.

C. The proposed regulations do not assure that Pennsylvania's assisted living residents will be cared for in safe and accessible facilities.

As proposed, facilities that exist as of the day the regulations take effect would not have to meet the current standards or practices for fire safety or even for wheelchair accessibility. The regulations do not address the issues of older construction that do not meet current fire or life safety or facilities that were grandfathered years back and never had to come up to current standards for safety and accessibility. The purposed of assisted living licensure is to create facilities to care for people who need long-term care and the ability to aging in place. Such facilities need to be accessible to persons with physical disabilities. No one has a right to operate an assisted living facility. Existing personal care homes can continue to operate as personal care homes if they cannot be brought up to current safety standards. Similarly, these facilities 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. We urge that the existing construction provision be removed because 175 square feet is too small to be accessible for anyone using a walker or a wheelchair.

D. The proposed regulations do not ensure that care is provided by sufficient numbers of adequately trained staff.

As written, the proposed regulations rely on the archaic labeling of residents as "mobile" and "immobile" and rely solely on those labels to determine whether the resident needs 1 versus 2 hours of direct care. This formula in turn defines how many staff an ALR must employ to care for residents. Instead, the regulations should establish a floor of at least 2 hours of care per resident per day with the actual care hours determined based on the assessed needs of each resident.

The proposed ALR regulations simply adopt the direct care staff qualifications and training required of personal care home staff despite the differences in the facilities and the greater care needs often found in ALR residents. As proposed, direct care staff would not have to complete a minimum amount of training hours and not all direct care staff must be trained in first aid and CPR. No minimum training or qualifications are articulated for third party contractors serving as direct care staff and there are no requirements that all supervisory staff 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. Finally, the regulations contain no affirmative statement ensuring that training requirements will not be waived.

E. The proposed regulations do not address many key areas and leave unanswered too many questions that must be addressed in order for the public to understand what assisted living means and what they can expect from an ALR.

The regulations fail to address marketing or set forth any parameters on how facilities can market or present themselves as "assisted living residences". We understand from state officials that they anticipate facilities having an ALR license but also having at least part of the facility licensed as a personal care home or a skilled nursing facility. Yet the regulations do not address this issue at all. The regulations do not set out any parameters nor do they address the requirements that would have to be met in order for a dual licensure to be allowed. The regulations also fail to define key terms and take no steps towards improving upon the inadequate enforcement provisions inherited from the personal care home regulatory system.

II. The proposed regulations contain some crucial improvements over the personal care home system. These provisions must, at a minimum, be retained.

It is crucial that the Assisted Living regulations go beyond the regulations for personal care homes. There are a number of provisions of the proposed regulations that are clear improvements upon the regulations for personal care homes. These provisions must be included in the final regulations and serve as a minimum for what the regulations include. Specifically, the proposed regulations:

1) Establish licensure fees that are meaningful and potentially sufficient to fund the licensure, 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 (in the past approval was at the outset and was never required to be renewed). 2800.14
3) Exclude many regulatory provisions from the list of provisions for which a facility could seek a waiver (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 substantial 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, contrary to personal care homes which 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 newly constructed facilities to have larger rooms than in personal care homes, with 250 square feet of living space (this is only for new construction). 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 provider's approval of resident's choice of healthcare provider where resident has insurance. We wholly oppose limits on resident choice of provider. And, this does not exist in the personal care home system. We are only minimally comforted by the idea that, and include this in

the list of positive attributes of the proposed regulations only because, a facility cannot unreasonably limit resident choice where health insurance or long term care insurance may pay only for specific providers. Please note, however, unreasonable withholding is not defined and there are no appeals processes or rights for consumers to challenge such determinations made by a provider. 2800.142

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. 2800.171
19) Require facilities to provide medication administration. 2800.182
20) Require facilities to obtain medications prescribed for resident and to maintain an adequate amount of the residents' medications on site. 2800.185
21) Require all residences to provide cognitive support services. 2800.119
22) Require a written decision if residency is denied with an explanation of why. 2800.224
23) Requires a nurse to review and approve the support plan, whereas in the current system, there are neither qualifications nor specific training requirements for the individual who conducts assessments or trainings. 2800.227
24) 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
25) 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
26) Require tracking of admissions and discharges and transfers by the facility – including those involving excludable conditions. 2800.228 and 2800.229.
27) Adopted a good standard for when an exception to the excludable conditions prohibitions would/should be granted. 2800.229.

III. Specific Problems with the Proposed AL Regulations Published on 8/9/08 for Public Comment by 9/15/08, provided by section number:

GENERAL PROVISIONS

Section. 2800.1 through 2800.5

1) 2800.4 - Definitions.
   a. The proposed regulations left out definitions of Assisted Living Services, Assistive Technology, NFCE, Third-Party Provider, HCBS Waivers, Living Unit and other key terms that require clear definition.
   b. The proposed regulations left in the definitions of Mobile and Immobile resident, terms that many find offensive. Staffing levels are elsewhere linked in the regulations to whether a resident is mobile or has mobility needs regardless of actual care needs.
   c. The proposed regulations failed to improve upon the definitions of Aging in Place, Supplemental Health Care Services, Ancillary Staff Person, Designee, and Neglect as we had recommended.
   d. The proposed regulations added a definition of Health care or human services field (because it relates to the work qualifications an Administrator must have) and this definition raises some concern (as the proposed regulations included a "kitchen sink" final phrase pulling in any background that involved human beings, it appears). 2800.4
2) 2800.5 – Access to the facility and the residents
   a. Proposed regulations do not state that a facility must permit family members, the resident's attorney, law enforcement, or building code inspectors to enter and access the facility.

GENERAL REQUIREMENTS

Section 2800.11 through 2800.30

3) 2800.11 Omits any standard by which the state will judge whether a personal care home is suitable for transitioning to an Assisted Living Residence. We recommend such things as in full compliance with new regulatory requirements and exemplary compliance history with prior applicable regulations.
4) 2800.14 – Fire Safety Approval – This needs to indicate the impact to the facility's license if the 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.
5) 2800.16 – Reportable Incidents – The regulations need to indicate that the facility must write up a report on the facility's incident investigation findings to make available at inspections and that the state should be compiling and publishing data on the nature and scope of reportable incidents that occur in ALRs.
6) 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 build.

7) 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.
8) 2800.20 – Financial Mgmt – The regulations need to, but do not currently, prohibit the facility from requiring that the administrator or any employee of the facility serve as any residents' representative payee for Social Security payments.
9) 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.
10) 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. See also, comments to 2800.220.
11) 2800.28 Refunds. The proposed regulations permit a facility to hold onto a resident's money for 30 days after they move out. Many residents have limited funds to begin with and need that money in order to afford to move out. The final regulations must mandate that a resident is given back her money on the day she moves out, unless the facility did not have advance notice of the move, in which case the facility should have 7 days.
12) 2800.30. Informed consent. The informed consent process lacks protections so that consumers are not forced to regularly or hastily release facilities of their responsibility to provide care and their liability for failure to do so. No independent entity is designated to help consumers determine the merits of entering into an informed consent agreement.

RESIDENT RIGHTS

Section 2800.41 through 2800.44

13) 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. See our specific recommended language in our line by line comments.
14) 2800.41 Complaint procedures. There should be standardized procedures that all facilities should follow when they receive a complaint from a resident. This is absent from the proposed regulations.

15) 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 the right to:
    a. Know all their rights and have them articulated fully in one discrete section.
    b. To choose ADL and IADL providers, healthcare providers, and supplemental healthcare providers.
    c. To use their health insurance to pay for covered services.
    d. To lock their door.
    e. To terminate their residency at any time
    f. To terminate an informed consent agreement at any time
    g. To privately communicate with friends, family and others
    h. To reside and receive services all year without sudden disruptions for vacations or holidays.
    i. To reasonable accommodations of resident needs and preferences.
    j. To refuse treatments or services prescribed or recommended.
    k. To self-administer medicine
    l. To file complaints and grievances
    m. To receive oral and written communications from the facility in a manner that is accessible
    n. To have records kept confidentially.
    o. To appeal decisions made by the facility
    p. To continue to reside in the facility pending the outcome of the appeal.

    And more...
16) We urge the addition of a section 2800.42a on Rights upon Transfer or Discharge and make specific recommendations as to these rights.

STAFFING

Section 2800.51 through 2800.69

17) 2800.51 – Criminal History Checks. All persons working for or under contract with the facility should have to go through criminal history checks and the criminal history checks should be ones that meet state constitutional standards. This is not currently in the regulations.
18) 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 have at least the direct care staff training requirements.
19) 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.
20) 2800.60 – Additional staffing. The proposed regulations do not require that a facilities have a nurse on staff or under contract to participate in all initial or ongoing needs assessments.

21) 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.
22) 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 requirements must be met without grandfathering of any kind.
23) 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 requirements must be met without grandfathering of any kind.
24) 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).

PHYSICAL SITE

Section 2800.81 through 2800.109

25) 2800.83 – Temperature. We would like to see a statement of the minimum and maximum temperatures the inside of the facility can be during the cold of winter and the heat of summer.
26) 2800.86 – We recommend that facilities be required to use carbon monoxide detectors.
27) 2800.88 – Surfaces – We recommend that any asbestos on site that is found be appropriately remediated.
28) 2800.90 – Telephones – The facilities should have at least one phone on each floor and they must be accessible to all residents.
29) 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 each facility have enough first aid kits in accessible locations throughout the facility to ensure that the staff can swiftly administer first aid treatments.
30) 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.
31) 2800.101 – Living Units - The proposed regulations authorize grandfathering of bedrooms (and facilities with bedrooms that are only 175 sq feet. This is not accessible to a wheelchair, why should it be 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 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. With regard to shared rooms, it is not appropriate to require roommates to share dresser drawers, lamps, and night tables. This is supposed to be a home-like setting where one resident can continue to read despite their roommate having chosen to go to sleep. Residents need privacy and autonomy and the dignity of their own storage space. Not even a college student is required to share dresser drawers with a roommate.

32) 2800.105 – Laundry. Personal laundry must be cleaned at least once a week, unless more frequently due to care needs. Laundry must be a part of the core benefit package a consumer gets with their price of admission.
33) 2800.106 – Swimming pools. If a facility has a pool or swimming pond, it must be fenced in and their must be lifeguards on duty during any hours that residents are permitted to swim.
34) 2800.108 - Firearms are permitted, whereas the prior draft would have prohibited firearms in an ALR.
35) 2800.109. Facilities are not required to accept service animals which provide critical support to persons with various disabilities.

FIRE SAFETY

Section 2800.121 through 2800.133

36) 2800.129 – Chimneys that are used must be regularly cleaned.
37) 2800.130 – Smoke Detectors need to be located throughout the facility and not just in living units.

RESIDENT HEALTH

Section 2800.141 through 2800.144

38) 2800.141 – Medical Evaluation – This must be done more frequently than annually. As a matter of course, these should be completed every 6 months, upon a change in condition, and 30 days after a discharge from a hospital.
39) 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 we understand the facility should be able to have minimum expectations of any outside provider (such as: licensed, insured, willing to follow facility's operating rules/procedures), this goes far too far! 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.

NUTRITION

Section 2800.161 through 2800.164

40) 2800.161 – Meal Planning. All meal planning should be done in consultation with a dietician and meal preparation should be done under the guidance of the same dietician.

TRANSPORTATION

Section 2800.171

41) An ALR must be required to transport or ensure transportation to medical and social appointments. If "coordinate" is meant to mean review and explain public transportation schedule that may get the consumer to the appointment or event but not necessarily at the appropriate time, which is not adequate to fulfill the obligation to ensure that consumers get transported to where they need to go. The ALR must ensure transportation and they must provide the transportation in a way that coordinates with the time the consumer needs to be at the place to which he/she is being transported.

MEDICATIONS

Section 2800.181 through 2800.191

42) We would like more details around how it is determined whether a resident is capable of self administering medications. We want to see a determination being made that the resident is able to use the medication as prescribed in the manner prescribed, for example, including but not limited to being capable of placing medication in own mouth and swallowing completely, applying topical medications and not disturbing the application site, properly placing drops in own eyes, correctly inhaling inhalants, and properly inhaling nasal therapies.

SAFE MANAGEMENT TECHNIQUES

Section 2800.201 through 2800.203

43) 2800.203 The proposed regulations do not use the bedrail provision from the PCH system and the Federal Government recommendations – what the proposed regulations have is less than PCHs and federal recommendations and needs to be revised.

SERVICES

Section 2900.220 through 2800.229

44) 2800.220 – Services – The regulations need to be clear 1) what are all the assisted living services that each facility must be equipped to provide and 2) what is 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. We add several services to the list of "assisted living services" and we specifically recommend language for what should be contained in the base core package

of services, allowing, of course, for facilities to provide enhanced packages or ala carte extra services on top of the base core package.

45) We urge the Department to add a section right after services that speak to marketing of assisted living; the section must address such things like how facilities present the ability to age in place, to continue residence even when care needs change or money runs out.

46) 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 these be completed prior to admission, by or with a nurse (at present the proposed regulations do not even demand that an assessor has to have any training in assessing care needs), and quarterly not annually as well as after a change in condition or hospitalization. The assessment section should also articulate areas the facility must be sure to identify

47) 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.

48) 2800.228 – Discharge and Transfer. We have many concerns about the lack of protections for consumers in this section. There are no appeal rights and no appeal process. The ombudsmen are charged with doing a job they are not currently equipped or trained or funded to undertake. Many among us would also say that they are not authorized, under federal authorizing legislation, to take on the designed role. Consumers must be provided with a right to appeal, a process through which to challenged facility decisions, an ability to remain in the residence pending the outcome of an appeal, and faith in an independent panel to hear their appeals. Additionally, the grounds for discharge must be limited to those which are fair. We have provided specific language about these concerns.

49) 2800.229. There are still excludable conditions that draw black and white lines in areas where there realistically are some shades of gray. For example, why should a resident be DISCHARGED for developing stage 3 or 4 decubiti? Why not transfer to hospital and readmit when healed? A tenant would never be evicted from a rental apartment for having to go to a hospital for a couple weeks, especially if continuing to pay the rent. And yet, the regulations require a discharge in the event of stage 3 or 4 decubitus ulcers, unless the facility opts to request an exception from the state in order to retain the resident.

SPECIAL CARE UNITS

Section 2800.231 through 2800.239

50) 2800.231 – Admission – We believe this section needs to be stronger to ensure that consumers are fairly treated in the discussion and decision about whether they move to a special care unit. We provide specific language to make sure

that alternatives to moving are discussed and that appropriate family members and healthcare providers are involved in the discussion.

51) 2800.235 – Discharge – The section should not be different from the general section for resident discharge in 2800.228. This section would give consumers with cognitive impairments fewer protections than other consumers.

52) 2800.238 – Staffing – We do not think the state should continue to label consumers as mobile or immobile. We make specific staffing level recommendations in 2800.57 above and in our line-by-line recommendations. These should apply to consumers living in special care units as well.

RESIDENT RECORDS

Section 2800.251 through 2800.254

53) 2800.252 – Resident Record – The proposed regulations do not identify key items that should be retained in the resident's record to track needs and progress.

ENFORCEMENT

Section 2800.261 through 2800.270

54) We urge the Department to include a section 2800.260 on "dual licensure" and provide recommendations for when and how a facility could be dually licensed as assisted living and something else.

55) 2800.261 and .262 – Critical steps need to be taken to improve these provisions on plans of correction and the Department's expectations.

IV. Recommended Line-By-Line Changes to the Proposed Regulations:

Please see **Attachment A** for our "track changes" edited version of the proposed regulations. We provide these line-by-line recommended changes along with margin comments, throughout, explaining the importance of making the recommended changes.

We thank you for the opportunity to provide input into the inception of assisted living in Pennsylvania. Please call Alissa Halperin (215)435-3257 or e-mail her at ahalperin@phlp.org should you have any questions or need additional information.

Sincerely,

The Pennsylvania Assisted Living Consumer Alliance

ASSISTED LIVING CONSUMER ALLIANCE

Shared Stories

Read stories submitted by Pennsylvania residents who have had personal experiences with an assisted living or personal care facility in the Commonwealth. PALCA is grateful to everyone who has taken the time to share their stories with us.

Alfonso Joshua from Philadelphia describes his personal experience at Kaysim Court Manor:

I was being seen by "Dr. Bill" who is not a real doctor; he is a physician's assistant under Dr Swartzman. He was the house doctor at Kaysim Court Manor, the home I have been living at for eight years. I started seeing Dr. Bill around the year 2000 up until 2006. He would see us a few times a month and all he would do is listen to my heart and check my blood pressure. He never sent me out for blood work or any other test and he would give me new prescriptions. He never told me what the medicine was for or what it was. The home never told me what medicine I took, they just gave me the medicines and I took it.

Sometime in 2006 I passed out in the hall on my way outside and I was taken to the hospital and Dr. Swartzman saw me at the hospital. They sent me home with more medicine. The hospital said my blood pressure was low, my cholesterol was high and my sugar was high; I guess the medicine was for that. A few weeks later I passed out again at my program and they took me to Albert Einstein Hospital and I was told to get a new doctor by my insurance company. I stayed there for three days and they ran all kinds of tests my new doctor ordered; his name was Dr. Ali. Dr. Ali said my prostate was swollen and he ordered three colonoscopies and I was sent to a urologist. They found prostate cancer. After 38 radiation treatments I am now cancer free. I don't want anybody to go through what I went through. I am alive today because I changed my doctor.

Sherry Weersing of Thornton shares her story about Sunrise Assisted living:

I am appalled to read in the Inquirer about the lack of training and staffing requirements for assisted living facilities while at the same time allowing them to take sicker patients. We had to move my mother out of Sunrise in Westtown, Pa. after we were promised that she could be there until the end of her life. She has Alzheimer's disease and moved there in 2001. After 2 years she had to move back to their locked "Reminiscence" unit, supposedly where they specialize in Alzheimer's care. There was only minimally trained staff there, mostly college students. The med givers were not licensed. Over and over again I found they were crushing long acting medications. My mother started having seizures after she was started on Effexor XL because they were crushing it. It has been 2 years since we took her off it and 1 1/2 years since we moved her and she has never had another seizure.

She bumped her toe on one of the many pieces of furniture they have lining their hallways. It became infected. I pointed it out to them, told them to have the doctor look at it and that she needed antibiotics. By the time I was able to come back 2 1/2 days later, the infection was up to her knee, she was confused, febrile and they had only started the antibiotic hours before. I told them that oral antibiotics would not work for that and I took her to the ER. She remained hospitalized for 7 days on IV antibiotics. If there are any instances on off-hours, the patients are sent out to the hospital as there is only a nurse on call, not in house. Even if the patient has a

living will and a DNR order, they will call the ambulance. They sent my mom to the hospital one night after she rolled out of bed, onto the fall mats. There was no change in mental status, no signs of a bump to the head, no other indications of a problem. She regularly rolled out of bed. She was a hospice patient and they still sent her to the hospital. I was at work so I had to call the hospital and tell them not to do anything and that I would be there after work.

Kari Burdeau of Phoenixville talks about her son's situation at the Devereux Foundation:

My son, 17 years old, soon to be 18, has a moderate to severe form of autism, non-verbal, and moderately mentally retarded. He has been at the MRDD program of the Leo Kanner Center run by the Devereux Foundation for nearly 7 years. I know there is a greater need to protect the elderly. (My 96 year old uncle and 94 year old aunt are is an assisted living situation as well. They are doing fine because they can afford a reputable place), but the younger ones with disabilities in these situations are getting the short end of the stick. The health care and insurance coordination are a problem. The Kanner Center did try to take over the decision-making on his healthcare and messed up several times. It was expected that my husband and I would cover the bills no matter what. I have paid at least three hundred dollars because of the staff's ordering of meds he was no longer on or the medicine was changed to over-the-counter not covered by any insurance. They use a pharmacy that does not coordinate with our private insurance and is more expensive to the Commonwealth as a whole because each dose is individually wrapped. It still didn't stop one of the staff from giving my son all of his medicines in one instance thereby having him be overdosed and sick.

My husband and I believe in paying our fair share and supporting our son financially but that does not give the providers the right to do things without our permission. We never gave up custodial rights to our son. This was supposed to be an educational placement. We seem to have some conflicting rules and regulations that need to be sorted out (IDEA 2004, MEDICAID, MEDICARE, 3800 and 6400 regulations; etc.) He is using a picture exchange communication system (PECS). He has had a form of that system since he was four. Three times in the last five years I have had to resurrect the communication system in the residence. The staff has either been not trained in PECS; allowed the pictures to be lost and not replaced; or not bother to make him use it or practice it. The staff ratios in his house are not consistent to what is appropriate for kids with autism. Many times it is 5 kids to one staff and there is not enough supervision. This adversely affects his educational plan as well as the service plan. Now they may increase the number of kids in the house without increasing the number of trained staff. It becomes very stressful to me and a hardship to the rest of family because I have had to constantly monitor what the staff and caregivers are doing. There are some staff that are very good but a lot of them are poorly trained and there is a high turnover rate. There does not seem to be any accountability for the quality of care and a chance for a positive outcome.

Emilio Pacheco writes from Philadelphia about an experience with Cambridge Retirement Community:

Vision for Equality [which assists people with disabilities and their families] had a client that needed to be moved out of Cambridge Retirement Community – assisted living and independent living – because they were closing. I went with my staff to pick up the client. This client was a mentally disabled, non-English speaking patient. When we arrived to pick up the patient, staff from Cambridge said that the patient was already picked up. This was not the case – what happened was that the unsupervised patient got on the bus (which he was capable of doing for appointment purposes) and left the facility. Cambridge Staff was unaware of the patient's whereabouts. The patient returned to the facility.

Upon discharge from Cambridge, a bag of the patient's medication was given. This bag of medication had no instructions. It was just a bag of medication. Also Cambridge would not release records of the patient, therefore not much was known about the patient and his special

needs. Cambridge was closing and would not give important information about the patient. They were uncooperative with our agency (Vision for Equality), an advocacy agency, who was trying to appropriately and safely transition the patient into a new environment.

Linda George, Greensburg, PA shared her story about her son, an adult with disabilities:

My son is 21 with ASD, MR and MH issues. We have searched for the appropriate type of housing and have not found anything that could meet his needs. The homes are either made for individuals with limited need for daily activities, or just can't provide the stimulating and appropriate kind of environment needed for someone with Autism who is high functioning. We want him to be independent but have no options other than to keep him at home with us. Keeping him at home seems to be limiting his ability to become more independent with limited resources for respite, work, and social experiences.

He needs a place that will structure his entire day and place him on a structured schedule that will keep him excited to be a part of an independent program – offering social experiences with others, activities to keep him busy all day, and learning independent living skills. We have not been able to find anything like this even if we were to pay for it privately. It would be nice to have an assisted living facility for adults with disabilities that provides active socialization, vocational, and recreational activities, for adults who are able to participate in such programs but are caught in the cracks of being too high functioning or not high functioning enough to be completely independent.

Barbara Russell writes about her mother's experience at the Sunrise Assisted Living facility in Haverford:

First I would like to say that there are many wonderful care managers at the Sunrise of Haverford, which is located in an affluent Main Line area outside of Philadelphia. They are caring and hard working. They are understaffed and overworked. And we have just been told that workers' hours have been recently reduced. The care managers are responsible for giving medications, serving in the dining room and caring for residents. Their duties are stretched thin. During meals it can be very difficult to find someone outside the dining room. When the facility is without any directors, which seems too often, the lead care manager is in charge of the director's job.

Concierges are understaffed, so care managers answer phones up until 8 pm if no one is at the desk. There is never anyone at the desk after 8 pm. They are expected to clean even though there is supposed to be a housekeeping staff. The evening care managers do laundry, vacuum & mop the common areas while being responsible for all the residents. Ironically, one of our complaints is that my mother's room was routinely not cleaned nor her laundry done.

The residents are supposed to have the same care managers assigned for them to learn their specific needs and personalities. This does not happen, especially with the high turnover of employees. My mother had her days/nights mixed up and was left to sleep throughout the entire day for periods of time because we were told they were unable to get her up. It became a cycle hard to break until we hired outside companions. They had no problem waking my mother or keeping her up and her days/nights were back to normal for months until we cut back the aides' hours and Sunrise once again said they couldn't wake her up. We are paying for a "higher level of care" and can't even get five minutes of time to wake her in the morning?

There was an incident recently when my mother's aide arrived late morning and found her crying in her room. My mother told her that a group of kids came in and hit her with sticks and she said please find who did this to her. The next day I found her hand was badly bruised and swollen. While we know that her story was not true as she told it, I believe something happened to her. I did report it to the director and nurse. I believe that one of the "bad apples" who has no patience

was in a hurry to wake my mother. There is no way of investigating so all we can do is express concern. I did specifically tell the director that we did not want one of the care workers to work with my mother, which we were assured would happen. Unknown to us, she was assigned to my mother that week.

There are the few bad apples who have been reported being overheard saying they spit in food, throw water on residents to wake them up and speak very unkindly to residents. They have been promoted to leads and sit in the office when the directors are gone while everyone else runs their tails off.

Furniture in the commons areas are soiled with urine and maybe worse. Residents can be found with dirty clothing. The same care managers serving food are expected to change a soiled resident and then return to their dining room duties! How can that pass health code??

My mother was 105 lbs for her entire adult life until she arrived at Sunrise. She has gained 30 pounds from a combination of poor nutrition and lack of exercise. The food is salty, fried, high fat, large dessert portions and usually unappetizing. The new director told me there is a nutritionist in charge of their menu, which I find difficult to believe. We were told up until recently that they couldn't serve egg beaters. The choices of foods they serve to an elderly population can be baffling.

For the past few years the residents have sat all day and slept. The new activity director is trying to get them active, but one person cannot do the job alone especially after conditioning them to be so sedentary. There is no outside patio area that the residents can walk or wheel to themselves other than the porch where they go from sitting inside to sitting outside. Some days you can find residents left inside to sit even when the weather is beautiful. There is a walkway that goes around the building. My mother who is a good walker cannot walk this alone as the walkway is not level and is impossible for a wheelchair. Without the private companion or family member there is no one to walk with. Once outside on the porch, residents are routinely not checked on, asked if they need to use the bathroom or are cold.

There has been no handicap accessible van for years. A new van has been in the parking lot for months. There are finally tags for it. Now they are waiting for corporate to send a check to file the tags. So still no handicap accessible vehicle available. Crazy. How hard is that?

Billing is always screwed up and we are charged for services we do not receive. In addition to our cost of the facility, we are paying an additional fortune which we cannot afford to have outside companions for a resident who can dress, bathe, feed and walk herself. Without them my mother doesn't get up in the morning, misses breakfast, becomes disoriented and agitated, is up all night and the cycle continues. The private companions also clean her room and do her laundry, which we pay Sunrise to do.

There is more, including how would such an understaffed night shift get three floors of residents out for a fire? No nurse on duty for extended times?

Considering such a large number of family members have complained loudly for a long time you would think the new directors would be there more, have their shifts covered when gone for a week's time and have contact numbers. Over the course of several months, many of us have complained to the past executive director, then her supervisor, the supervisor's boss, to the Vice President of East Coast Operations, Human Resources and directly to Corporate. The new executive director has promised changes and asks for patience. It is very frustrating.

Here's the big question - why are we still there? We chose this Sunrise because of it's location to family and the facility is small enough that my mother, who has dementia, can find her way around. Now we are worried about the trauma of relocating and believe that Sunrise should

make the needed improvements and provide the quality of care we are all paying for and that the residents deserve.

I would like to share a story which had a big impact on me. My mother is a good story teller and comes up with some whoppers. Some are inspired by TV (which should be monitored), newspapers and conversations. One night not long ago, I called her and found her very upset. She said that the hotel she was in was terrible, that her room did not have linens and she had to take her own from home. The story then switched to her room had not been cleaned from the night before and had blood in it from that the prior guest giving childbirth in the room. HOLY SMOKES!

The next night I relayed the story to one of the night care managers. I learned that night that there are truths even when we don't understand it. It turns out my mother's neighbor who had psychiatric problems had tried to kill herself and awoke my mother screaming at 2 am. My mother came out into the hall to find the woman being taken to the hospital all bloody. Afraid to go back into her own room, my mother took her pillow and found an empty room to sleep in. That was a reminder to me when I heard the story of the kids hitting her with sticks and finding her bruised hand.

To read more stories or to share your own story, click on
www.paassistedlivingconsumeralliance.org

ASSISTED LIVING CONSUMER ALLIANCE

NEW COALITION PRESSES FOR QUALITY STANDARDS FOR ASSISTED LIVING FACILITIES IN PA

Consumers and advocates join the fight to protect Pennsylvania families from inadequate regulations

PHILADELPHIA, PA—(July 7, 2008)—A new organization of consumers, family members and advocates for the elderly and the disabled is pushing for quality standards in Pennsylvania state regulations covering assisted living facilities.

The Pennsylvania Assisted Living Consumer Alliance (PALCA) formed this year to ensure that new licensing rules will protect elderly and disabled residents. About 50,000 people in Pennsylvania currently live in facilities that may call themselves assisted living facilities.

"It's essential that we get these regulations right to protect all of Pennsylvania's families," said Alissa Halperin, Senior Attorney and Deputy Director of Policy Advocacy at the Pennsylvania Health Law Project, the organization leading the efforts of the Alliance. "We are committed to championing and supporting individual rights and quality care for everyone."

The Pennsylvania Health Law Project is primarily using operating support provided by The Pew Charitable Trusts to fund the campaign.

The Pennsylvania General Assembly last year passed a bill to license the fast-growing assisted living industry. The regulations are expected to be released this month, and the public will have a chance to comment on them before they are finalized. Until now, state regulations have lumped assisted living facilities together with a wide range of homes for the elderly and disabled.

"The passage of Act 56 was a great first step for consumers," said Halperin, "but now we need to make sure that the law isn't window dressing. We need regulations that will protect the residents' rights to access their own doctors and caregivers, to have adequate living space and to be served by appropriately trained staff."

Assisted living has emerged in the past generation to house people who are not so sick that they require a nursing home. But they generally need more help with bathing, dressing, medication management and other basic care needs than may be provided in personal care

homes. Assisted living has been a marketplace phenomenon for consumers who want independence, privacy, and choice, but who also want the ability to "age in place" - meaning they will not have to move when their care needs increase. In the past, however, state regulations have been so minimal and enforcement has been so lax that numerous reports of bad outcomes and, even, tragic results for residents have been published.

"The assisted living industry will be caring for increasing numbers of Pennsylvania residents and we need to make sure these facilities are places where we confidently can entrust the care of our mother, husband or grandfather," said Diane Menio of the Center for Advocacy for the Rights and Interests of the Elderly. "Thus far, the quality of care has varied immensely from facility to facility, with the differences depending far more on the intent of the facility owner than on meaningful standards for ensuring good care. We need solid requirements coupled with meaningful enforcement to ensure that quality care is available."

"PALCA has been set up to give consumers a voice in developing state regulations," says Halperin, as she invites residents and their family members to get involved. "Those who are most affected need a seat at the table."

PALCA members have met monthly since January and regularly talk to state regulators in the Pennsylvania Department of Public Welfare. The Alliance consists of numerous individual consumers and family members as well as several local and statewide organizations. The statewide and local organizations participating in PALCA include:

- The Pennsylvania Health Law Project (www.phlp.org)
- The Center for Advocacy for the Rights and Interests of the Elderly (CARIE) (http://www.carie.org)
- The Disability Rights Network of Pennsylvania (http://drnpa.org)
- Mental Health Association in Pennsylvania (MHAPA) (http://www.mhapa.org)
- Mental Health Association of Southeastern PA (http://www.mhasp.org)
- The National MS Society—PA chapters (http://pae.nationalmssociety.org)
- Liberty Resources (http://www.libertyresources.org)
- Pennsylvania Statewide Independent Living Council (http://www.pasilc.org)
- Pennsylvania Association of Area Agencies on Aging (http://www.p4a.org)
- SEIU Healthcare Pennsylvania (http://www.seiuhealthcarepa.org)
- Elder Law Section of the Pennsylvania Bar Association (http://www.pabar.org/public/sections/elderlaw)
- Community Legal Services Elderly Law Project (www.clsphila.org)
- PA Brain Injury Network (www.abin-pa.org)
- Pennsylvania Council on Independent Living (www.pcil.net)
- Pennsylvania HomeCare Association (www.pahomecare.org)
- PA Statewide Independent Living Council (www.pasilc.org)

- United Cerebral Palsy (www.cup.org)
- Speaking for Ourselves (www.speaking.org)
- Southwestern Pennsylvania Partnership for Aging (www.swppa.org)
- Vision for Equality (www.visionforequality.org)

The Pennsylvania Assisted Living Consumer Alliance encourages you to share your Assisted Living experience with us at www.paassistedlivingconsumeralliance.org and to share your opinions on the proposed regulations with policymakers this summer.

Media contact: Barbara Beck, 215.209.3076 (office); 610.246.9167 (cell)