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From: Jeff Iseman [JIseman@pasilc.org]
Sent: Monday, September 15, 2008 4:21 PM *Rec'd IRRC*
To: IRRC; gweidman@state.pa.us
Subject: From PA SILC: Comments on Assisted Living Regulations (PDF Link Enclosed)

To IRCC and OLTL:

This was also sent via US mail to OTL, DPW and others involved in the process of providing input for the Assisted Living Regulations. Please contact us if you did not receive our correspondence, cannot open the enclosed link or have questions.

<http://www.pasilc.org/documents/SILC.ALRegulations090408.pdf>

Sincerely,

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Pennsylvania Statewide Independent Living Council

A Governor Appointed Leadership Organization of People with Disabilities

2 North Second Street • Suite 100 • Harrisburg, Pennsylvania 17101

September 5, 2008

John Michael Hall, Deputy Secretary
Pennsylvania Office of Long Term Living
P.O. Box 2675
Harrisburg, Pa 17105-2675

Dear Secretary Hall:

The purpose of this letter is to provide comments related to Pennsylvania's Assisted Living (AL) Waiver that is being created. We appreciate the opportunity afforded to Milton Henderson, PA SILC Board President, to be a part of the group providing recommendations on the initial formation of the AL regulations.

We ask that you consider our comments offered below as you submit this waiver to CMS later this month. While PA SILC largely agrees with comments made by Pennsylvania Assisted Living Consumer Alliance, we would note the following:

- **Clear choice of service and supports providers-including medical care- that are separate from one's AL residence is not clear here.** PA SILC recommends that individuals residing in an AL residence be allowed to choose their services, which may include an outside organization separate from their residence
- **No grandfathering of existing personal care homes (PCH) and nursing home (NH) facilities into the new AL system.** PA SILC believes that this is a new system and should start clean and clear from the biases of these existing systems.
- **Adequate living space standards for residences:** PA SILC recommends 250 square feet instead of the 175 square feet as is currently proposed. The additional space is necessary for proper usage of mobility devices and other reasonable accommodations.
- **100% accessibility for all AL residences: both old and new construction.** While we applaud OLTL on its efforts related to new construction, many current PCH and NH facilities are inaccessible and should not be considered as perspective AL residences. All AL facilities must meet ADA accessibility guidelines that allows people with disabilities using wheelchairs, scooters and other mobility supports to live independently.
- **Clarify the meaning of 'cognitive' and 'neurological' in the AL regulations.** While it appears to refer to Dementia and Alzheimer's in some cases, in other instances, it is not clear that these terms could be

- referring to mental health, mental retardation, autism, brain injury or another disability.
- **Any licensing request should be rejected if the AL residence or service provider has uncorrected violations in any system of Pennsylvania or any other state.** It is possible that some entities will seek to repackage themselves to become AL residential or service providers who have violations in existing systems in Pa. or elsewhere. We request that all providers be reviewed in the following Pa systems (and their out of state counterparts) for licensing violations: PCH, NH, MH/MR, Autism and Children and Youth and other systems of a similar nature.
- **AL licensing staffing issues:** While we commend the Administration's efforts on addressing the challenges of the PCH system, it has taken significant time along with consumer suffering. This should not be the case. All AL Licensing staff should be trained in the final AL regulations and standards, regardless of their experiences with PCH, NH and other systems.
- **Have a package that is affordable toward low and moderate income individuals.** Much of what is considered AL in Pennsylvania and elsewhere is tailored to upper and high middle income populations. This limits the participation in such programs and in some cases will reduce potential cost savings to our Commonwealth and the individual.
- **Minimum standard of residential and service supports:** While variance can be helpful in terms of consumer choice, PA SILC recommends having a minimum standard for AL residence and services to be offered to all participants.
- **Privacy protections:** This has long been a concern of advocates related to other systems and now in the AL regulations. Privacy standards on health related matters -at a minimum- should be in compliance with Federal 2003 HIPAA guidelines. No information of any sort, unless covered under another governmental policy, should be shared related to AL resident's personal life. This should cover mail, cyber (computer) activity and all other forms of communications.
- **Lack of Adult Protective Services (APS) for Ages 18-59 to report abuse:** The regulations indicate that individuals age 60 and older may contact Older Adult Protective Services for support, nothing exists for individuals with disabilities under 60 years of age. Pennsylvania remains one of 5 states that do not have an APS system for vulnerable adults in this age group. An APS for ages 18-59 should be established.
- **Standardization of staff training at AL facilities:** There needs to be minimum baseline for AL staff. Among those trainings that would be recommended: First Aid/ CPR, Medications, Universal Precautions (OSHA/ Blood-borne Pathogens), HIPAA /Privacy Policies, Aging and

Disability Issues (re: related to AL facility residents of that site) along with an agency orientation.

- **Visible posting of important public documents for AL staff and individuals:** This includes current AL Resident Rights, Labor Laws and important facility policies at eye level so that they could be seen by an individual using a wheel chair.

Thank you for taking the time to read our concerns and respond to them in a timely manner.

Sincerely,

Zainab Jama
Executive Director

cc: Secretary Estelle Richman, Dept. of Public Welfare
Secretary Nora Dowd Eisenhower, Dept. of Aging
Representative Phyllis Mundy, House Aging and Older Adult Services
Committee, Chair
Senator Pat Vance, Senate Aging & Youth Committee, Chair
Alyssa Halperin, PALCA