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Disability Rights Network of Pennsylvania

A merger of PP&A and the Disabilities Law Project

Advancing the rights of people with disabilities

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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 Disability Rights Network of Pennsylvania hereby submits comments to the Proposed Assisted Living Regulations - # 14-514.

DRN is a statewide, non-profit corporation designated as the federally-mandated organization to advance and protect the civil rights of adults and children with disabilities in Pennsylvania. DRN works with people with disabilities and their families to ensure their rights to live in their communities with the services they need, to receive a full and inclusive education, to live free of discrimination, abuse and neglect, and to have control and self-determination over their services. Our clients are among those who may need assisted living services which maximize their independence while affording them appropriate care.

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.

We have analyzed these regulations and we 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

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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. 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.

Fundamental changes must be made to the proposed regulations before they are finalized 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.

While the proposed regulations make small steps in the right direction, we do not believe that the proposed regulations make adequate strides towards 1) assuring safe and accessible physical sites, 2) meeting residents' care needs, and 3) guaranteeing that all consumers have meaningful rights of which they are aware and that they are free to exercise their rights. We urge the Department to take additional steps towards ensuring that our clients can be safely, happily, and healthily served in Pennsylvania's assisted living facilities. We will address each of these issues separately below.

A. 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 best available standards or practices for wheelchair accessibility. Similarly, they 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, needs only have 175 square feet of living space and this is unacceptable as it is too small and not accessible to a wheelchair user. There are other issues which we will address through our recommendations.

We recommend that the regulations (2800.101) require that the resident living space include no less than 250 square feet of usable space in the living unit, in addition to the space occupied by the bathroom, kitchen area, closets, and

storage spaces and must be accessible to potential residents who use wheelchairs. We recommend that the regulations (2800.101) explicitly refer to the Americans with Disabilities Act Accessibility Guidelines (ADAAG) or other accessibility guidelines throughout the requirements for living space. There should be no grandfathering of any accessibility requirements. Without such a changes in the regulations, many people who use wheelchairs or walkers will have great difficulty in moving around in their rooms. We recommend that the definition of "Living Unit" in 2800.4 (and 2800.101(b) (1)–(5)) be amended as follows:

The resident living space that cannot be shared with more than one person except upon the request of the resident, that includes no less than 250 square feet of usable space in the living unit, in addition to the space occupied by the bathroom, kitchen area, closets, and storage spaces. All living units must have lockable doors. Any double occupancy units shall have separate bedrooms with lockable doors to the living space and a lockable bathroom door. All units must be accessible to potential residents who use wheelchairs.

We recommend that the regulations (2800.101) require that each living unit have a bathroom and storage closet and adequate storage space for resident storage of durable medical equipment or assisted devices. Without such storage space needed for equipment, the already-cramped living space will be further reduced. We recommend this in order for the residents with disabilities to have 4 ft. clear access aisle and room for the maneuverability of durable medical equipment such as a Hoyer lift.

We recommend that the regulations (2800.101) require living units to have kitchenettes with counter space, cabinet, microwave, refrigerator, and access to a sink.

We recommend that the regulations (2800.101) require that each Assisted Living Residence have a designated number physically/wheelchair accessible units, e.g., 75%, including accessible bathrooms (a reasonable percentage of those must have roll-in showers).

We recommend that the regulations (2800.133) require access to exits in all Assisted Living Residences be required to be marked with readily visible signs indicating the direction to travel. The current proposal requires such signage only for ALRs with 9 or more residents.

We recommend that the regulations (2800.18) explicitly refer to accessibility design requirements in ADAAG or other accessibility standards.

We recommend that the regulations (2800.98) require that all common areas and hallways must be wheelchair accessible in order to ensure access throughout the facility.

We recommend that the regulations explicitly permit appropriate service animals to be used by clients of an ALR.

B. The proposed regulations do not assure that Pennsylvania's assisted living residents will have their care needs met.

1. Assessment and Care Support Plans

As proposed, our clients 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 his/her care needs and explain to the him/her and his/her family whether the facility can meet his/her needs, how it proposes to meet those needs or even how much his/her care would actually cost. Although there is a short-form, pre-screening checklist to determine whether there exist conditions that would require exclusion from the facility or is permissible to be admitted, real comprehensive needs assessments need not to be completed until "within 15 days" after admission to an assisted living facility. The care plan need not be completed until "within 30 days" after admission to the facility. As proposed, the regulations put our clients in the position of having to move into a facility without knowing for certain if they will be able to remain there. Moreover, the lack of assessment and care plan at the beginning of residence can place our clients in danger (as well as staff) if staff are not fully aware of their needs. With the possible exception of an immediate discharge to the Assisted Living facility from a hospital, a comprehensive assessment should be completed prior to admission and should determine whether she can live in the facility successfully, what are her care needs, whether they can be met (and whether they can be met in a way that comports with her choices around how and when to receive care), and what are the costs associated with her care in that facility. Also, the support plan must be developed prior to admission and implemented within a week to ensure that our clients are receiving the care and support that they need immediately.

We recommend that the regulations (2800.22(A)(3)) be modified to require that the assisted living residence assessment be completed prior to admission on a form specified by the Department. Furthermore, the regulations should require that, in the event of an urgent admission upon discharge from a hospital, the assessment may be completed up to 72 hours after admission.

We recommend that the regulations (2800.22 (A)(4)) be modified to require that the support plan be developed prior to and implemented within 7 days after

admission. Furthermore, the regulations should require that, in the event of an urgent admission upon discharge from a hospital, the support plan may be developed up to 14 days after admission and implemented up to 21 days after admission.

2. Use of Physical Restraints

The use of physical restraints is generally prohibited in any community residential facility licensed by the Department of Public Welfare. There are exceptions which must be consistent with the client's needs as documented in his/her care support plan and closely monitored. The proposed regulations attempt to lower the standards by which the use of bedside rails can be authorized and implemented by an Assisted Living Residences. There is no possible justification for lowering standards below that required in personal care homes for ALRs in light of the fact that ALRs will be permitted to admit many clients with serious medical problems and are intended to allow clients to age in place (with the understanding that they will, over time, probably have more physical and medical problems) Our clients will suffer real harm that can occur as a result of lowering standards on physical restraints.

We recommend that the regulations (2800.203(b)) be amended to add the following language:

- (b) Half-length rails are permitted only if all of the following conditions are met:
- (1) A physician has completed an assessment during the past six months and completed a signed, time-limited, written order for the use of the rails which specifies the specific medical symptoms that warrant the use of bedside rails;
 - (2) The rails meet Food and Drug Administration safety guidelines;
 - (3) Staff persons complete a physical check of each resident who uses a half-length rail at least every 15 minutes during the time the bedside rail is in use;

3. Provider Choice

As proposed, the regulations prohibit unreasonable withholding of approval of providers of residents choice if resident has insurance. We wholly oppose limits on resident choice of provider. Ironically, such a restriction on the use of one's own medical provider does not exist in the personal care home regulations. As noted above, the ALR regulations are intended for a group of individuals that are more fragile, have more medical problems and who are permitted to age in place. We are only minimally comforted by the idea that 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 care services. One of the hallmarks of the disability rights movement and steadfast concerns of people with disabilities is the choice of one's own providers. Such choice is enshrined in all the federal programs such as Medicare and Medicaid and the Home and Community Based Waivers under Medicaid. A consumer sometimes need to have the doctors or providers they have been receiving for continuity of care. If you trust someone and that person is no longer allowed to provide assistance that can be traumatic and lead to other health issues. For example, a client who has had a personal care attendant for years should not be forced to change his/her attendant simply because of his/her residence in an ALR. To limit such choice at all is a travesty and should not be countenanced by the Department by appearing in these regulations.

We recommend that the regulations (2800.142) be amended to make clear that a resident may use any provider of his/her choice in obtaining any health care—either primary or supplemental. Moreover, in no event should a resident be required to use a provider approved or designated by the residence. Finally, the ALR should have no power to withhold approval of a resident's choice of provider.

4. Grandfathering of requirements for staff and administrator qualifications

As proposed, the regulations do not explicitly prohibit the grandfathering of requirements for staff or administrators of assisted living residences from persons who met the lesser requirements of the personal care home regulations. Since the population to be served in ALRs is more fragile and permitted to age in place with the attendant health care and other problems associated with aging, it makes no sense to permit staff and administrators meeting lesser standards for training and experience to be "grandfathered" into meeting the requirements under the proposed regulations.

We recommend that the regulations (2800.19(b) and 2800.64; .65; .66) be amended to make explicit that there should be no grandfathering of administrative training, experience or any other requirements from the Personal Care Home regulations under the ALR regulations. However, we recognize the fairness of abbreviated training for those who met the 2600 qualifications and training requirements since 10/2005.

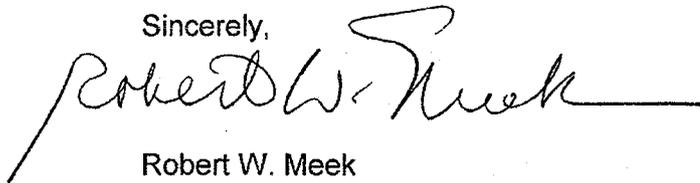
C. The proposed regulations do not assure that Pennsylvania's assisted living residents have meaningful rights of which they are aware and that they are free to exercise their rights.

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. The proposed regulations make no changes to the rights provided to personal care home residents despite the differences in the models and the greater frailty or care dependence of the population being served. Additionally, the "rights" section is what the residents are provided as their list of "rights". It is also what is posted in the facility as the residents' rights. Yet, the residents right provision of the proposed regulations does not articulate a consolidated statement of all the rights the resident has. The right to view your records or to be notified of egregious incidents or violations are embedded elsewhere in the regulations. However, they do not appear in the official statement of "rights" and most consumers never know about these other rights nor how to exercise them. While It is important to provide a handbook of rights to consumers and families, it is not sufficient. They need to be organized in the regulations in one place that is clear and accessible to all. All resident rights must be contained in a single section of the regulations to which consumers and their families can turn to understand how or whether they are protected. And consumers must be provided meaningful rights and protections beyond what are already in the personal care home regulations.

We recommend that the regulations (2800.41) set out specific wording of the rights and require the posting thereof in a conspicuous place.

Thank you for your time and attention to these comments and recommendations. Should you have any questions, kindly contact Robert W. Meek (215-238-8070) or Pam Auer (717-236-8110).

Sincerely,



Robert W. Meek

Pam Auer

Disability Rights Network of Pennsylvania