#2712 Rec'd 6/3/10

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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BY EMAIL AND FIRST CLASS MAIL
Independent Regulatory Review Commission
333 Market Street, 14th Floor
Harrisburg, PA 17101

RE: Regulation ID #12-514 (IRRC #2712)
Department of Public Welfare
Assisted Living Residences

To the Independent Regulatory Review Commission:

The Disability Rights Network of Pennsylvania (DRNPA) hereby submits our comments on the final-form 2800 Regulations for Assisted Living Facilities.

DRNPA 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. 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. As part of our efforts to fulfill our mission, DRNPA submits these comments and urges the IRRC to reject the Assisted Living Regulations as written. While there are some improvements over the proposed regulations, the number and the magnitude of extremely problematic provisions cause us to urge rejection. We will briefly note those provisions which are valuable and helpful to consumers with disabilities and then we will set out in more detail the concerns we have for those provisions which are harmful and unfair to individuals with disabilities.

Provisions Which Are Improvements Over the Proposed Regulations

Section 2800.22 (Application and Admission) requires a written decision when an admission is denied due to a supposed inability to meet a person's needs. This is an important protection which will help to uphold consumers' rights under the Americans with Disabilities Act not to be unlawfully excluded from services and facilities. Similarly, proposed section 2800.229 (Excludable Conditions; Exceptions) requires the residence to document how it responds to a request by a resident or applicant to seek an exception relating to an excludable condition, and when an excludable condition affects a decision to admit or transfer/discharge.

The inclusion of an appendix where all residents' rights are clearly articulated is very useful and helpful to consumers with disabilities. This will make it easier for consumers to access and understand their rights upon admission, during residency, and upon discharge. We also agree that the addition of consumer-friendly language to this section by prohibiting mental, physical and sexual abuse and exploitation, neglect, financial exploitation and involuntary seclusion is helpful.

Section 2800.220 (Service Provision) defines the core package of services that will be provided to consumers at assisted living residences. Defined base core packages will help with predictability of costs to residents. It will also help consumers compare "apples to apples" when evaluating facilities in their area. Defining both the broad array of services that are available within a facility and the fixed core packages that consumers would be purchasing upon admission to any facility is very useful for consumers to make informed choices regarding assisted living residences in which they might wish to live.

Section 2800.224 (Initial Assessment and Preliminary Support Plan) requires assessments and support plans to be completed prior to admission, in most cases, laying out the care needs of the new resident and the plan for addressing them. This provision, as well as the incorporation of the final support plan into the resident-residence contract, as required by **Section 2800.227 (Development of the Final Support Plan)**, are very helpful and useful to consumers in ensuring that their choices of assisted living residences are appropriate to their needs.

Provisions Which Are Highly Problematic and Harmful

Although the final-form regulations include many positive changes for consumers, some important changes recommended by a coalition of organizations of which DRNPA was a member, the Pennsylvania Assisted Living Consumer Alliance (PALCA), were not made. Moreover, the Department made some very significant changes which are detrimental to the health and safety of people with disabilities. We note several major outstanding issues we see as health and safety concerns in the final regulations. We enumerate and discuss these concerns below.

Section 2800.25 (Resident-Residence Contract) seems to require a co-signature by a designated party "if the resident agrees." There should certainly be no requirement for the designated person to co-sign a contract. The designated person is simply an individual chosen by the resident for notification in case of an emergency, termination of service, or assisted living residence closure. An agreement to be contacted in case of an emergency should not bind the designated person to financial liability under the terms of the contract. Although the final-form regulations state a resident must "agree" to this, we anticipate boilerplate contracts that recite the resident's supposed agreement to the designated person co-signing. Collection suits brought against unsuspecting "designated persons" who thought they were just agreeing to be a contact person have been a major problem in the nursing home context, and the federal statute governing nursing home residents' rights prohibits nursing homes from requiring a co-signature as a condition of admission. 42 U.S.C. § 1396r(c)(5)(A). Moreover, such a requirement undermines a core

value that DRNPA supports---consumer independence.

Section 2800.30 (Informed Consent Process) removes the "imminent risk" and "substantial harm" tests for requiring informed consent. The new language permits a provider to initiate the process whenever it perceives a "risk of harm" to a competent resident, other residents or staff members. In the first instance, the Department failed to adequately explain the change from the Proposed Regulations to the final form in its response to the IRRC's comments. Secondly, this test is too broad. It puts consumers at risk of being required to get extra care, at potentially great expense, or be subject to restrictions on liberty if the residence perceives any risk of any harm. DRNPA is particularly concerned with the potential for abuse of the informed consent process involving mental health consumers. Unusual behaviors, which could easily designated as "risk" by the residence but do not cause any harm, might be a basis for demands on the consumer to agree to greater restrictions on her liberty or subject her to onerous and unwanted medical interventions. It also puts consumers at risk of possible eviction from the residence for such behaviors if the residence determines that the "risk" could not be ameliorated.

Section 2800.53 (Qualifications and Responsibilities of Administrators) adds employment as a personal care home administrator as a qualification for assisted living facility administrator (along with passing the administrator test). This new language effectively removes requirements for any educational qualifications (including a high school diploma) for administrators of assisted living facilities. We are also very concerned that the training requirements under proposed sections 2800.64 (Administrator Training and Orientation) and 2800.65 (Staff Orientation and Direct Care Staff Person Training and Orientation) are inadequate. Despite the higher acuity of assisted living residents, the number of hours of required training for administrators is only 100 hours, the same level required for personal care home administrators. Similarly, 18 hours of training for direct care staff is grossly inadequate.

Section 2800.101 (Resident Living Units) significantly reduces the new and existing unit sizes for single and double occupancy units[1] from previous versions of the draft regulations and permits facilities to house residents in rooms with an average 7' ceiling height. DRNPA strongly rejects the notion that such unit sizes are appropriate and sufficient for individuals with disabilities, especially those using wheelchairs. DRNPA supports the view that Pennsylvania's assisted living consumers should benefit from rooms sized in accord with "marketplace" standards of at least 250 square feet, and up to 500 square feet for a single bedroom living unit.

As to new construction, the Department offered no rationale for the reduction in room size requirements in its response to comments from the IRRC. Instead, the Department in

[1] Compared to the interim draft regulations, new construction unit size is reduced from 250 square feet to 225 square feet for single occupancy units. For double occupancy units, new construction unit size is reduced to 300 square feet from 330 square feet. Similarly, standards for existing structure unit sizes were reduced from 175 square feet to 160 square feet for single occupancy units. For double occupancy units, the standard was reduced to 210 square feet from 235 square feet.

its response to IRRC comments stated: "Since the requirement that the living unit must not only provide space for a resident's bedroom, but must also contain 'living space' and 'kitchen space' to allow for [sic] the individual to [sic] a private place to relax, entertain family and friends, and possibly prepare meals (if the resident chooses to have appliances in the living unit), adequate square footage must be provided to accommodate all of these activities." To say the least, such a response is ironic as an explanation for a **reduction** in new construction room size requirements.

As to existing facilities, the rationale offered for a reduction in unit size by the Department in its response to comments from IRRC is based on a flawed statistical analysis that is wholly based on alleged economic concerns of the assisted living industry. Even if the analysis were sound, the conclusions drawn from it are nonsensical. In October 2008, a survey of 1437 personal care homes was conducted by the Department with 723 responding representing 28,774 rooms. Of those rooms, 20,648 were reported (but not verified) to have a bathroom and 5,409 were reported (again, not verified in any way) with a kitchen or kitchen facilities (undefined). The Department estimated that, using the 175 square foot requirement in the proposed regulations, there were 220 personal care homes in which at least 90% (no basis offered for this statistic) of their rooms would meet that requirement. The Department also estimated that, using the 160 square foot requirement in the final form regulation, there were 243 personal care homes in which 90% of their rooms would meet the requirement. The Department admits in its response to IRRC's comments (p. 23) that "it is unknown how many of the[se personal care homes] plan to pursue licensure as an ALR." Thus, in exchange for the remote possibility that some of the 23 personal care homes which might meet the 160 square footage requirement (but not the 175 square footage requirement)—based on a seriously flawed survey analysis---would actually pursue licensure and thus be available to consumers at a lower price than a 175 square foot unit, consumers lose almost 10% of the square footage required in existing facilities. That is not an equitable exchange. Moreover, attached is an architectural drawing for a single-occupancy unit with all the accouterments required by the final form regulations (bed, table, chair, closet space, kitchen space, etc.) which demonstrates that the minimum space required for a wheelchair user which meets the Americans with Disabilities Act Accessibility Guidelines (ADAAG) is 182 square feet exclusive of the bathroom and closet space. Thus, the 160 (and even the 175) square footage requirements fall short of ADAAG requirements. As a result, residents will be forced, as many are now, to wait in bed for an aide to come and transfer them because they do not have enough room to roll their wheelchair next to the bed and self-transfer or to move about their units comfortably.

Even more troubling is the new provision in Section 2800.101, which was not in either the proposed or the interim draft regulations, permitting an exception to the room size requirements at the Department's discretion. No process, standards, or criteria are articulated for residences seeking to be excused from the room size requirements. Nor is there any rationale offered to support an exception process. In contrast to the provisions relating to waivers in section 2800.19, the regulations do not provide for public posting of the room size exception request or a period of public comment prior to final review and decision. Since an "exception" is in fact a "waiver," the same requirements should be in

place. However, DRNPA contends that such an exception in the case of existing facilities is completely uncalled for in light of the already-inadequate square footage requirements. Moreover, in new construction such an exception is absurd. If an assisted living residence is built after the operative date of these regulations---should they pass---the operator of such a facility is on notice as to unit size requirements. No exception could reasonably be granted under such circumstances. DRNPA wholly rejects any exception process for either existing or new construction.

Section 2800.203 (Bedside Rails) adds subsection (b), which provides limitations on the use of bed rails. However, these requirements do not meet or exceed the rules for bed rail use in personal care homes, which have been strengthened through the Department's interpretive guidance following the deaths of hundreds of personal care home residents (this guidance is available at http://www.dpw.state.pa.us/PartnersProviders/LongTermLiving /PCHNewsletters/003675863.htm). In personal care homes, bedside rails can only be used when: a physician has completed a recent assessment and specified that bed rails are appropriate for the resident; the rails and space between rails and mattresses meet the guidelines of the Food and Drug Administration; staff complete frequent physical checks of residents while bed rails are in use; and the resident's assessment and support plan addresses the resident's needs and health and safety protections necessary for the use of the rails. By contrast, the final-form assisted living regulations require only that the resident's assessment or support plan address the medical symptoms necessitating use of the rails and the health and safety protections necessary for their use. In this regard, the personal care home standards are clearly higher than the proposed standards articulated for assisted living facilities. Since the statute requires the assisted living regulations to "meet or exceed" the requirements of the personal care home regulations on which they are modeled, DRNPA contends that this regulation is not consistent with the intent of the General Assembly.

Section 2800.142 (Supplemental Health Care Services) allows the residence to designate any medical care provider other than the resident's primary care physician, including psychiatrists, neurologists, cardiologists, and a host of other medical specialists. While DRNPA recognizes that the statute requires assisted living residences to provide supplemental health care services, the regulation allowing the residence to designate these supplemental health care providers for its residents rather than allowing the resident to choose their providers is simply 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, consumers must retain the freedom to make choices that consumers exercise daily in their own homes. This provision is a direct affront to the independence, control and self-determination rights of people with disabilities. Notably, even in nursing facilities, consumers retain choice of pharmacy and doctors.

Section 2800.131 (Fire Safety) changes the proposed regulation's requirement that each floor and each living unit have a fire extinguisher (except if contraindicated by

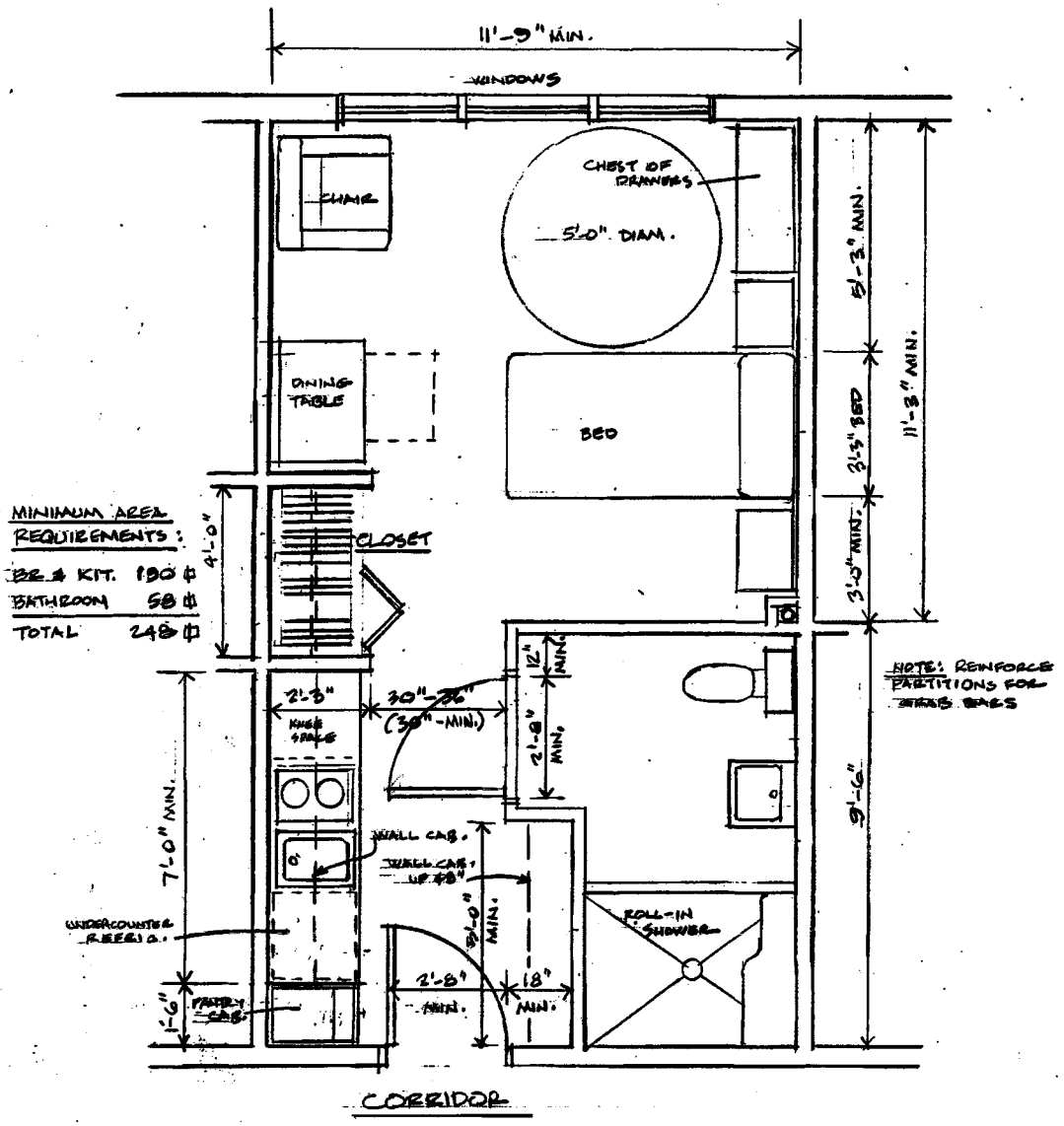
the resident's support plan) and merely requires a fire extinguisher on every floor and every 3,000 square feet, including public walkways and common areas. Since residents will now be permitted a kitchen area where electric appliances would be in use and thus creating potential fire hazards, the dilution of the fire extinguisher requirement is a significant concern. It is incredibly ironic that the Department would choose to dilute the fire safety requirements in these sorts of facilities. Lest we forget, the genesis for regulating personal care homes was the horrendous fires that killed many residents because of the lack of fire safety requirements. Fire safety is of even greater concern in assisted living residences where it is expected that there will be many residents with higher acuity needs and many more incapable of self-preservation in the event of a fire emergency. The International Building Code (IBC) and the Pennsylvania Building Code (PBC), which adopted the IBC in 2004, require facilities housing individuals incapable of self-preservation to have sprinkler systems as a means of fire suppression. Assisted living residences clearly will house many such persons. If, in fact, the IBC and PBC are enforced against assisted living residences, DRNPA's concerns about the fire safety regulations would be greatly reduced if not eliminated. However, enforcement of those codes is left to individual municipalities in most cases which can lead to inconsistent or non-existent oversight. Since no predictions can be made regarding what, if any, building code requirements will be enforced against assisted living facilities, this provision is far too weak to protect the lives of this vulnerable population.

Thank you for taking our comments into consideration. I can be reached at 215-238-8070, ext 206 or by e-mail at rmeek@drnpa.org.

Sincerely,

Robert W. Meek, Esq.
Disability Rights Network of Pennsylvania

c: Senator Pat Vance, Chair, Senate Health and Public Welfare Committee
Representative Phyllis Mundy, Chair, House Aging and Older Adult Services (by first class mail only)
Jennifer Burnett, Deputy Secretary, Office of Long-Term Living, Department of Aging
Elaine Smith, Bureau of Policy and Strategic Planning, Department of Public Welfare



Project: ASSISTED LIVING BEDROOMS **Drawing Title:** MINIMUM 1-BED UNIT

Project No: 0911 SCALE: 3/8" = 1'-0"

Date: 02.23.09

Revision Date: 03.11.09 ; 03.31.09 **Drawing No.** 1 Of 2

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