

## **Disability Rights Network of Pennsylvania, Inc.**

Testimony on Proposed Assisted Living Regulations-September 18, 2008

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### **Introduction**

My name is Linda Anthony and I work for the Disability Rights Network of Pennsylvania (DRN). DRN is a statewide, non-profit, federally mandated organization whose mission is to advance and protect the rights of Pennsylvanians of all ages with disabilities. DRN works with people with disabilities and their families to ensure get the services they need, 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 and/or want assisted living services that maximize their independence while affording them appropriate care. One day I may be one of those "clients". You will hear today from many professionals and providers who testify in favor of and in opposition to various parts of the proposed regulations. But, I want you to hear because I am out here, in the real world, living with a disability for the last 25 years.

It does not matter whether you acquired your disability as I did on an icy country road on the way to work one morning, whether you were born with a disability or whether you acquire a disability as you age. From my experience, I understand what it is like for people who reach 80 or 90 years old and need assistance for many aspects of your life. I know what it takes to get around in a wheelchair, and I know what I need to manage my bowel and bladder routine, of which I no longer have any control, but which I have learned to manage for my day to day living. I know what it is like to be totally dependent on others for equipment, for breathing, for staying healthy, for moving within my community, and for having a life of my choosing. I struggle every single day of my life. Good Assisted Living Residences (ALRs) can be the answer some of us struggling to keep some choices in our life and stay out of nursing facilities.

### **Access**

We applaud the administration for requiring facilities to have 250 square feet of living space for new construction. That is the minimal amount of space that I need to be able to maneuver this wheelchair that I am using today. Think about your routine in the morning as you prepare for the day. Simply turning around, to face another area in the room requires a five foot by five foot turning radius. The required 250 square feet will still be tight for some people using wheelchairs or walkers, but without this minimal amount, people will be forced to "back up", risking falls and other damage.

Many, many people with disabilities, who enter an Assisted Living Facility, need some form of "assistance" to manage their day-to-day activities. Whether that assistance is in the form of a wheelchair, walker or other mobility device, they often seek out alternate living arrangements because of their mobility needs. Over 21% of the people who will be living in Assisted Living Facilities will use wheelchairs, and another 44% will use walkers. And, as individuals with disabilities age, their mobility needs often increase and change from one type of mobility aide to another- such as a walker, to a manual wheelchair to a motorized wheelchair or scooter. With over two-thirds Assisted Living residents needing accessibility for mobility aides or transfer aides like a Hoyer lift, we strongly support the requirement of 250 square feet per living unit, including accessible bathrooms without exception, for both new construction and existing structures. It is my fervent hope that you will reject the industry's plea to waive this requirement to allow for 175 square feet in existing structures.

### **Fire/Safety**

One of the most terrifying things for people who use wheelchairs, walkers or who simply cannot move quickly is the fear that they will not be able to get out of a building in a fire. And all too tragically, here in Pennsylvania, people have perished in buildings where there was no good evacuation plan, or poor signage and preparedness for such a disaster or poor maintenance of facility safeguards. As a professional, I enter buildings almost every day that I would have difficulty evacuating in the event of a fire. As a wheelchair user, I trust that professionals within the structure have done their job of giving me a good exit path and plan. I accept these daily challenges and I pray.

We applaud the administration for proposing that fire safety approval be renewed every three years, that all living units have a fire extinguisher and smoke detector and finally that the facilities at all times be under the supervision of a person who is trained in how to operate and manage the facility. This is a vast improvement over what we have seen in the personal care home system where a qualified individual need only be present in the facility 20 of the 168 hours in a week. Lives in Pennsylvania will be lost when fires and other disasters strike these Assisted Living facilities if the regulations fail to address older construction that does not meet current fire or life safety or if the regulations grandfather these older facilities so that they will never have to come up to current standards for safety and accessibility.

### **Aging in Place**

We support the administration commitment to the idea that Assisted Living can and should be a facility where people can "age in place," as evidenced throughout these proposed regulations. The proposed regulation that the entire facility must be air conditioned is a good example. As a person with a spinal cord injury and a person who is aging, I find it difficult to lower my body's temperature

once it has been exposed for any length of time, to extreme heat. This has caused a number of health consequences. Without this requirement of providing air conditioning for the entire facility, many residents would not be able to function or maintain their health. People with Multiple Sclerosis or a history of strokes, blood pressure problems, bedsores and other skin-related disorders cannot live without the relief of an air conditioned environment. It may seem like a luxury to some, but it is a life line to others.

We again applaud the administration's requirement that all living units must have kitchenettes with counter space, cabinet, microwave, refrigerator, and access to a sink. Illness or just a really tough day may limit my desire to leave my home, or to share a meal. Sometimes, all I want is a cup of soup, a cup of tea or a sandwich or I just want to warm up something a friend has delivered, which I could not eat when it arrived because I just could not eat right at that moment. Having the ability to access these small amenities within my own "home" is very important to me, my overall disposition, and ultimately my health. If the facility is truly to allow persons to "age in place", it is imperative that we support the regulation to require assistance with meals and cueing for meals for residents who require this assistance. Requiring assistance with meals and cueing would allow people truly to "age in place" as their abilities decrease.

Another reality for those with mobility disorders is the development of a decubiti. These are sores or holes in the skin that occur when there is excessive pressure to one area of the body. I have not met a person with a mobility disability who does not know or who has not personally been inflicted with the problem of a pressure sore, whether due to poor seating, prolonged illness, or prolonged lack of movement from one position. I am extremely distressed that the proposed regulations permit the facility to discharge a resident because of a decubiti. A much better approach would be to implement a plan as designed by the person's physician, bringing in additional health professionals as prescribed, and/or, if necessary, admit the person to a hospital. Upon discharge, the person should be able to return to his or her Assisted Living Facility, especially when he or she continues to pay "rent" while he or she are in the hospital. Likewise, some of the excludable conditions provisions (which permit rejection and discharge) must be made more fair and reasonable so that we can protect the resident's ability to remain in the only place that the resident calls home.

When a resident or family member is told that the person will be able to "age in place," he or she expects that when that person's mental capacity begins to diminish as he or she gets older or new disabling conditions begin to occur, the person will be able to stay in the familiar surroundings he or she now calls home. Removing someone from familiar surroundings, the upheaval of moving once again, and the individual and the family member's frustration with finding new and reliable housing are things that only aggravate the cognitive impairments older adults endure. We strongly support the administration's proposed regulation to require all Assisted Living Facilities to provide cognitive support

services, as another assurance that the person will indeed be able to "age in place."

### **Choice of Provider**

One of the many, many lessons that I have learned over the last twenty-five years while having a spinal cord injury, is the absolute, life-saving job of finding or training a physician, specialized or otherwise, who will listen to you, and I mean really listen. Because of the cellulites that has plagued me for fourteen years, I have found an excellent infection control doctor who has not only helped me cut down the revolving door that so often accompanies bouts of cellulites, but he has helped me cut down the onslaught of very serious incidences that have often led to hospitalizations and dangerously close calls with death. Having access to the medical doctor who treats me for general purposes is so enhanced by his exposure and experience with me as a person with a spinal cord injury that having to go to a doctor who is unaware of my past medical history has had some dire consequences for me.

While we whole-heartedly support the proposed regulation that will require Assisted Living Facilities to obtain medications prescribed for the resident and to maintain an adequate amount of the resident's medications on site, we cannot support the proposed regulations which give the facility total control over where residents get all of their medical care and supportive services. In fact, the proposed regulations would allow a facility to force a resident to use providers that the facility chooses. If I am a resident in an Assisted Living Facility, and I become ill, I should have the availability of outside health care services, especially when it prevents hospitalization or further disabling consequences. Using outside providers also provides a check and balance system that the person is receiving adequate care and support. People must have the right to their choice of providers. Although some would say a doctor is a doctor is a doctor, for those of us living with a disabling condition, it is all too often a matter of life and death.

We thank you for allowing us to provide comments on these regulations and look forward to the development of yet one more option for people and their families in meeting long term care needs and supports.

Respectfully submitted,  
Linda Anthony, Policy Director  
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