



Statement of the Pennsylvania Adult Day Services Association

In front of the

House Aging and Older Adult Services Committee

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Presented by

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Good morning. My name is Patricia Shull. I am here today representing adult day centers around the Commonwealth in my role as President of the PA Adult Day Services Association. My daily work is that of CEO of Adult Care of Chester County, a nonprofit agency that has provided adult day services to the residents of Chester County for more than 26 years. Working with family caregivers for that long, provides me with experiences and information to share with you. In our two adult day centers combined, we serve nearly 90 people each day. I also served as Chair of the National Adult Day Services Association and therefore have a National perspective of the field of adult day services as well as that of a provider and statewide leader.

Thank you for the opportunity to speak to this committee about the benefits of adult day services, both from the perspective of those attending centers and also on behalf of the family caregivers that share in the care giving and are a vital link to the ability of the person remaining in the community.

Rather than list the services we and many other adult day centers provide, I would like to share the story of one family and the impact that our adult day center had in their lives. This is just one typical example of the services that are provided at day centers across the Commonwealth.

We will call her Matilda to protect her privacy. In April 1989 Matilda's husband approached us with his story. His wife was in rehab following a massive brain bleed and surgery. She was unable to bear weight for transfers and was confined to her wheelchair. Her upper extremities were very spastic with closed fists and she was unable to do any of her own grooming and, clearly, could not feed herself. She required total care. The recommendation from the hospital and rehab center was for nursing home placement.

He was not ready to give up and place her. His question to us was very simple: Would we accept her and could we provide the level of care she needed? The answer to both was yes. With the day-to-day interaction of the nurses and other staff members, we provided an enhanced level of care. Staff worked on gradual, slow rehab of upper extremities. The first physical target was to help her gain the ability to self propel her wheelchair. It took a very long time but when the center moved to a new facility with a large gathering room, she was very happy that she could move about and visit other areas without anyone having to help her.

Matilda was very pleased with her level of independence that upper body ability gave her. She could apply simple make-up and feed herself. She still had limited movement of the upper extremities but the staff made sure to adapt the activities so she could participate and succeed. She often assumed the role of score keeper and greeted everyone by name when they arrived each day.

Matilda was involuntary of bowel and bladder and needed personal care services throughout the day and two showers each week. She was part of the “enhanced exercise” group and received physical and occupational therapy at different times in her stay. She received medication at the center and, after being diagnosed with Diabetes, her blood glucose was monitored. The daily range of motion exercises helped keep her extremities mobile.

Her husband was able to work much of that time, only retiring after his own health issues arose. We provided this enhanced level of care for her for 20 years until she died from cancer. After her death he wrote a letter and I would like to share part of that letter with you now:

“Her death came almost twenty years to the day from the time she started going to your center. At that time, she only weighed about 100 lbs, hardly spoke more than a yes or no, had almost no short term memory and no way of expressing her feelings or thoughts. Pretty quickly she started to come around and respond to her surrounding and the times. Somehow, the staff and clients brought her out of her shell and created a new personality that truly seemed to enjoy life despite being basically a quadriplegic who had to put up with every else’s time schedule and attitudes. How she was able to develop such a memory for names and faces was a mystery since her neurosurgeon said that she probably would not have a short term memory after the damage had been done to her brain.”

For Matilda's family, the need for subsidized care was great. Even though during most of the twenty years she attended the center her husband was working, they lost her wages as a nurse when she became ill. Their income was not low enough for Medicaid or Pennsylvania's Options Program, but they could not afford the full private pay fee. As a not-for-profit agency we try to raise funds each year to subsidize the private pay fees but the funds are limited.

Like Matilda's, many families struggle to pay the fees because they are slightly over the income level, because they are on a waitlist for Options or they are receiving options funded services but need more services than the \$714.00 per month cap allows. It is getting more difficult to provide subsidized care as the rates for some providers are being decreased and funds must be raised to meet expenses to maintain the quality care. As an example, Adult Care of Chester County suffered a rate decrease of \$24.00 per day just this week on one of its government contracts.

There are many stressors for family caregivers of older and impaired adults, some are financial and we don't have much control over that, but we can provide a comprehensive adult day program for their loved one and give the caregiver a rest. Quality care programs for participants and respite for caregivers are the two primary goals for adult day centers across the Commonwealth.

Many centers survey their families for quality improvement purposes and to gather other data, such as caregiver stress levels. In a recent survey of our members, results showed that across responding adult day centers, 76% of the caregivers responding reported their stress level was greatly decreased while their loved one attended a center. Another 20% reported that it was moderately decreased. Dr. Steven Zarit is conducting the DASH study that is looking at the physiological effects on the family caregiver of a loved one attending an adult day center.

Following are some of the comments received from caregivers about what effect their loved one's attendance at the adult day center has on them, in response to this question: *What does it mean to you, the caregiver, to have your loved one attend the adult day center?*

- It gives me time to relax and to do household chores. Care giving is very stressful. I have to know where he is all the time. It gives me a break and time to rest up. It is a tiresome job making sure you know where he is at all times.
- Rest. Being apart for a while helps me keep my stress level down. When at home, she wants me in the same room with her all the time.
- Enables me to work and therefore keep her in the family/home. Occasional Saturday allows day of Respite.
- Allows me to keep my job...and my wits:)

- Gives me a chance to work by attending the center; gives me peace of mind knowing she is in good hands and safe.
- Tries to help and lets us have our work and family time. Gives us peace of mind five days a week! Just to know she or he is safe, happy, and keeping active to make them happy so we can continue to work and have our life too.
- Gives me peace of mind so that I can work and not be a burden to society. If I had to stay home we would be on state assistance of all kinds.
- It allowed me to go to work without worrying about her being at home alone. It also gave her something to look forward to 2 days per week.
- Allowed me to continue to work and know that he was in a safe and caring environment, although toward the end of his tenure at Adult Care, daily care became challenging for all parties concerned due to his advancing dementia.

There are two common themes in these statements: “allows me to work” and respite from care giving. Family caregivers want to continue working and want to be able to keep their loved one at home but they need support in their care giving.

The Pennsylvania Adult Day Services Association urged the Department of Aging to move forward with the recently enacted Enhanced Waiver and provided feedback from its members. We, as providers, have been helping to keep people from being placed into much more expensive nursing homes. We now are looking forward to providing care to people moving from nursing homes back into the community by utilizing adult day and other community based providers to create a care plan that offers benefits to the consumer and a cost savings to the taxpayer.

Despite community education done by providers, adult day services are still an unknown to many residents of the Commonwealth. HB 269 sets a goal to change that and has some strong points but also needs to have some modifications to be effective in getting the information to the public and other referral sources. We

believe that the Department of Aging and the Office of Long Term Living (OLTL) is working in that direction and we will continue to work with them.

I want to thank you for your time and attention and invite you to visit an adult day center in your district and witness the consumers enjoying the programs and receiving the sometimes complex services I have described. And I encourage you to meet with family caregivers of those utilizing services. We, at PADSA, would be glad to help make arrangements for those visits.