

Wendy Campbell
President of the Alzheimer's Association Delaware Valley Chapter
Monday, May 3, 2004

I am Wendy Campbell, President of the Alzheimer's Association Delaware Valley Chapter. Mr. Chairman and Committee members we thank each of you for taking time out of your incredibly busy days to specifically focus on learning about Alzheimer's disease and the funding issues encountered over the past few years in Pennsylvania.

Today's hearing began with testimony on the impact of Alzheimer's disease on Pennsylvania. The demographics of our aging population, prevalence of Alzheimer's disease presented by Bob Marino certainly outline a tremendous public health issue for our state. The tidal wave that will begin to strike when the baby boomers reach their 60's will severely test our state's ability to quickly develop effective care systems that maximize utilization of scarce dollars and scarce human resources.

You heard about the substantial free services provided by both the Delaware Valley and the Greater Pennsylvania Chapters. We provide education, information, support, as well as programs and services to caregivers and those with Alzheimer's disease or a related dementia. You have heard about the Chapter's responsiveness to the wishes of the Department of Aging over the past years as well as how we exceeded their expectations by taking our Contact Center/Helpline to 24/7/365 with 140-language translation service. The number of calls is growing dramatically as we have made increasing awareness one of our key objectives for the next three years. The Contact Center/Helpline number is included in the Department of Aging services summary book.

The only problem has been obtaining increased funding which was exacerbated this year when not only was there no increase but Chapter funding was cut in half.

Our first state funding was through the Department of Health for \$200,000 in 1999-2000 for the Alzheimer's chapters in Pennsylvania to help support some of our Core services. The next year this funding was moved to the Department of Aging. Since 2000 our range of services has increased, our quality of services has increased beyond the single 800 Contact Center/Helpline number which now serves the entire state. We have been selected for a number of model programs for the entire 81 Chapter network in the US, most recently for the Safe Return Program. Our funding however has not increased even though our combined Newsletters now serve 56,000 this last quarter. Our core services permit family caregivers to provide care in their homes for the maximum amount of time often through death for a disease that can last over twenty years and averages 9-10 years. Providing caregivers with the education, training, Helpline and emotional support, which delays or prevents institutionalization saves the state billions annually. This line item must be restored to \$250,000 so the Chapters can receive their annual \$200,000.

Dr Trojanowski's testimony on the impact of the diagnosis on the family, caregivers health, its wage earners, the tremendous cost of institutional care both Medicare and Medicaid and the staggering \$4.6 billion dollars saved by caregivers providing care in

their home helps to define why we need community services to support our medical system. The wisdom of developing programs that introduce families to the social service network, creating new less costly community based services, help for family members to keep them working and contributing to our state's productivity is the forward-thinking strategy our Commonwealth must fund. Programs which reduce or prevent the spending of scarce Medicare and Medicaid funds and reduces business costs for a disease with the current and future community impact of Alzheimer's should not be ignored.

You heard a description of the Administration on Aging model program. Danita Vetter who wrote the grant was too modest. We are proud to have developed this superb model program, which successfully competed for these AoA funds and brought the potential of \$1,050,000 federal funds to Pennsylvania. During the wrap-up of our first federal site visit last year we were applauded by the surveyors who have seen every other states' projects. They informed us that this program should be their poster program as it was exceeding every model program service expectation and time frame.

You have heard the intensity of the testimony of both caregivers and providers. Indeed the very presence of these family caregivers with their "36-hour day" stress is evidence of the importance of this program. We must stimulate the development of community and home-based services especially those services which provide dementia care. The AoA Memory screening program project opens the door to these services for the multicultural community.

The only problem is funding.

We applied for the AoA grant in the spring of 2002. The Chapters developed the model screening program grant application and submitted it to the Department of Aging. The Department could only commit \$40,000 funds toward Year One through Three at that time as it necessitated departmental and legislative approval to commit more but we went forward because the Department's plan was to include the entire year 2 and year 3 match in the Department budget. The grant was submitted by the Department of Aging and less than 2 months later on June 17, 2002 approval was sent to Harrisburg along with 7 other states. (25 other states, which were funded in previous years, had continuation grants) Indeed the Chapter Newsletter announcement and press releases which had to be approved by the Department of Aging before publication stated "The Department of Aging will also be contributing matching funds for the grant at a minimum of \$40,000/year."

The Department of Aging called a meeting in July of 2002 instructing the chapters to commence work on the grant. The chapters agreed and promptly commenced work. At the July 2002 meeting, in addition to the federal government requirement of two bi-annual program and financial reports for each year of the grant, the Department of Aging added additional requirements of monthly reporting to the department. The chapters agreed and honored this additional request sending the first report in August of 2002.

We were told a contract would soon be sent for signature. It finally arrived almost 6 months later on December 30, 2002. The cover letter stipulated that the Department of Aging agreed to provide a contribution of \$40,000 in year one and "The Department of Aging will continue to explore other matching options and want to assure you that we are partners and committed to the success of the project." We signed the contract and returned it quickly on January 10, 2003. We attempted to submit bills for the first 6 months of the project.

On April 1, 2003 we received notification that the contract would begin on April 1, 2003 and not cover the work performed in the first 9 months of the grant. We were advised to immediately submit April billing and since there were only three months left in the first year the state match would be reduced from the promised \$40,000 to \$21,000. Over the summer thanks to the leadership of the Department of Aging we negotiated a Settlement agreement to cover the first 9 months of the project. Ironically, the payment for the work performed between July 1, 2002 and March 31, 2003 was received on April 1, 2004.

The AoA money was available to be drawn down for use throughout the grant process beginning on July 1, 2002. It appears that Pennsylvania budget regulations severely handicap its ability to utilize Federal grant programs. By April 2003 we were informed during our site visit that all other 7 states receiving new grants had already received federal reimbursement. The Department of Aging's responsibility was to draw down that money for use by the chapters and submit reports generated by the Alzheimer's Association Chapters semiannually to the AoA. We did not receive a single payment until the end of October 2003 when the Secretary intervened. The chapters were forced to raise all of the match money, implement the program; meet contractual goals of the grants; provide quality care to families and FLOAT the entire cost of the grant for the first 15 months of the grant process.

In March 2004 the Greater Pennsylvania Chapter's Board of Directors decided to withdraw the chapter from the AoA project because they were unable to afford the cost of the project and meet the matching requirements. Written testimony provides details of this decision. As of April 2004 there is no longer a rural component to the project. The Delaware Valley Chapter is struggling financially to keep the project afloat. Frankly raising private funding is difficult as most seem to believe the responsibility for funding a demonstration project on this scale to be the state's.

As a service the project is very valuable and offers a successful, innovative model of care for underserved communities that will be able to be replicated throughout the Commonwealth as well as other states. Financially, the project has been a disaster from the second month.

Speaking to colleagues from other states at the National AoA conference has revealed the match requirements have been creatively addressed by other states. Most states have actively partnered with their Chapter to identify funding, provide matching dollars, using state respite services and even assistance with cash flow issues by small Chapter subcontractors by paying the required respite vendors through Area Agencies on Aging.

Indeed the AoA will no longer allow the state to be merely pass-through participants but rather require active partnership. We are the last pass-through state grant to be funded. We have been told that accountability of what the state is contributing will now be required in all future AoA Memory Loss screening grant applications.

We are asking for support for Representative Crahalla's budgetary amendment to restore \$105,000 to the Department of Aging funding of the Alzheimer's Chapters AND support of \$ 188, 000 for year two AoA match and \$ 286,000 for year three AoA match. This \$724,000 would be funded by a recalculation in the Department of Public Welfare County administration statewide appropriation based on a personnel recalculation.

I close by reminding the committee that there seem to be few opportunities to have federal dollars directly provide vitally needed dementia services to the families of Pennsylvania and to have the ratio be for every 35 cents provided by the state results in 65 additional cents from the federal government and even with the increase in the required match in year 3 to every 45 cents provided by the state resulting in the federal government providing 55 cents.