

August 15, 2011

[REDACTED]

Re: Request for Information (RFI)
Shared Living Program (SLP)

Pam Kuhno
The Pennsylvania Department of Public Welfare

Dear Pennsylvania Department of Public Welfare

I am a parent of a 21 year old son who has multiple disabilities; he uses a communication device to speak, physical supports, and assistive technology for fine and gross motor tasks. Over the years we have attended many trainings and have connected with many adults with disabilities who are successfully supported in the community to become more aware and informed of the possibilities for his adult life. Temple University's Institute on Disabilities has opened our eyes to lots of possibilities that are more cost efficient and beneficial to him, the community, and the taxpayers.

I apologize if this doesn't meet your exact requirements to input information, but your requests are not really family friendly, and that is part of where I see much of the barriers and problems beginning. Everything built and decided should begin around the end recipient first. All funding and decisions should be based on the individuals and the families, who should have the greatest input, along with a strict adherence to best practices, person centered practices and least restrictive environments.

Because of our knowledge and networking, my son has always been successfully included in general education with appropriate supports and services and has grown up with same age friends without disabilities from our community, successfully participating in the same activities. We know what success looks like. We know what supports he needs and what it takes to plan and accommodate him, and we know how greatly it benefits not just him, but others in the community. He indicated that he wanted to attend college like his peers, and more specifically Lehigh University like his father, and he is now the pilot program and the first student with significant disabilities to participate on campus and take classes at the university. Anything is possible with the right supports and planning.

Our goal has been for him to have equitable opportunities as everyone else for the same reasons, to give him self-determination to make his own choices, and to make

sure that everything begins first around him and with the same assumptions for his future that would be made if he did not have a disability.

We know how to plan for his success. We know what is possible. We know what would benefit him and maintain his quality of life, the life he has known growing up. Because of this, we feel that life sharing would be a huge step backwards from where we have always been and have headed, and it does not match the dreams or plans that he, his friends and family have envisioned for his future.

Just like when he was in school and they wanted to send a van to drive him, I said, we have a van and if it were only just about getting a van ride, I'd drive him, but it's far bigger than that. We wanted him to ride the same bus as his peers from the community for many other reasons; one big reason was that we saw it as a values and civil rights issue. So for the State Department of Welfare to offer him "another family" as a way to provide his adult care, I say again, if it were only about providing care, we'd just do it, but it's far bigger than that. Again it's a civil rights issue and it's about having freedoms and choices like everyone else. We don't want him forced to have a close relationship and live with others because the state decides it for him. That is so impersonalized. That is not the community life or anything near what we have ever planned or envisioned for the past 21 years.

The funds are needed to support him as a person, not as a commodity to be shipped to another family to be paid to house him. That literally makes me feel ill to think about it happening to him, almost as ill as the thought of him ending up in an institution. Both scenarios are dehumanizing because they don't start with the person and building supports around the person, where they are, and where they prefer to be.

With the technology and the right supports, my son and others can live much more independently and interdependently than ever before. We want him to have choices of where to live and with whom. We want him to have ownership, privacy, control and choices about whom and how they provide him assistance; otherwise his quality of life would be greatly diminished.

To us, life sharing would be just like shifting him to a mini institutional setting, because it would deny him those choices, the ownership the opportunities and control that his friends without disabilities have available. It would be like adult foster care, and that is not something we desire for him in the least.

Yes he is at a great risk to be forced into an institutional setting if he is denied funding for supports in the community and if something happens to either of his parents. Without community supports he is at great risk for regressing physically, socially, emotionally and in self-help skills. But yet here he is 21 and we don't know if he will be l

the consolidated waiver next June or not, even though the state has been well aware of his needs since he was an infant.

The average cost of an institution in Pa is \$256,000 and the average cost for community support is \$107,000. We are willing to get our son set up to live out his life in a quality situation. We want to create a microboard, and we want to purchase a house where he can own it, either by himself or with friends (with or without disabilities by his choice). We want to plan out all the details and bring people together so everything is in place and designed and is flexible around him first, rather than him having to fit into only what is offered. We need the state to work with us, not against us.

We are a well educated and eager family, and we are knowledgeable about the how-to's, and have witnessed years of success for our son with significant disabilities and have met many successful adults with disabilities living in the community. We have utilized solution circles, circle of friends supports, vision building, MAPS and Paths planning with national leaders and we are greatly aware of the technology and possibilities.

The problem is that our son may likely end up on a waiting list until there is a crisis which would force him into a less individualized and more restrictive and costly setting than he has ever been and one we have never desired, verses setting up everything now to be a higher quality, less costly more beneficial situation for the long term and rest of his life.

The priority should be individual choices and preferences from the get go, and no funding stream should force individuals into a more restrictive setting than the typical settings they would be in if they did not have disabilities. The least restrictive most typical and natural environments should be the starting point without exception. Shared Living should not be forced as the answer, because it is more restrictive and not natural. It is being promoted based on reasoning that sounds very similar to how institutions were first rationalized, and that should put up many red flags. Anytime people are forced into atypical situations based on labels of disability, it becomes no different than forcing people into institutions where they lose their self-identity, freedoms and choices.

The costs would be less and the outcomes would be greater for our son when he has supports that are designed around him and his needs and preferences in the least restrictive setting, preferably his own home first. We don't want him with another family, that's not what we want forced onto him in place of the future that we have envisioned.

The department should be reaching out to well established disability advocates in the state such as Temple's Institute on Disabilities, the Centers for Independent Living, PEAL, The Disability Rights Networks, ADAPT of Pa and others, who all too well know the possibilities and the barriers that have occurred over the years.

Treat people with disabilities as people first. Just like with education, the greater opportunities and access, the higher expectations, and people with disabilities will rise to levels that were previously not thought possible. Anything less than starting with least restrictive environments is discriminatory and diminishes quality of life, and is ultimately more costly in more ways than just dollars to the individual, families, communities and taxpayers. Please put people, individual's preferences, the natural and least restrictive settings, and overall quality of life first.

Sincerely,

A solid black rectangular redaction box covering the signature area.