

Letter for Shared Living Program RFI

To: Pam Kuhno (sharedliving@state.pa.us)

Pennsylvania Department of Public Welfare

Re: RFI for Shared Living Program

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

I am the parent of a MR daughter who is currently living in a Shared Living Program. The provider is Shared Support, located in Doylestown, Pennsylvania.

In July of 2009 my wife died, leaving me and my live-in mother to care for my daughter, [REDACTED]. My mother died the following spring and it was determined that [REDACTED] needed to be placed in assisted living. Up to the point of meeting representatives from various support providers I was under the impression that the group home model was the only alternative available. We were presented with two shared living alternatives by three different providers; one was that [REDACTED] would be placed with a family, and the other was that she would be placed with an individual, trained caregiver in her own living situation. [REDACTED] was determined to be an excellent candidate for the one on one model. We have never regretted that decision. It has given her a level of independence and pride no other alternative ever would have approximated.

From the start [REDACTED] has been treated like an adult, able to determine the course of her life....with assistance! Living in a group home or another family situation, I am sure, would have kept [REDACTED] a child forever. Shared Support has provided [REDACTED] with a life model that she can grow in. She considers her live in caregiver as her friend and roommate. [REDACTED] at last can follow the dream of every young adult and has been given a chance to follow her natural inclination toward independence to the fullest degree that her multiple disabilities will allow.

[REDACTED] is now learning skills that I as a parent could not teach her because I always treated her like a child. [REDACTED] is being taught how to creatively use her alone time, how to clean her own house, how to clean her own bedroom, how to do her own laundry, how to prepare her own meals, take her own medications, and generally how to be independent and lead her own life. I cannot fully express how important this is to [REDACTED] and to me a parent of a disabled child who now is becoming an adult. I do not think that the "group home" model or the "family as

caregiver” model would have provided her with the opportunity for such a level of pride and independence as the single live-in caregiver. Through the interview process caregiver compatibility was an important issue. [REDACTED] and her caregiver are a great match. I have only good things to say about Shared Support.

I would hope that, as the Pennsylvania Department of Welfare moves forward, they would not abandon the one on one model for independent living. I am sure that the Group Home model services many of our disabled citizens and many of those with disabilities may need a family to foster them; but there are those who, if given the opportunity, can achieve a higher level of independence and pride through living in their very own home.

A disadvantage of the one on one system is that the caregiver needs a break and respite care can be an added expense. I have often thought that another model could be two on two. That would provide each caregiver time to themselves on a mutually agreed upon schedule, hopefully eliminating respite. A financial advantage would be in sharing the rent between two clients. The downside would be resolving more complex compatibility issues between the two caregivers and the two clients.

I appreciate being given the opportunity to provide this information and feedback to you. I hope that my input is of some value.

Thank you,

[REDACTED]