

■■■ Story...

My 45 year old son has multiple disabilities, he is physically disabled and has a mild mental developmental disability with Intermittent Explosive Disorder. It is because of his one individual provided service in a single home that his behaviors have improved and he continues to grows intellectually.

Family Living offered through the Office of Developmental Programs, option of Department of Public Welfare, as I understand it, is living with an existing family in their home. This arrangement would not work for ■■■. His disruptive outbursts would be devastating to a family. Besides the trauma of seeing an outburst the replacement of personal property would be costly if possible to replace.

At the age of 26 and living at home with his parents and sister, life became unbearable for all. ■■■ was placed in a CLA (Community Living Arrangement) home shared with two other young men. The County, Provider, and family tried everything for twelve years to make it work but it never seemed to meet ■■■ needs. With ■■■ having a startle reflex to noise; needing his own space; liking to be the center of attention; and other individual traits his needs were not being met and his behaviors got worse. Battles with the other residents continued. It was just impossible to give all three residents the individual attention needed to make them compatible. ■■■ was a very unhappy individual.

After so many years of turmoil ■■■ family was determined to find ■■■ housing that would be comfortable for him. They wanted him to be happy. The goal was set to have ■■■ acquire his own home and have live-in staff for support so he could have an everyday life. This goal of having his own housing was achieved in 2005. He has been living in his home for six years. It became a reality by taking advantage of public opportunities. Through USDA (United States Department of Agriculture), Rural Development, he was able to get a 38 year loan at 1 1/2% interest for people with low income. With the help of HUD (Section 8 housing program) assistance he is able to pay the mortgage, utilities and maintain his home. He also receives Food Stamps. At that point it was just a house. Now he needed a live in staff. It was the provider Shared Support who made it possible for ■■■ to have staff to meet him needs. They were the only Provider (after putting the job out for bid) willing to provide the service ■■■ needed. Shared Support with their motto "One person at a time" provided ■■■ with the 24/7 support he needed in his own home. Thus the success.

His housing is permanent. There is no risk of him being uprooted either by a family terminating their contract or a CLA agency moving him from house to house. He is a contributing member of his community and has friendly helpful neighbors. The assistance he receives from the Housing Authority, Food Stamps and his Social Security Disability check goes back into the community to maintain his home. It is used to pay utilities and taxes; buy furniture, household needs and food; do maintenance; pay for recreation, everything he needs for everyday life.

■■■ program is a different version of Family living or Life Sharing . ■■■ and his family know that his version is the best for his needs. These past six years have been the best years of his adult life. He would/will tell you so. His behaviors (outburst) are few and far between. He is a happy person. He loves his house.

His goal is now to get a job. Whether it be a typical job or an entrepreneur remains to be seen. But he is working on it.

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As ■■■■ mother I would make the following suggestions for PA Shared Living Programs.

Encourage individual to purchase their own housing. What is more natural and “everyday life” than owning property and contents of the housing.

The government has programs in place to help people with low income and people with disabilities other than the Waiver programs. By taking advantage of this available money then the money in the waiver programs could be used to reach more individuals.

Look at each person needing services as an individual with their own individualized needs. Then look for a service that would best serve this person. Placing a person in a service that is available does not always meet their need. It is good to remember that behaviors are their way of expressing their unhappiness. Some folks like their own space others need companionship, one like blue others like green, etc.

Trust that the Provider will provide the security and trust needed to make this work one person at a time. Individual needs can be provided as they are needed if the reimburse monies come to the Providers in a timely fashion. Guide lines are already in place saying what each individual needs (ISP) thus gives the approval for services.

Transportation is always a problem for people with disabilities. If the money that waiver pays per mile for providing transportation would be available for individuals to purchase their own vehicle there would be less difficulty in getting to and from. Being able to come and go is just part of everyday life. Having to plan days in advance for transportation arrangements, fitting individual schedules into the bus/van schedule, not being able to go to a movie on the spur of the moment, is not everyday lives. All individuals have staff members to drive their vehicle. Maintenance of the vehicle would also have to be provided by the waiver transportation money. Making a car payment and maintenance is I'm sure a lot cheaper than paying per mile for transportation.

Purchasing cars/vans, insurances, appliances, etc. is a good way to build a credit rating for the individual. It also increases the sale of autos, insurances, registrations, increases the work load on the auto mechanics, tire manufacturers, etc all this adding to our country's economics. Putting money back as well as taking out.

Submitted by:

■■■■ Mother

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