

To Pennsylvania Department of Public Welfare  
"Shared Living" Request For Information  
Attn: Pat Kuhno, Office of Developmental Programs

Re the DPW Consumer & Family Forum on Shared Living :

Thank you for the RFI and invitation to attend the Forum on 10-6-2011. It was most important for families to give their input and show DPW how vital it is to support our loved ones.

Every person with a disability is unique. Each situation is different and has specific and varying needs. They cannot all be put into a "category" and have DPW or ODP surmise that one budget rate fits all for each person and each county.

Our son [REDACTED] is an adult with intellectual disabilities. He functions well in a life-sharing situation with his caregiver/housemate, [REDACTED]. They also attended the Forum with us. It took several arrangements to find the right match for [REDACTED], but this has been successfully accomplished. We would not want this arrangement to be changed or altered due to a cost-saving budget plan initiative.

Following is a summary of our thoughts on Shared Living, [REDACTED] statement, and [REDACTED] statement. We appreciate the opportunity to comment and look forward to receiving a compilation of the ideas and discussion from the Forum.

Sincerely,

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

October 7, 2011

## HOW TO MAKE A SHARED LIVING PROGRAM BETTER

### 1. The Big Ideas About SLP's:

- \*Provide better on-going training for caregiver staff.
- \*Give state-wide training/info sessions for providers so they can be knowledgeable about programs, changes, state/federal regulations & requirements.
- \*Increase caregiver stipends so a quality person can be hired and retained. Create a benefits system so they have incentives to stay. Create a respite program so both the caregiver can have some relief/time off to refresh, and the same for the consumer to have a change of personnel &/or scene.
- \*Develop a manual for families as to processes & resources available for the disabled.
- \*Develop training programs for families & caregivers that focus on relationships in life-sharing, and can keep up-to-date on available services in their communities.

#### a. What Is Important For SLP's:

- \*That they be a safe environment for the disabled consumer both inside and outside their residence.
- \*That their caregiver be fully checked re background for criminal or abuse behaviors.
- \*That their caregiver receive on-going adequate training in relationships and safety.
- \*That their caregiver receive an adequate stipend and benefits.
- \*That respite be provided for the consumer and the caregiver.

B. Better training for the Providers, so they are knowledgeable of all venues available for each consumer. Get more input on what providers need to implement & continue a good consumer relationship.

C. SLP's should be supervised by the counties and run by direct care providers interacting together.

D. Need to consider this a while.

E. SLP's would need to be customized to each consumer's unique & special needs. This would require being detailed through each provider working with the consumer's family members for input.

F. DPW would need input from each consumer's county MH/MR support coordinator, a school or facility ISP, the disability diagnosis, and specific level of physical, environmental & emotional needs that must be met for them to function.

G. Run statewide, this could become another bureaucratic mess. Who would regulate it...who would decide on the regulations, provide necessary & accurate legislation to stabilize & uphold the true reason & function of and for the SLA's? Who will regulate the quality of the caregivers?

### 2. How the SLP Will Be Run:

a. Family members and non-members can provide supports by visiting the consumer, advise & help set up the SLP, have continual circle meetings, have routine set meetings with the provider staff, form good relationships with the caregivers.

b. It is very difficult to make a good and long term match for caregivers. A definite increase in stipends along with some benefits will attract a better quality of applicants, and give them an incentive to stay with the consumer. The family/provider/consumer need to make a plan for what is needed in respite time – both for the consumer & caregiver. If institutions are closing & moving consumers into SLP's – why wouldn't those good employees have the opportunity to apply as caregivers in the new situation?

c. The SLP's could take many forms, as presented by a variety of persons at the Forum.

d. Each county should have a supports coordinator assigned to those people to work with their family & a provider to access the best placement.

E. DPW should develop a network of emergency services and placements with each county's providers.

F. The caregiver should have a referral in place by the provider. Could they be utilized for those emergency situations or used to staff a respite facility?

G. The county MH/MR units and providers should have training sessions so they are aware of all available SLP's & what they can do to help the consumer. Meetings should be held for interested families to give them access to information on all types of SLP's and their various positive and negative aspects for their individual consumer. The specific needs of the consumer are unique in every case, so a collaborative effort & input from family members, support coordinators & providers must be considered in making a placement.

### 3. Data Collection:

a. Hire quality people and give quality benefits. Give enough training to the providers staff, the caregivers, and families.

B. Have an outside group give oversight and home visits.

C. SLP's should be answerable to specific licensing for the homes. This creates a safety check to protect the consumer. A program could be created for the caregiver of training sessions that would lead to certain certifying levels. This would be a good goal to providing better long time caregivers and an incentive for them.

D. Records must be kept of expenditures/receipts, initialed & turned in to the provider staff for timely review.

E. Who & why would they report each day to? Do not understand this statement. A program/activity log booklet could be set up as a calendar for the person's activities.

F. DPW – keep in mind – each person is an individual with their own level of capabilities and needs. You cannot “over the board” fit everyone with a disability into the same general

category.

G. Get input from the families, caregivers, consumer's provider staff on how the consumer is doing, and if their goals are being met.

#### 4. Concerns Or Problems:

How is DPW going to define what is an SLP? What is "shared living"? If this becomes a "family living" program situation where the consumer moves into an existing families' home, there are many risks to the person with disabilities. It will not promote self-determination. The person may have less choice of activities & rights. There is no guarantee that the family dynamics will work out well, and the family may choose to discharge the person at any time if they aren't compatible. This is an unstable situation. There are not nor ever will be enough host families available to take in persons with a wide variety of disabilities and needs.

If the SLP becomes a "group home living" situation, many of the consumers simply cannot adapt to living with other individuals, all with their own set of exceptional behaviors & needs. Activities are limited in a CLA, depending on the availability of staff (their own motivation to accommodate the consumers) and needs of the other residents.

Life-Sharing, where a consumer is matched with a caregiver to occupy a home, is less costly than a group home setting. Already 4 years ago, the individual budgets for each person were condensed into one flat rate. This just created an unfair comparison. If further drastic cuts are made to the budget, there would not be enough income for the disabled persons to buy food, pay their rent & utilities or other basic needs. Many would have to reduce the stipends or discharge their caregivers, and move into lower rent areas (a safety issue). This would be a dire situation and seriously affect everyone involved & create extreme consequences.

We value greatly the life-sharing model of living our son has and would not want it disrupted. Look into other ways to cut the state budget....do not take away more from those who are truly the vulnerable and helpless individuals in our society.

### **A SUMMARY OF OUR SON'S EXPERIENCE**

Our son ■■■ is a 36 year old man with intellectual disabilities. He lived at home with us until the age of 32. Answer this.... How long did you live at home with your parents? What was your life situation at age 21..26...30? It took many years of planning, organizing a circle of friends, having meetings, ■■■ being on a waiting list, choosing a credible provider when finally getting a waiver & housing voucher for him. It took some time on an apartment search to locate an owner that would accept the HUD voucher, let alone find a suitable apartment in a safe environment. Then there were interviews to find a qualified caregiver to be in a life-sharing situation, followed by meetings & outings with ■■■ to see if they would be compatible.

We have had 4 caregivers (3 in 2 years) during the 4 years ■■■ has been independent: 1<sup>st</sup> a college senior (found he couldn't mesh all ■■■ needs & activities with his school requirements). 2<sup>nd</sup> was found to be a social loner quiet personality that did not fit with ■■■. 3<sup>rd</sup>. This person was not as responsible for providing ■■■ care and needs. Finally (4<sup>th</sup>) we found a great match with ■■■ as the caregiver. They have been buddies for 2 ½ years.

During the 4 years, ■■■ has stayed in & maintained his townhouse apartment. It has been the only stable thing, aside from our family, in his life. There have been many adjustments & disappointments along the way, but also some good things. He has had the opportunity to grow in his skills, develop a dependable relationship, and experience a stable home of his own. We would like this to continue and feel it is the best living model for him.

██████████ Statement:

I am █████. I am a 36 year old man. I lived at home with my mom & dad. My dream was to have my own apartment. I was on the Lancaster County MH/MR waiting list for many years. Finally my waiver & housing approval came about. My mom & dad had to look a lot to find an apartment that was safe & nice for me, & the owner would accept the HUD housing. They took me shopping for furniture and I could decorate my own place. People from my church helped me move in.

Now I have had my own apartment for 4 years and live with my housemate █████ in Life-Sharing. We have lived as buddies for over 2 years. Before that I had 3 different caregivers.

I like living in my own apartment, and taking a walk around where I live. I go to work at the Lighthouse Vocational Services from 8 A.M. to 3 P.M. every day, and do volunteer work in the community 1 day a week.

In my own place I can be independent & pick out my own activities. I have learned that I can do more things and be responsible for my home. I take care of the outside by sweeping the walk & mowing the lawn front & back. Inside I can vacuum, set the table & use the dishwasher. I can do my own laundry, fold my clothes & put them away, and watch TV or listen to music when chores are done.

██████████ takes me to work & back, to do grocery shopping together, to the dances, and all the Special Olympics sports I am in – bowling, softball, soccer. She takes me to church where I am a head usher, and to my doctor appointments. █████ has to use her own car to take me places.

We are buddies and I don't want to change that. I am a responsible citizen. I pay for all my utilities & my rent portion & groceries. I do not want to live with another family (shared living) or in a group home. I have a family – my mom & dad & █████. Please do not take away from my funding!

██████████ Statement (██████████ Caregiver)

From: ██████████  
██████████

Subject: RE: Info Re Forum Meeting Thursday

Date: Thu, 6 Oct 2011 08:20:33 -0400

My name is ██████████ I am the live- in caretaker of ██████████. We have been together since April 20th of 2009. Changing things now for ██████████ would be an extremely hard thing because ██████████ loves having his own home, He has shared with me that he would not like to live with other people in a group setting. One of these reasons is due to ██████████ ability to not respond well with loud noises and sharing his space with other residents.

██████████ and I have become a family and have now shared each others lives, which is different than the group settings. If things are changed ██████████ care will suffer thus making ██████████ and his life very difficult. ██████████ needs continuity in his life which he would not have if he were in a group setting. ██████████ needs to have supervision which is what he has me for.

If the budget were changed I would have to find a part-time job making it difficult to do all the things I need to do for ██████████ like his after work schedules. Examples are special olympics activities, movies, games, etc, .I have now been with ██████████ for 2 1/2 years we are a family and to change that now would be a horrible thing for his mental state and his well being. People with disabilities need stability in their lives in order to live a productive and happy life and when ██████████ and I met each other he finally found that, so that he could live on his own with the help of someone besides his Mother and Father.

So ██████████ and I ask that you keep our lives the way they are because we are happy and to change it would disrupt it especially for ██████████. Also there is no respite care in place with my company. Therefore I work 24/7 with only 4 days off a month every other weekend). If I want any extra time off I have to pay somebody out of my own stipend to keep ██████████ for me so I can have extra time off. I think this needs to somehow be changed it's not right for a caretaker to take what monies they make and have to pay someone to keep their person for them .As caretakers we need to rejuvenate ourselves so we can give the best care possible, and with no Respite for over 2 years a person can get burned out. That is why this industry has such a high turnover rate.