



**Pennsylvania Advocacy and Resources  
for Autism and Intellectual Disabilities**

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**TESTIMONY ON SHARED LIVING**

Provided to  
**THE PA HOUSE OF REPRESENTATIVES HUMAN SERVICES COMMITTEE**

by  
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PAR - Pennsylvania Advocacy and Resources for  
Autism and Intellectual Disabilities**

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PAR appreciates this opportunity to show our support for the Shared Living model. PAR members provide the majority of the Shared Living services in Pennsylvania.

Chairman DiGirolamo, Chairman Cohen and committee members, thank you for creating this forum to enable others to learn more about Shared Living, which is referred to in regulation as Family Living and is also commonly referred to as Lifesharing.

PAR, which stands for Pennsylvania Advocacy and Resources for Autism and Intellectual Disabilities, is a statewide provider association which has been in existence for over forty years and whose members currently support over 52,000 individuals with autism or intellectual disabilities throughout Pennsylvania in more than 7,900 locations. PAR's mission is to build the capacity of the private sector to fully support the needs of Pennsylvanians with autism and/or intellectual disabilities.

PAR members have been providing Shared Living opportunities (which are people living with families that are not their parents) for many years. We believe the expansion of Shared Living opportunities in Pennsylvania has the potential to be a powerful tool in helping reduce the waiting list for intellectual disability services. But some changes need to be made to enable expansion.

Under the prior administration, the Lifesharing Subcommittee of stakeholders authorized by the Office of Developmental Programs (ODP)'s to provide recommendations to ODP developed an extensive list of recommendations to ODP, county government, and providers. PAR members participated in that group. PAR also offered to partner with the ODP and organized 17

community-based intellectual disability service providers willing to participate in a test model to expand Shared Living using these recommendations. You can imagine our disappointment when these promising initial conversations stalled, and then were forgotten by ODP.

We were pleased to see a Request for Information (RFI) for Shared Living issued by the Department last fall. In response, PAR submitted proposals in October of 2011.

Today, I would like to focus on what steps you, members of the legislature, can do to facilitate the expansion of Shared Living. **You can amend the existing regulations governing Shared Living. The amendment that is needed would provide the ability for grandparents, brothers, sisters, aunts, uncles, nieces or nephews to provide these services to their relative.**

Current regulations, adopted in 1991, preclude relatives from becoming Family Living providers. Title 55 Chapter §6500.3(f)(1) Family Living Homes states that the chapter does not apply to the private homes of persons providing care to a relative with mental retardation. At §6500.4 “relative” is defined as a parent, child, stepparent, stepchild, grandparent, grandchild, brother, sister, half-brother, half-sister, aunt, uncle, niece or nephew.

Family Living was initiated in the early 1970’s under the community living arrangement guidelines in order to offer individuals a more normal integrated living environment with a family or other caretaker in the family’s home. The intent was to allow up to two individuals to move in with a caring family or person who was already established in the neighborhood and to live as part of that family. The benefits included the opportunity to develop a more stable relationship, unlike group homes where staff are shift workers and there was an average turnover of 42% (noted in 1999 by the Legislative Budget and Finance committee (LBFC) *Report on Salary Levels and Their Impact on Quality of Care for Client Contact Workers in Community-Based MH/MR Programs*). The 2005 Pennsylvania OMR Residential and In-Home Services Turnover and Vacancy Survey found that, 6 years later, turnover was still alarmingly high, averaging 36.3%.

The Family Living home offered a greater opportunity for the family and individual to develop a closer emotional and supportive relationship – not always possible with shift workers who don’t live in the home. And Family Living did not have zoning issues. Zoning issues continue to cause us to struggle through zoning hearings to establish group homes in communities.

Family Living helped reduce costs as family living homes already had furnished homes and a home environment that included natural overnight support.

With the cost of developing and maintaining group homes and the constant concern over finding and keeping qualified staff, it is time to make a concerted effort to expand this option for residential services for individuals that can no longer live with their parents.

The Centers for Medicare and Medicaid Services (CMS) does not allow parents to provide and be reimbursed for waiver services if it is a service they would typically provide as a parent; CMS does, however, allow relatives to provide such services.

Allowing individuals to utilize their natural supports and compensating relatives who are capable of providing the often specialized and demanding work required to support an individual with intellectual disabilities would provide more Shared Living opportunities for individuals and potentially save dollars that could be used to support people on the waiting list.

We do need to mention that not all families of individuals with intellectual disabilities are enamored with the idea of Shared Living. Here are a couple of reasons:

There are some situations in which the level of clinical support is so specialized that immediate access to medical and other professionals is needed and might not be readily available in a Shared Living setting. There are other instances in which a family would rather not see their son or daughter supported in another family setting and strongly prefer a group home setting. Lastly, some individuals might not choose to be under the watchful eye of another parental unit, preferring instead the camaraderie of living with friends in a group home or semi-independently, offered in a supported living arrangement.

We bring these examples to your attention to point out that Shared Living is a wonderful option for many people that should be fully supported and expanded. But it is not for everyone. It is not a cure-all, nor a magic bullet. What it *is* is a cost-effective way to provide services to many individuals with intellectual disabilities who prefer a family-like setting – a setting that is currently under-utilized and under-supported by ODP in the state of Pennsylvania.

There are reasons you have not seen a substantial increase of Shared Living settings in Pennsylvania. Barriers include but are not limited to:

- Cost issues: Inadequate reimbursement; inflexible funding which hampers providers' ability to recruit families as Shared Living providers.
- Health insurance costs.
- Transportation – getting individuals to and from work, for example.
- The lack of education of families and the community on the value of Shared Living.

As you heard in testimony to this Committee in December of 2011, given by Access Services' Executive Director Rob Reid, Shared Living was not immune from the across-the-board negative 6% rate adjustment imposed upon providers last November. This has helped to further hamper this cost-effective option.

If the Shared Living model is going to flourish in Pennsylvania, we need to ensure families who are sharing their homes that they will be supported, that they will have access to the clinical and professional staff needed to support the individual who lives with them, that they can access respite services, and that they will be paid rates that cover the costs of providing support to the individuals with intellectual disabilities that are in their home and in their care.

**The first step in expanding this option is to rescind the rate cut from Shared Living and amend Pennsylvania's regulation at Chapter 6500 to allow relatives, excluding parents, to**

**provide Shared Living in their homes. These actions would go a long way toward expanding the availability of caring Shared Living providers.**

PAR's October 7, 2011 response to the Department of Public Welfare's Shared Living Request for Information offers several additional recommendations to the Department. They include:

- Supporting up to two individuals living with family and non-family members, excluding parents
- Instituting pilot programs using a pre-paid capitated payment model
- Emphasizing the importance of home studies
- Developing financial incentives for agencies moving individuals from more costly to less costly living environments like Shared Living when an individual's needs can be met
- Establishing a central repository for training resources, tools and equipment that can be used by Shared Living providers
- Certifying agencies instead of licensing individual Shared Living homes
- Allowing for minimal daily reporting to help insure a more homelike atmosphere
- Focusing on quality and meeting individual outcomes
- Using specific quality indicators
- Introducing a comprehensive residential habilitation procedure code that could be tested in pilots that would provide more flexibility in the provision of services

We would be happy to speak with members of the committee about any or all of these recommendations. We will provide a copy of our response to the Department's Shared Living RFI to this committee at your request. We know that many of our members as well as other stakeholders submitted recommendations in response to the Shared Living RFI. **We respectfully request that this committee place an inquiry into the Department to determine how and when they intend to act on the information they requested and received.**

We are capable and ready to work with you, the legislature, and with DPW to create an improved service system more capable of supporting more people. We need you to help us promote policies that will enhance rather than reduce our ability to manage within this restrictive economic environment.

Thank you for considering PAR's comments and recommendations.