

Testimony to

**Commonwealth of Pennsylvania
House Human Services Committee**

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Good morning Chairman DiGirolamo, Members of the House Human Services Committee and guests. Thank you for allowing me the opportunity to speak on behalf of Family Living, also known as Lifesharing or Shared Living.

My name is Charles Hooker, and I serve as the Senior Vice President of Keystone. Today, I am joined by Pam Foreman, Division Director of Support Services, and Jim Malesky, Lifesharing Service Director, to address concerns regarding the Life Sharing Program that Keystone operates throughout the Commonwealth of Pennsylvania.

First let me tell you about Keystone Human Services then I will specifically discuss Lifesharing services. One aspect to consider is that not all services are right for all people. Therefore it is important to have a comprehensive system of care or an Integrated Delivery system in order to assure that people's needs are being met properly. Within that comprehensive system of care, Lifesharing is a service that is most natural, as it mirrors a true family situation, therefore more likely to facilitate assimilation of an individual into their community and lead to favorable outcomes.

Keystone Human Services through its agencies is the largest licensed provider of Family Living Services in the Commonwealth of Pennsylvania. We are the second largest provider of Community Living Arrangements. We support 1100 individuals in the community-based system of care for individuals with intellectual disabilities which is regulated and monitored by the Office of Developmental Programs (ODP). We provide a variety of human services to support vulnerable members of our society. Some of our services serve families and children with mental health needs or autism, or children in our Head Start programs and preschool programs. Others serve adults with intellectual disabilities, autism, or mental illness. Some of our organizations provide a full range of supports and services to all. Overall, this past year we supported over 6500 individuals in over 377 locations with a staff compliment of 3,207.

Keystone provides supports from a geographic range in Pennsylvania - as far west as Allegheny County, as far north as Wyoming and Luzerne counties, in the east in the greater Philadelphia area, all of Central Pennsylvania, the Lehigh Valley, and to the south in York, PA. We also are a major provider in Delaware, and in all regions of the State of Connecticut.

We are a recognized world leader in deinstitutionalization, sharing our expertise in Moldova, Russia, Azerbaijan, and Romania. We have close to 100 volunteer Board members that comprise the 7 nonprofit community-based 501c 3 organizations that are Keystone Human Services. This is the infrastructure that keeps the vision alive and vibrant. We are continually recognized for our untiring efforts, to "Advance the Human Spirit" which is our theme.

In our Lifesharing services, we support 120 individuals in 94 homes. These individuals live with host families, referred to as Lifesharing Providers, who have opened their home to support and share their lives with people with immense needs. The enduring relationships that are formed are an important part of developing life skills and self-esteem, as well as a rich family, community

and civic life. Individuals increase their skills in daily activities while engaging in typical family and community life. The stigma that accompanies many individuals with disabilities goes away as they are simply seen as part of a family and not as part of a 'system'. It's that environment, and view, that provide the opportunity for each person to grow and develop to their fullest potential as an integral, participating member of their neighborhood and community. We have been fortunate at Keystone to witness the significant life changes that occur when individuals are granted the occasion to live this way.

The host family, or Lifesharing Provider, may be a single parent, empty nesters, a married couple with no children, or a married couple with children. The type of "family" is secondary to the relationships and the opportunity to live in a caring household, sharing life experiences with supportive person(s).

Lifesharing Providers provide comprehensive person-centered supports within their home to one or two individuals with intellectual or developmental disabilities. We provide training for all of our Lifesharing Providers and our coordinators provide assistance with problem solving, resources and respite for the Lifesharing Providers. All homes in our Lifesharing services are inspected and licensed annually by the Pennsylvania Office of Developmental Programs within the Department of Public Welfare.

Keystone Human Services (KHS) is currently one of the largest providers of Lifesharing Services in PA. Despite the fact that Lifesharing services are cost effective, and in the long run there are significant savings if more individuals are served in this setting, and despite our commitment to grow these services, we have had great difficulty expanding services because current regulations and payment approaches make it hard to interest more individuals and families in this service option. We are happy to have the opportunity to provide input that could help expand services in these programs.

It is important that the Department improves our ability to expand this program by providing flexibility in service and payment policies that allows individual's needs to be met including enhancing our ability to rapidly respond to changes in needs.

The program needs to have reimbursement rates attractive enough to recruit family caregivers. The Department needs to take into consideration startup costs which are currently incurred by an organization prior to an individual's placement, which makes the startup costs prohibitive for many organizations even though this is a very cost effective model of service. When funding provider organizations, it needs to be recognized that there are significant up-front costs incurred in cultivating potential caregivers. Startup costs may include: recruitment efforts, home studies/home inspections, transportation costs, reimbursements to families and adaptations to the home or vehicles. These costs often prohibit organizations from expanding into Lifesharing or prevent growth of the program. This is a result of short sighted policies and funding structures since the program has very significant long-term cost savings.

We are pleased that this administration is seeking to find viable ways of expanding this program, as it will take proactive changes in policies and funding structures to expand this option into what it could be.

The “matching” process, matching individuals with the most appropriate caregiver, is one of the most critical aspects of long term, successful services. Resources to support this, is paramount to its sustainability. Some of the qualifications we look for in our Lifesharing Providers include commitment to provide a home for an individual in connection with their community (social, civic, church groups), a good support system (extended family, church, neighbors, friends), openness to a variety of Human Service Professionals in their home on a regular basis, and good communication skills to advocate for individual when necessary.

There are additional impediments, such as regulations that are burdensome and arbitrary and outdated. Regulations need to be streamlined and focused on outcomes directly related to the individual’s health, safety and welfare. When living in a family home it is important to have protections in place without over-dependence on rules and regulations that do not add value to the individual’s life nor directly ensure their protection. The consensus across the Commonwealth is that regulations should be revisited and revised to address this issue.

Current regulations limiting participation of natural families as ‘Providers’ need to be closely looked at and changed to support this as a viable option for some. Siblings or other relatives could be ideal caregivers and their prohibition results in families pursuing higher cost settings for their family member. Many individuals could be cared for by siblings but instead move toward a more expensive setting and less fulfilling relationships.

The system also needs to be supportive in addressing the changing needs of individuals especially as they grow older. These could be short term issues or long term as individual’s conditions and situations change. A great life sharing situation can often last many, many years. But over these years the person’s needs change. We don’t see the current system sufficiently supporting the caregivers in providing increased support to them as the individual they are supporting has greater needs. It then becomes very difficult for them to continue. Reimbursement rates need to be sufficient to attract and retain Lifesharing Providers. Though financial gain is not the primary reason a family agrees to provide the service, we need to be responsive in financially supporting their efforts.

In addition, the program needs to be available for multiple populations that can benefit from life sharing. There is currently some energy across the Commonwealth addressing this issue. It is advantageous to continue the efforts to fruition so the system is structured in a way that will meet the needs of all persons able to benefit from this type of service.

One of the impediments to growth is the limited involvement of case management services from referring agencies. Placing an individual in a life sharing situation is not an exact science. It involves the individual and the caregiver taking a risk. We've been in situations where the placement has not worked. With a proactive approach and when resources are available, we are often able to divert an emergency and provide services without a tremendous amount of delay or burden to the individual. However, we are most often left on our own to solve "the problem". "What are you going to do" has been a consistent response when we ask for help with solutions and/or alternative placements. When left on one's own with limited flexibility, given limited fiscal support and a complicated system, it severely limits who one is willing to consider supporting through the life sharing option even though overall it is much more cost effective and much more family and community oriented. If the system were flexible and supportive of people who might not otherwise be given an opportunity to experience life in a family home, we are certain that we would meet with a high degree of better outcomes for people.

We have continued to develop a national model of supports to adults with autism through Keystone Autism Services and the Adult Community Autism Program which now serves over 94 individuals in 4 counties Cumberland, Dauphin, Lancaster, and Chester. Besides the fact that this is a new service to support individuals who desperately needed services and had none, it is also supported by a new funding model that provides the kind of flexibility that enables providers to meet people's most pressing needs.

We are developing new ideas and structures that build on our expertise and experience to serve our communities more effectively. Here are a few:

Funding models- We believe the best payment option to meet individual outcomes with the most flexibility and least amount of complication is a pre-paid capitated payment system similar to the LIFE and Adult Community Autism Program (ACAP) models. A capitated approach will provide the Department with a known financial commitment for the year. It will reduce administrative burdens and cost and allow providers to focus on innovation and serving more individuals. Outcomes can move from a transactional basis to meaningful outcomes about the individuals being supported. The current fee-for-service structure has stymied development and increased costs even though rates are too low and the regulatory requirements are high. Further refinement of a fee-for-service model will still lead to a system with high administrative costs for both the providers and the Department will remain unsure of actual costs as the fiscal year progresses.

Under a capitated approach, payment to caregivers would be made by the provider organizations as a responsibility of the capitation received. Provider organizations would be free to determine the rates, but they would be in competition to recruit caregivers and would have to pay a competitive rate. Provider organizations could choose to pay rates based on the level of need of the individuals supported.

The capitated approach would provide significant flexibility to the provider agencies. This approach would be far more advantageous than the current system of state-determined rates which have not encouraged system growth.

A very important option, somewhat similar to a capitated payment model, is the Comprehensive Residential Procedure Code. This would allow a single rate and cost report for community residential services which would offer significantly increased flexibility and cost effectiveness. The first phase of this proposal only includes group homes supporting up to four persons. However, it is proposed that as a second phase, shared living would be included in the Comprehensive Residential Procedure Code. This would allow shared living to operate as part of a more flexible and more comprehensive community residential system. Most important the shared living program would be back up by a more structured community residential resource so that when a family living placement breaks down because of illness, divorce or other life change in a family living provider there is an immediate and good alternative available for the individual.

In summary, may my testimony be representative of the commitment of providers like Keystone to maintain the highest levels of human service standards, ensuring that our most vulnerable citizens are prepared for the challenges of today's world. As part of the provider community, we too are engaged in expanding expand our partnership with families and citizens of Pennsylvania who desire to choose a resource that works for their loved ones. Thank for this opportunity to address the committee; we are available to answer any questions you might have at this time or at any time.

Respectfully,

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