

Pennsylvania Association of Resources
Autism • Intellectual Disabilities

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Mr. Kevin Casey, Deputy Secretary
Office of Developmental Programs
Department of Public Welfare
P.O. Box 2675
Harrisburg, PA 17105-2675

Via email: ra-ODPComment@state.pa.us

Re: Comments by the Pennsylvania Association of Resources for Autism and Intellectual Disabilities (PAR) on the Draft Bulletin *Lifesharing Safeguards*

Dear Mr. Casey,

Thank you for the opportunity to provide comments and make recommendations on the Office of Developmental Program's (ODP's) draft bulletin on *Lifesharing Safeguards*.

PAR thanks the Department and the Lifesharing Subcommittee for developing this draft bulletin and accompanying documents, which help to standardize the lifesharing application process and improve safeguards for individuals receiving lifesharing services. As you know, PAR is very supportive of expanding community service options, including lifesharing. The fact is that PAR members provide most of the lifesharing supports in Pennsylvania. Our comments and recommendations are intended to aid the Department in achieving this shared goal in an efficient and cost-effective manner.

Included below are our comments and recommendations.

Section: Policy (pg. 3)

Discussion: The draft bulletin states, "All counties, Supports Coordination Entities, provider agencies and lifesharers are expected to comply with the safeguards established in this bulletin as they apply to their responsibilities." Does this mean that the bulletin applies in its entirety to non-licensed lifesharing programs? The draft bulletin appears to require for non-licensed programs – via an ODP policy bulletin – various safeguards included in the 6500 licensing regulations. While we understand that ODP bulletins often apply to non-licensed services, we are concerned about effectively implementing licensing standards through a bulletin. As your office knows, a bulletin does not go through the regulatory process, does not carry the full force of the law as a result, and should not be used as a vehicle to apply licensing standards on a non-licensed program.

Recommendation: Clarify that non-licensed lifesharing programs are not required to comply with the 6500 licensing regulations in order to operate and be funded.

Discussion: This section states, “Funding for the cost of implementing these lifesharing safeguards is expected to be included in the provider’s rate for services, in accordance with Bulletin 00-05-04, *Lifesharing through Family Living*.”

Based on the draft bulletin’s requirements, many providers will have to revisit the outlined 3 – 6 month start-up costs outlined in Bulletin 00-05-04. Here are just some of the projected additional costs associated with the draft bulletin:

- Expanded criminal background checks
- Expanded training costs
- Expanded paperwork
- Revised policies, procedures, lifesharing contracts
- Expanded substitute care
- Expanded habilitative services
- Revised rate setting procedures

Recommendation: While developing the new rate setting methodology, and when approving new lifesharing rates, recognize and factor in these new costs.

Section: *Relationships and Social Responsibility* (pg. 3)

Discussion: The draft bulletin states, “People who work in the service system are expected to respect and utilize these informal safeguards in ways that contribute to people feeling safe and secure in their homes and communities.” How will ODP monitor this expectation? What are the expectations surrounding the inherent risks that we all face in our communities?

Recommendation: Add “recognizing that there is some inherent risk when also promoting choice” to the end of this statement.

Section: *Criminal Background Checks and Child Abuse Clearances* (pg. 4)

Discussion: In this section, it should be made clear at the outset that criminal background checks only apply to individuals over the age of 18.

Recommendation: Add “over the age of 18” in the first sentence, after “Lifesharers and other household members.”

Discussion: There are new criminal background check requirements in this bulletin for lifesharing programs; i.e. for substitute care. This is a cost passed on to the provider that is not reimbursed by ODP.

Recommendation: Reimburse all providers for criminal background checks.

Section: *Home Study* (pgs. 5-6)

Discussion: Provider agencies should have the ability to modify these documents to fit their own needs and the needs of the particular individuals they serve. This same principle should apply to the draft applications.

Additionally, we are aware that discussions have occurred with ODP regarding ownership of the home studies; i.e. if that information will reside with ODP or with the provider agencies. The home study documents should reside with the provider agencies - the information collected is sensitive and should be maintained in a confidential manner, not shared widely as we have heard ODP plans to do (e.g. with Supports Coordinators and various team members). The lifesharing families need to be assured that the information collected about them will be kept confidential and that disclosures will be minimal. It would be acceptable to have some agreed upon information about potential host-family providers being made available to Supports Coordinators, individuals and their families, and other team members, but not the entire home study document.

If ODP keeps the home studies, it puts providers in a potentially difficult position based on the evaluator's recorded impressions and potential issues that might be present in the home. Home studies are used as a tool for providers to make decisions about the potential use of a person/family as their independent contractor providing lifesharing and in making determinations on potential matches with consumers looking for a lifesharing placement.

The final decision to contract with a host-family/LS provider must remain with the organization responsible for providing the service. Of course, individuals must be involved in all decisions regarding where they live.

Recommendation: Clarify that provider agencies have the ability to modify the home study documents and applications according to their agency's needs.

Recommendation: Clarify that the home study documents will reside with the provider agency.

Recommendation: Work with stakeholders to determine what pieces of information from the home study documents can be disclosed to Supports Coordinators, individuals and families, and other team members.

Section: *Program Supervision* (pgs. 6-7)

Discussion: The draft bulletin states, "The Family Living/Lifesharing Specialist is responsible to visit the lifesharer and person receiving services at their home at a frequency based on the needs of the person when any of the following conditions apply...A reportable incident is being investigated and is not closed."

Recommendation: Add "unless the person has been removed from the home" after "not closed."

Discussion: The draft bulletin states, "Substitute care shall be disallowed whenever the substitute care constitutes a risk to the health and welfare of the person." The obvious intent of this sentence is that of course providers would not have a person go into substitute (respite) care if there were risks to health and welfare. However, there are some who believe that if individuals don't do well in respite situations, they should have the choice not to ever go into respite. Because respite is key in helping providers manage difficult situations and in addition creates longevity, providers can't say that because of a certain individual's needs, they are not entitled to respite. Substitute care should not be disallowed across the board and other options should be looked into in the event of health and safety concerns.

The draft bulletin does not seem to comport with ODP's 11/21/2007 letter to Administrative Entities which provided clarification on lifesharing and addressed substitute care. In that letter, it was clarified that substitute care can be provided on an "in kind" basis by a qualified provider when approved by the lifesharing agency.

Recommendation: Clarify that other options can be looked into whenever substitute care constitutes a risk to health and welfare and that substitute care does not have to be disallowed across the board.

Recommendation: Add the information from the 11/27/2007 lifesharing clarification letter to Administrative Entities clarifying that substitute care can be provided on an “in kind” basis by a qualified provider when approved by the lifesharing agency.

Discussion: This section outlines the responsibilities of the program specialist, and states “The Family Living or Lifesharing Specialist is responsible to ensure that the following safeguards are applied...” While the Lifesharing Specialist has important responsibilities to fulfill, it is the lifesharing provider/lifesharer that sees the individual every day and the provider (lifesharer) should also be responsible to ensure that safeguards are met.

Recommendation: Revise the above statement to read “The provider (lifesharer) is responsible to ensure that the following safeguards are applied. The Family Living or Lifesharing Specialist is responsible to ensure that the provider (lifesharer) is carrying out and applying the following safeguards.”

Section: *Roles, Activities, Structure – Structure of HCQUs* (pg. 8)

Discussion: The draft bulletin states in #3 (a) in reference to the Director, “It provides direction for the HCQU staff and is responsible to the AE or County consortium.” ‘It’ should be replaced with ‘he or she.’

Recommendation: Replace ‘It’ with ‘He or she.’

Section: *Lifesharer Application/Attachment 1*

General Comment: Each question in the application and home study should be reviewed carefully to determine why the information is needed and what it will be used for. Some of the questions seem unnecessarily intrusive and could deter potential lifesharers from completing the application process. Examples include asking about personalities, attitudes, mental health background, periodic stress, and so forth.

Recommendation: Review questions carefully to determine why the information is needed and what it will be used for. Delete unnecessary questions.

Discussion: The application states, “Applicants are considered without regard to race, color, religion, sex, national origin, age, marital or veteran status, or the presence of a non-job-related medical condition or disability.” On page 4 of the application, the following information is requested “Mental Health Services received (including counseling & inpatient services with dates.” While it may be good to know if a potential lifesharer has received any mental health services, if an applicant was rejected due to mental health issues, it could be construed as discrimination, per the first statement of the application noted above. Additionally, sexual orientation is missing from this statement.

The draft application asks various health-related questions but does not discuss how this information will be protected or stored, or if privacy laws such as HIPAA will be enforced.

Recommendation: Address the potential mental health and discrimination issue in the draft lifesharer application.

Recommendation: Add “sexual orientation” after “age.”

Recommendation: Clarify how health information will be protected.

Discussion: The draft application asks for information about an alternate lifesharer. If a potential lifesharer lives alone or does not have an alternative to disclose, it is not clear if he or she still has to answer this question as part of the application process.

Recommendation: Clarify that the section of the application regarding alternative lifesharers does not need to be answered if not applicable.

Section: *Lifesharer Home Study/Attachment 2*

Discussion: The home study requests the following information: “Neighborhood and Home Site (Overview of neighborhood composition, access, location, safety, size, wheelchair accessibility, home allergens such as smoking and pets, etc.)” There is no discussion about or reference to crime rates or the overall safety of the neighborhood. The home description should enable one to assess the general safety of the area. Families and individuals would also benefit from knowing this information.

Recommendation: Add crime rate and general neighborhood safety after “neighborhood composition.”

Discussion: The draft study requests the following information, “Describe the personality of the Lifesharer and Alternate and each member of the household?” First, very little room is given to answer this question. Second, is this supposed to be reliable information? And how is the rater supposed to get this information from a single sitting interview? Personality is far too vague a term. Furthermore, personality isn’t supposed to be a hiring criterion, and if it is on the home study, it is part of the hiring decision. The study would be stronger if it asked standard “how would you deal with...” questions instead of vague questions related to personality. The questions following this section seem to achieve that purpose.

Recommendation: Delete the “describe the personality...” question.

Discussion: The draft home study asks the following, “Give examples of the ways in which each person tends to interact with others in the home.” It is doubtful that the person conducting the study will have an opportunity to sample interactions sufficiently well to put objective information here. It is assumed that they will have to rely on the verbal reports of those being interviewed. That information may not be reliable.

Recommendation: Delete this question.

Discussion: The draft home study asks the following, “What are the attitudes of extended family and friends to the idea about including an individual with disabilities in your home?” ‘Attitude’ is a subjective term and not appropriate for inclusion in this home study. The study should attempt to identify patterns of behavior which is more objective than a term like ‘attitude.’ Further, attitudes of others are irrelevant if the lifesharing applicant has the desire and interest.

Recommendation: Delete this question.

Section: *Lifesharing Home Study Physical Site Review/Attachment 4*

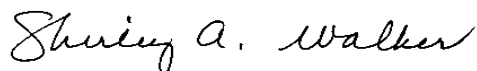
Discussion: The draft site review requires the following: “Fire extinguishers inspected & approved within 12 months by local fire department or labor & industry.” This requirement actually exceeds the Chapter 6500 licensing regulations, which state at §6500.108(c) *Fire*

extinguishers shall be listed by Underwriters Laboratories or approved by Factory Mutual Systems.

Recommendation: Replace this proposed requirement with the current requirement in §6500.18.

Thank you for considering our comments and recommendations. If you have any questions, please do not hesitate to contact me.

Sincerely,



Shirley A. Walker
President and CEO