



For Review and Comment Purposes Only – Not for Implementation  
**DEVELOPMENTAL PROGRAMS BULLETIN**  
**COMMONWEALTH OF PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE**

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SUBJECT:

Lifesharing Safeguards

BY:

Kevin T. Casey  
Deputy Secretary for Developmental Programs

**SCOPE:**

Administrative Entity (AE) Administrators/Directors  
County Mental Health/Mental Retardation Programs  
Supports Coordination Entity Directors  
Family Living Agency Directors

**PURPOSE:**

The purpose of this bulletin is to outline policy and practices regarding safeguards for people residing in lifesharing homes.

**BACKGROUND:**

Lifesharing involves people with mental retardation living and sharing life experiences with supportive persons who form a caring household. Lifesharing is recognized as being both a close personal relationship and a place to live. Since its inception in 1982 in Pennsylvania, lifesharing has consistently demonstrated itself as a cost effective option for people whose needs for services and support are best met in a shared home environment. The Office of Developmental Programs (ODP) has identified expansion of lifesharing as a major initiative and expects lifesharing options to increase as people choose where and with whom they live.

In order to ensure that lifesharing is provided in ways that ensure the health and welfare of persons receiving services it is necessary to clarify ODP policies on certain roles and responsibilities of individuals providing lifesharing services, provider agencies, supports coordinators, AEs, Counties and Department licensing staff.

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

**The Appropriate Regional Program Office**

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This bulletin serves to clarify the following areas in light of current policy and regulations, including:

- Articles IX and X of the Welfare Code
- 55 Pa. Code Chapter 6500 Regulations, which are designed to protect the health, safety and well-being of individuals with mental retardation living in licensed Family Living homes
- Medicaid Home and Community Based Waivers that require that necessary safeguards are being taken to protect the health and welfare of the recipients of services
- Older Adults Protective Services Act (OAPSA) and the Child Protective Services Act (CPSA), which require criminal background checks and clearances for human service workers
- Department policy established to ensure health and safety including Bulletin 6000-04-01, *Incident Management*
- Bulletin 00-05-04, Lifesharing through Family Living

### **Definitions**

**Home Study** - A study where a Family Living Specialist, Lifesharing Specialist or other qualified professional reviews the characteristics of the lifesharing situation to ensure that the person needing services and the lifesharing household form an appropriate match that will fulfill the needs and aspirations of the person. The home study determines whether the person needing services and the lifesharer, together with other members of the household, have compatible expectations regarding their relationship, roles and responsibilities and whether the lifesharer and other household members are able and willing to provide needed services and support to the person in light of existing work, household, social and other community commitments.

**Family Living Specialist** - A qualified professional who meets the requirement of and performs work pursuant to 55 Pa. Code 6500.43.

**Lifesharing** – Lifesharing can occur in a number of ways that are described in this definition. An arrangement where one or two people with mental retardation live with an unrelated family or individual(s) who support the person's everyday life, needs, and aspirations. Lifesharing is provided in Family Living homes licensed under 55 Pa. Code Chapter 6500 and in unlicensed homes providing room and board for one or two people with mental retardation who are 18 years of age or older and who need a yearly average of 30 hours or less direct training and assistance per week per home.

While domiciliary care homes certified by the Department of Aging serving three or fewer persons are also considered under the category of lifesharing, domiciliary care homes only apply to this bulletin when additional ODP funds are being used to support the person in a domiciliary care home.

ODP funding can be made available to support licensed lifesharing through the Consolidated Waiver and the county base allocation. ODP funding can be made

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available to support unlicensed lifesharing through the Consolidated Waiver, the Person/Family Directed Support (P/FDS) Waiver, and the county base allocation.

Lifesharing safeguards - Practices that ensure the health and welfare of persons who live in lifesharing and Family Living homes. Lifesharing safeguards consist of both formal quality assurance measures such as regulations, policies and prescribed service system practices, as well as the informal personal commitments that people have for one another that are not required by policy or regulation. Lifesharing safeguards are practiced by people living in the lifesharing home, neighbors, family and friends, the lifesharing or family living specialist who supervises services, other direct support professionals who are subject to report under OAPSA, supports coordinators, AEs, counties, ODP licensing representatives, and the community at large.

Lifesharing Specialist - A qualified professional assigned to perform work similar to that of a Family Living Specialist for people receiving lifesharing in an unlicensed setting as per 55 Pa. Code 6350.3(f)(5). A Lifesharing Specialist must meet the same qualifications as a Family Living Specialist or the qualifications of a Qualified Mental Retardation Professional (QMRP) as defined in 42 CFR 483.430.

Substitute Care – Paid relief for the lifesharer who is the person’s primary caregiver when the lifesharer is temporarily absent or unable to offer needed services due to an illness, family crisis or other circumstance that is built into the rate for the lifesharing service. Substitute care replaces “respite” as a service definition for people in lifesharing. Respite will no longer be the defined service that is provided for people in lifesharing, even for people receiving substitute care in a licensed respite home. Substitute care can be provided on a part day or 24 hour overnight basis, and can be provided in the lifesharing home, another lifesharing/family living home, another community residence or in the community.

**POLICY:**

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. 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*. Where applicable, lifesharing agencies and Supports Coordination Entities are expected to clarify their policies regarding program supervision, substitute care, training and technical assistance in light of these policy clarifications.

Relationships and Social Responsibility

Relationships and social responsibility play significant roles in assuring a person’s health and welfare. People who have regular and ongoing relationships with family members, friends, neighbors, shopkeepers, coworkers, and others have people to help safeguard them from harm, potential abuse and neglect. Utilizing community resources

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to assure a person's safety makes communities stronger for everyone. Regulations and policy requirements are expected to build on the mutual trust, communication and caring that is developed through lifesharing and other community relationships. 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. Personal and family traditions, cultural expectations, beliefs, and experiences play a key role in recognizing and developing informal safeguards for persons in lifesharing relationships.

#### **Written Agreement for the Provision of Services and Support**

A written agreement between the provider agency and the lifesharer is expected to be signed before the person receiving services moves into the lifesharer's home. This agreement is expected to include a statement that the provider agency and lifesharer agree to carry out Department of Public Welfare regulations and policies related to the health and welfare of persons in the lifesharing home.

#### **Criminal Background Checks and Child Abuse Clearances**

Lifesharers and other household members who are not recipients of services must have a criminal background check and be issued a criminal history clearance pursuant to OAPSA. When a person under the age of 18 is served in a lifesharing arrangement, a child abuse clearance is required pursuant to CPSA. Any new household member age 18 and older who is not a recipient of services, that moves into the home after the person receiving services, is also subject to a criminal background check and child abuse clearance, if applicable, and shall not be permitted to be left alone with the person receiving services until these checks and clearances are completed.

Any individual who provides substitute care or other services for the person must meet the provider qualification criteria for lifesharing services, including criminal background checks and child abuse clearances, if applicable. This requirement applies to all relatives, neighbors, adult household members, companions and friends of the lifesharer, as well as staff and direct support professionals, who are paid to provide services for the person. Lifesharing agencies are authorized to reimburse or pay for the cost of criminal background checks and child abuse clearances.

Any agency staff or lifesharer who knowingly allows a person with a criminal background prohibited under OAPSA or CPSA to move into the lifesharer's home and/or knowingly permits a person without a criminal background check and applicable child abuse clearances to provide services to a person, is subject to sanctions up to and including licensing actions, actions by the lifesharing agency, and/or restriction of the providers ability to provide services. Additionally, these situations must be reported through the Department's incident reporting system.

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**Home Study**

The lifesharing agency and the AE/county are responsible to ensure that a home study is completed and reviewed with a person's Individual Support Plan (ISP) team to determine the appropriateness of the lifesharing match. Each home study is expected to include an interview with the person considering a move to the lifesharer home, the prospective lifesharer, and all household members. The home study is completed together with other requirements relating to licensing such as household member physicals and Mantoux tests, as well as criminal background checks and applicable child abuse clearances prior to the person being authorized to receive services in the lifesharing home. Home study information also needs to be considered along with information obtained through trial visits and other opportunities for the person and the lifesharer to become acquainted.

The Lifesharer Home Study (Attachment 2) is to be conducted by a qualified professional who may be a Family Living or Lifesharing Specialist with at least two years experience in supervising lifesharing services or with a minimum of 12 hours training in family dynamics, a Qualified Mental Retardation Professional under 42 CFR 483.430 with at least two years of lifesharing experience, or a Child Welfare Professional with at least two years experience in conducting home studies. The home study is not needed for people receiving temporary respite/substitute care in lifesharing homes.

Effective with this Bulletin, the attached four-part Lifesharing Home Study (Attachments 1 – 4) is to be used for all persons considered for lifesharing funded through the ODP. This Lifesharing Home Study is to be included as part of the ISP process and shared with the person's ISP team for purposes of determining the appropriateness of the lifesharing match. The following questions are expected to be affirmatively answered by the ISP team through its review of the home study and any other assessment and compatibility information it receives:

- Does the home study and/or other assessment information indicate that the prospective lifesharer is able and appropriately motivated to provide necessary habilitation and other services for the person, including support in addressing health care and emotional needs, in light of the lifesharer's work, family and other responsibilities?
- Does the home study and other assessment information indicate that all prospective household members and the home environment will be compatible with the person's aspirations, needs, expectations, developmental growth, self-determination, and health and welfare?
- Does the home study and other assessment information indicate that the prospective lifesharer and the person needing services share compatible interests and expectations regarding their life together?

All home studies are confidential and must be handled accordingly. ISP teams, Supports Coordinators, and agency personnel who review home studies are responsible to ensure that access is limited to persons who need to know this information for determining the appropriateness of the lifesharing match. Persons considering a move into the lifesharer's home and their families may confidentially review applicable home study information before deciding on what homes to visit.

An abbreviated home study, Lifesharing Home Study Supplement (Attachment 2A) must be completed whenever a new household member who is not in need of services

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moves into the home and is expected to live in the home for at least 30 calendar days. The attached abbreviated home study is to be used with all new household members effective with the issue date of this bulletin. Homes licensed under Title 55 Pa. Code 6500 providing only respite/substitute care for less than 90 days a year are excluded from this requirement.

When the new household member is a person needing services, the entire Lifesharer Home Study (Attachment 2) must be completed by a qualified home study professional prior to the person moving into the home or within the first 10 calendar days when the new person moves in following a personal emergency or crisis. The supplement is in addition to the required criminal background check and applicable child abuse clearances.

Based on its review of the home study supplement and other pertinent information, the ISP team, that includes the provider agency and supports coordinator, must affirm that the addition of a new person to the household does not negatively affect the quality of services or health and welfare of the person already residing in the home.

#### **Choice of Lifesharers**

People considering lifesharing must have free choice of willing and qualified providers. People should generally have the opportunity to interview more than one potential lifesharer and have the opportunity to visit more than one home before making a lifesharing choice. Exceptions to this include situations where:

- The person and family have selected a friend, coworker or staff person to be their lifesharer and are not interested in considering additional lifesharing and other opportunities at this time, or
- Initial visits to the potential lifesharer indicate that there is an appropriate match and the person is not interested in reviewing other lifesharing home considerations.

#### **Program Supervision**

Each lifesharer must have a Family Living or Lifesharing Specialist supervise the services and supports the person receives. The Family Living or Lifesharing Specialist is responsible to ensure that appropriate supervision is provided for the person receiving services and that the lifesharer is trained and able to carry out their responsibilities.

Due to the differences in supporting lifesharing and other forms of community residential support, such as community homes, ODP recommends that Family Living and Lifesharing Specialists will be assigned to only support lifesharing homes whenever possible. The maximum supervisory ratio of one full-time Specialist to eight lifesharing homes (serving up to 16 persons) that applies to licensed family living homes is the maximum ratio recommended for Lifesharing Specialists supervising lifesharing in unlicensed homes (as per §6350.3(f)(5)). While up to 16 people, regardless of service, can be supervised by one Family Living Specialist, ODP recognizes that lower ratios are justified, especially during a time when agencies are developing new lifesharing services for people.

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The Family Living or Lifesharing Specialist is responsible to ensure that the following safeguards are applied:

- The person receiving services is not left alone unsupervised with a person who is not 18 years of age or older, unless the absence of direct supervision is consistent with the individual's assessment and their ISP.
- The person is attending all in and out-of-home medical and social services appointments.
- The person is attending his/her job, school, or other non-residential programs and activities, including socialization events included in the ISP.
- The lifesharer is fulfilling his/her responsibilities to provide services and receive training, technical assistance, and support.
- The lifesharer and substitute care persons meet provider qualification criteria, including criminal background checks, applicable child abuse clearances, and training; and receive the support they need to carry out services in an effective and efficient manner.
- Additional services that are authorized for the person in the home and community are being provided in accordance with the ISP.
- The Family Living/Lifesharing Specialist is available by telephone should an emergency or need for consultation by the lifesharer or person receiving lifesharing arise.

Supervision of services requires that the Family Living or Lifesharing Specialists visit the home of the lifesharer on a routine and regular basis. The ODP expects the Family Living or Lifesharing Specialist to visit the lifesharing home at least once each calendar month. During these visits, the Family Living or Lifesharing Specialist is expected to discuss home life and services with both the lifesharer and the person receiving services, determine if there are any changes in the occupancy of the home, verify service delivery, and assess satisfaction of the household members with services and home life. Discussions at the lifesharing home can include a private interview with the person receiving services to verify information and ensure that the person is satisfied with services and support.

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:

- The person has been in the home for less than ninety calendar days.
- The Family Living/Lifesharing Specialist has supported the person and lifesharer for less than ninety calendar days.
- The person is not attending outside programs and activities as indicated in their ISP.
- Services are not being provided in accordance with the ISP.
- A reportable incident is being investigated and is not closed.
- The agency is operating with a provisional certificate for licensure or under appeal of a licensing action due, at least in part, to deficiencies found in the lifesharer's home.
- The lifesharer, other household members, or the person receiving services is exhibiting behavior that causes concerns for the person's health and welfare.
- A new person has moved into the home within the last thirty calendar days.

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- The lifesharer or person receiving services is going through a family or personal crisis, illness requiring the person to stay at home, or other life situation that changes lifesharing support responsibilities in the home.
- The lifesharer and the person have relocated to another home within the last thirty calendar days.
- The health and welfare of the person is jeopardized by factors in or out of the home.

In addition to these face to face visits, each Family Living/Lifesharing Specialist is expected to maintain ongoing contact with the lifesharer and person receiving services through telephone, e-mail and other forms of communication. Telephone or e-mail contact is expected to be at least weekly for the first ninety calendar days of a person moving into the lifesharing home and at least once every two weeks thereafter. More frequent contact is expected whenever exceptional conditions, including those indicated above, apply.

As part of this supervisory responsibility, the Family Living/Lifesharing Specialist is expected to approve all providers of substitute care and ensure that each substitute care provider is qualified to provide services for the person. Substitute care shall be disallowed whenever the substitute care constitutes a risk to the health and welfare of the person. The Family Living/Lifesharing Specialist is responsible to report health and welfare concerns to the person's Supports Coordinator and to work with the lifesharer and person receiving services to resolve these concerns. When the health and welfare of the person is in question, the Family Living/Lifesharing Specialist is expected to take appropriate action to resolve the matter, including removal of the person from the home when warranted.

### **Supplemental Support and Services**

While many types of support can be learned and provided by the lifesharer through experience, training and technical assistance, some persons in lifesharing need additional support and specialized services from qualified professionals. For example, a person with severe behavioral episodes may need services from a qualified behavioral specialist. Needed specialized services, such as therapies, are to be provided based on the person's current needs and included as a distinct service in the person's ISP.

Habilitative services that are needed to supplement the lifesharing service and meet the current needs of the person must be provided as part of the lifesharing service. These services must be included in the rate for the lifesharing service. The additional services are billed to the provider agency, who pays claims from the lifesharing rate. These services may not be included on ISPs as distinct services as Residential Habilitation services must be developed in such a way to meet all of the home habilitation needs of the person receiving services.

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**Training and Technical Assistance**

The lifesharing agency is responsible to ensure that the adult family member who will have primary responsibilities for caring and providing services to the person in the lifesharing home receives the following training before the person moves into the home:

- 24 hours of training related to mental retardation, family dynamics, community participation, ISP planning and implementation, relationship building, and the requirements related to their responsibilities.
- Certification training in first aid and Cardio Pulmonary Resuscitation (CPR) life saving techniques by a qualified professional.

Pre-service training is also expected to include information on reportable incidents, abuse and abuse prevention, rights of persons receiving service, stress management, and alternative communications when a person who does not communicate using words will be served. Training can be provided to other household members at the discretion of the provider agency based on care responsibilities the household member may have.

In addition, the agency is responsible to ensure that lifesharers and Family Living/Lifesharing Specialists receive 24 hours of annual training. Part of this annual training will be a refresher on reportable incidents, abuse and abuse prevention, rights of persons receiving service, stress management, relationship development, and alternative communications for persons who do not communicate using words. Refresher courses in first aid, fire safety, and CPR are also expected.

The agency is responsible to ensure that a record of training is available for review by ODP licensing personnel (if applicable) and Supports Coordinators. This responsibility applies to people living in licensed Chapter 6500 Family Living homes as well as unlicensed lifesharing homes. All training requirements for licensed Family Living homes must comply with the Chapter 6500 Family Living regulations. Lifesharing agencies are expected to pay for training provided outside of the lifesharing home, including reimbursement for transportation when applicable.

**Home Areas Subject to Inspection and Monitoring**

Rooms and areas of the home and property where the person receiving services lives are subject to inspection and monitoring by ODP licensing representatives, Supports Coordinators, and agency representatives. Rooms and areas subject to inspection and monitoring include locked and unlocked non-residential buildings on the property, garages, basements, common areas, yards and attic spaces.

Bedrooms of household members can be entered by an ODP licensing representative, other ODP representative, Supports Coordinator, or agency representative when there is a reasonable expectation that a licensing violation exists or there appears to be a hazard in the bedroom area that can affect the person's health and welfare. The lifesharing agency is responsible to ensure that lifesharers are informed of home areas subject to inspection. The lifesharing agency is also encouraged to assign an agency representative to accompany an ODP representative on home visits. Denial of access to any area of the home or property, including household bedrooms, to ensure health and welfare of the person may result in denial or revocation of a license certificate, or restriction of the providers ability to provide services.

### Supports Coordination

Supports Coordinators are responsible to coordinate and monitor services received by persons in lifesharing homes. Supports coordinators must monitor services for waiver participants at the frequency outlined in the current, approved waivers. ODP encourages Supports Coordinators to monitor non-waiver participants at the same frequency.

ODP expects that each Supports Coordinator obtains answers to the following probe questions on their visits to lifesharing homes. The answers to these probe questions must be recorded as a Home Community Services Information System (HCSIS) service note, until the ISP monitoring tool can be modified to include these questions for lifesharing home visits. Upon modification of the ISP monitoring tool, responses to these questions should be documented in the ISP monitoring form in HCSIS rather than a service note.

- Have there been any significant changes in the lifesharing home since the last visit?
- Have any new people moved into the home or are any new people expected to move into the home in the near future? If yes, what affect will new people in the home have on the type, frequency and duration of services and support to the person? Is a home study supplement done or in process?
- Have any incidents occurred which require reporting or follow-up actions, including actions taken in response to a licensing inspection? If so, what is the status of incident review?
- How is the health of the person receiving services, the lifesharer and other household members who may require care and services? Have health changes affected the quality of life and services provided?
- How is the person's and lifesharer's satisfaction with support, services and the quality of their home life and relationships?
- Has the Family Living/Lifesharing Specialist been visiting and making contact on a routine basis in accordance with ODP policy?
- Are services at home being provided in accordance with the ISP?
- Is the person attending programs, social and community activities in accordance with the ISP?
- Is the person and lifesharer satisfied with the person's participation in outside activities and programs?
- Have there been any recent issues or concerns expressed regarding the safety and security of the home or people in the home?

### Heath Care Quality

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Lifesharing agencies have responsibilities to ensure that people in lifesharing receive appropriate health care. Family Living/Lifesharing Specialists, individuals providing lifesharing services and people receiving lifesharing services are encouraged to utilize their area Health Care Quality Units (HCQU's) for training and technical assistance related to the health conditions of people in lifesharing homes.

Training schedules, consultation on medical and behavioral health related challenges, health risk profiles, and lending libraries are generally available on request. For further information on the HCQU services available, agencies should contact their AE HCQU contact person.

**Attachments**

**Home Study Attachments:**

Attachment 1 - Lifesharing Application

Attachment 2 - Lifesharing Home Study

Attachment 2A – Lifesharing Home Study Supplement For New Household Members

Attachment 3 - Individual Profile for Lifesharing

Attachment 4 – Lifesharing Home Study Physical Site Review

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