



MENTAL RETARDATION BULLETIN

COMMONWEALTH OF PENNSYLVANIA

DEPARTMENT OF PUBLIC WELFARE

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SUBJECT:

Lifesharing through Family Living

BY:

A handwritten signature in black ink that reads "Kevin T. Casey".

Kevin T. Casey

Deputy Secretary for Mental Retardation

SCOPE:

County Mental Health/Mental Retardation Administrators
Support Coordination Entity
Non-State ICF/MR Directors
State ICF/MR Directors
Community Home Directors
Family Living Directors

PURPOSE:

The purpose of this bulletin is to provide policy so that Lifesharing opportunities are expanded in Pennsylvania.

BACKGROUND:

This bulletin has been developed in collaboration with the Lifesharing Subcommittee of the Office of Mental Retardation Planning Advisory Committee (OMR-PAC). The Lifesharing Subcommittee can be a good source of information and support for agencies interested in providing Lifesharing services. The subcommittee has been meeting since 1988 as a network of individuals, family members, providers, OMR staff, County MR Staff and Support Coordination staff who are invested in making a difference through Lifesharing. For further information, see the Lifesharing website www.pennsylvanialifesharing.org

Lifesharing means *living with and sharing life experiences with supportive persons who form a caring household*. Lifesharing is recognizable as being both a close personal relationship and a place to live.

Individuals supported in Lifesharing include children and adults with a wide variety of needs and challenges. Lifesharing enhances and enriches the lives of individuals by

offering an alternative to traditional residential living such as Intermediate Care Facilities for the Mentally Retarded (ICF/MR) or Community Homes.

Lifesharing can be provided in a number of ways within Pennsylvania's community mental retardation (MR) program. Lifesharing through Family Living is provided in homes licensed in accordance with regulations established in 55 PA Code Chapter 6500, which limit services to a maximum of two people. Unlicensed Lifesharing is offered in homes providing room and board for one or two people needing services, who are 18 years of age or older, and need a yearly average of 30 hours or less direct training and assistance per week in the home.

Lifesharing can be funded through the consolidated waiver or the county's base allocations. Lifesharing services can also be provided through private funds.

DISCUSSION:

The Department supports and encourages expansion in the use of Lifesharing based on the quality and cost effectiveness of support provided in these types of living arrangements.

County MH/MR Funding Requirements:

The cost of Lifesharing through Family Living depends on the level of support an individual needs, as developed through the Individual Support Planning (ISP) process. Lifesharing provided in a licensed Lifesharing home is funded under the family living procedure codes specified in MR Bulletin 00-03-12. Unlicensed lifesharing would use applicable habilitation procedure codes, W7057 through W7061, and all other appropriate codes related to the services specified in the person's ISP.

Agencies that support a Lifesharing program must have adequate funding for both start-up and ongoing costs, including payment to the lifesharing family to cover the cost of each individual's services, room and board, and training as well as related expenses by the family or single person. Payment to the Lifesharing family is non-taxable under the Job Creation and Worker Assistance Act of 2002, H.R. 309, Section 404, pursuant to MR Bulletin 00-02-10.

County funding of Lifesharing agencies needs to include start up costs which can be utilized to:

- Organize and maintain the agency's Lifesharing program and practices.
- Encourage the development of relationships between individuals, supports coordinators, providers of service, family and friends of individuals, and Lifesharing families.
- Recruit families.
- Conduct home studies.

- Develop respite options.
- Introduce and match individuals to life sharing families.
- Support agency administration based on reasonable costs allowed under the Fiscal Manual for the County MH/MR Program, 55 Pa. Code CH. 4300.
- Allow for payment to the prospective Lifesharing family to cover costs of initial visits and training.
- Comply with regulatory waiver and accessibility requirements, including home and vehicular modifications.

The above list of start up costs pinpoints some major areas; however, it is not comprehensive and it also includes some areas that are ongoing costs which should be recognized as such. Payment for initial visits is optional and should be decided upon by individual providers.

In order to make a successful match, three to six months start up funding is needed to facilitate the development of relationships and place a person in the county where they want to live. Established agencies are those which have a Lifesharing program in place with prospective Lifesharing families to match with the individual. In an established area, agency personnel will be aware of community supports such as transportation, day programs and medical facilities. Nine to twelve months start up funding should be anticipated when counties or agencies are not already established. Agencies which will begin to provide Lifesharing in a county will need additional time to familiarize themselves and establish connections and resources.

Ongoing payment of Lifesharing through Family Living must cover the costs for:

- Lifesharing Coordinator functions including regular visits and contact with the Lifesharing home, training and communication with outside agencies and supports coordinators.
- Lifesharing agency administration costs pursuant to 55 Pa. Code CH. 4300, the Fiscal Manual for the County MH/MR Program.
- Services provided by the Lifesharing family, including transportation and participation in community resources and activities.
- Other services needed by the individual at home, including specialized therapies and visiting nurse which are based upon the individual's needs. Generally these costs are covered by the individual's Medical Assistance (MA) benefits, but can be provided under the Home and Community Based Service (HCBS) waiver when MA funding is denied under the appropriate procedure code as specified by OMR Bulletin 00-04-10.
- Temporary respite care not to exceed 31 days for an individual in a calendar year (per 55 Pa. Code CH. 6500.4).
- Emergency respite services costs which will vary based on the health and circumstances of Lifesharing individuals and families.

- Attendance for Coordinators, Lifesharing staff and family at Lifesharing trainings and gatherings, including Regional & State Lifesharing Committee meetings.

County Planning and Supports Coordination:

Per OMR's Fiscal Year 2005-2006, Stage II of the *County Plan & Budget Guidelines* counties should provide detailed descriptions of their plans to serve additional individuals, through Lifesharing/Family Living opportunities, if additional funds were made available to them. Counties wishing to submit a proposal for possible additional funds should focus on Lifesharing/Family Living.

Additionally, all counties are asked to develop a strategic plan to expand Lifesharing beginning in Fiscal Year 2005-2006. The strategic plan should be developed in conjunction with existing and potential providers, individuals and families. Expansion planning should be in the context of the County's quality management framework that focuses on improving outcomes of individuals living with whom and where they want to live. Regional staff will be assigned to support this effort. The strategic plan for Lifesharing is expected to ensure that:

- Individuals and their families are informed of the benefits and have the opportunity to choose Lifesharing when they apply for out-of-home residential services, including individuals who are exiting the school system and/or Early Periodic Screening, Diagnosis and Treatment (EPSDT), and individuals who need mental health supports and services.
- Individuals in residential services and their families are informed of the benefits and have an opportunity to choose Lifesharing during the individual's annual plan review.
- Supports coordinators receive training and technical assistance on how Lifesharing is provided.
- Individuals and their families have choice of the provider agency and Lifesharing family or companion.
- Interested County and support coordination staff are supported and encouraged to participate in State Lifesharing Subcommittee meetings, training and regional gatherings.
- Information on Lifesharing is shared at agency, county and regional events such as conferences and provider fairs, family conferences and media opportunities such as newspaper articles, TV ads, radio spots and websites.
- Information, including this bulletin, is shared with self-advocates, birth families, Lifesharing families and companions.

Residential Agency Requirements:

County MH/MR Programs are encouraged to support residential agencies in their development of Lifesharing opportunities, policies and practices. These policies and practices should ensure that each residential agency:

- Considers and includes expansion of Lifesharing as part of their strategic planning in collaboration with individuals, families and the County MH/MR Office.
- When possible, designates residential program coordinators for Lifesharing.
- Has an agreement in place with Lifesharing families and companions for the provision of services and support, including formalized grievance procedures.
- Adopts promising practices that lead to improved satisfaction and outcomes including but not limited to:
 - On-call supports in the event of emergency or crisis.
 - Ongoing relevant training to better enable Lifesharing families to fulfill their roles and responsibilities as effectively as possible.
 - Support services brought into the home to assist the family and single person based on the ISP.
 - Mechanisms to review individual satisfaction and outcome data and information for quality improvement purposes.

OBSOLETE BULLETINS:

- MR Bulletin #99-87-04 entitled “Information on Changes in the Federal Tax Code Affecting Taxation of Payments Made to Family Living Providers”.
- MR Bulletin #00-90-15 entitled “Family Living Guidelines”.