



Shared Living: A New Take on an Old Idea

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SHARED LIVING

Systems are Changing. Economic and demographic forces are pressuring state service systems to look toward alternative, more sustainable ways to support people in need. The confluence of workforce shortages, the recent recession, growing waiting lists and the increasing costs of shift-staff residential programs are leading states to seek equally effective, less costly support alternatives. Emphasis on building the capacity of families to support their family member with disabilities, as alternatives to traditional 24/7 shift-staff residential programs, are key to states' ability to expand services, particularly to those who are on waiting lists. In order to meet growing demand—and assure sustainable, effective and cost-effective programs—states are turning to shared living.

What is Shared Living? Shared living is an arrangement in which an individual, a couple or a family in the community and a person with a disability *choose* to live together and share life's experiences. The approach is based on a mutual relationship where both parties agree to share their lives. Other terms that encompass the shared living approach include mentor, host family or family home, foster care or family care, supported living, paid roommate, housemate and life sharing. The approach is designed to enable people with support needs to experience a real community life; one that is not controlled by the formal service delivery system.

What Shared Living is *Not*. Shared living does not refer to a place, nor a "facility," or a group home. It is neither traditional foster care, nor a bed in a boarding home or a small "setting" serving three or four individuals. Shared living is not a "residential program" or a supported program with multiple staff working in shifts, and is not a "model" of service or a program to fix people.¹ Shared living is not for everyone, it must be freely chosen and structured to afford the person receiving support the life and life-situation that matches and meets his or her needs. It is one option among many but the flexibility necessary to support individuals with wide arrays of needs.

WHAT MAKES SHARED LIVING WORK?

Commitment and Leadership. For the concept of life sharing to be a viable alternative that endures over time, the state Developmental Disabilities (DD) agency must first make an affirmative

¹ "Creating Innovative, Individualized Living Options For Persons with Developmental Disabilities: It's not about a model; it's about an approach", New York State Association of Community and Residential Agencies, Prepared for: New York State Developmental Disabilities Planning Council, December 2009.



commitment to promoting and supporting shared living. This can be accomplished through the use of specific service definitions and attractive payment rates, reworking rules to increase operational flexibility, and by developing strategies for enhancing opportunities for shared living throughout the state's DD service delivery system. It is important that shared living not be viewed as a "rebranding" of old models of family or foster care, but rather as an innovative approach designed to support people to be independent and self-determined in person-centered ways.

The Match. As Pennsylvania notes in its shared living bulletin, "The success of shared living rests on the thoughtful and careful process of introducing people to each other and assuring the relationships work." The Pennsylvania bulletin emphasizes the importance of the match between the individual with disabilities and the family, or person he or she lives with and the fact that life sharing arrangements can take time to develop, "In order to make a successful match, three to six months start-up funding is needed to facilitate the development of relationships..."² Pennsylvania reports that the length of relationships is remarkably stable, particularly when compared to staff turnover rates in other residential settings. Of the 842 individuals in shared living, for example, 262 individuals remained in the same setting for 5 years, 126 lived together for 10 years, and 75 persons with disabilities stayed with their "host" families for 15 years.³

Support. An essential component of shared living is the nature of the support furnished to the shared living provider. States with effective programs typically offer a variety of training resources, information and assistance that enables the provider to focus on the person they are supporting. This includes ensuring the availability of other professionals as well as access to consultation, respite and emergency services if needed. State DD agencies can assure this support for the shared living provider by contracting with another entity, such as a provider, county, or contracted regional administering authority to assist with consultation, supervision, training, and paperwork. **Pennsylvania**, for example, has developed a shared living provider network to enable providers to meet and talk with each other, sharing experiences and solving issues.⁴ In Massachusetts, the managing agencies provide access to consultation from a Behavioral Clinician, a nurse, as well as to crisis, emergency and safety management supports. Georgia offers up to 30 days of "alternate care" to the shared living provider to allow the shared living provider time off.

Making a House a Home. The primary responsibility of a shared living provider is to make a real home where the person providing supports and the individual have a mutually satisfying and meaningful relationship: a home that really feels like a home to everyone. This is particularly important when an individual moves into the existing home of the person providing supports. In true shared living, the individual being supported is not just moving into a room in someone else's house, he or she is agreeing to enter into a personal relationship that can be expected to endure over time. Providers have to be able to assist the individual integrate into the home setting and to be willing to change themselves to adjust to the needs of the person being supported. The provider additionally

² "Life sharing through Family Living", MENTAL RETARDATION BULLETIN, COMMONWEALTH OF PENNSYLVANIA • DEPARTMENT OF PUBLIC WELFARE, NUMBER 00-05-04, DATE OF ISSUE August 8, 2005

³ Pennsylvania Office of Developmental Programs, "FY 2008-09 Lifesharing Through Family Living Directory Lifesharing Agency Survey Results", PowerPoint Presentation, p. 5.

⁴ The Pennsylvania Lifesharing Committee brochure can be found at:

<http://www.temple.edu/thetrainingpartnership/resources/lifesharing/docs/LifesharingBrochure11-09-2009.doc>



commits to assure that the person receives adequate health and medical care, is safe and free from harm and has the support that he or she needs to take risks and to work and participate in community activities.

Most state DD agencies administer shared living arrangements through regional offices or another entity such as a county, regional center or an individual provider agency. Some states, however, manage the program directly.⁵ Typically the administering authority recruits and screens shared living applicants, “matches” the individual with the home provider, oversees the shared living provider, offers consultation services, arranges for support and respite care, furnishes training, and performs other functions such as billing. **Vermont**, for example, contracts with private, non-profit organizations, “Designated Agencies” or “Specialized Services Agencies,” that provide or arrange for developmental disability services.⁶ These agencies subcontract directly with the shared living providers for services. As subcontractors, the providers are not employees of the agency. The designated agency provides information, opportunities for training, support and oversight, as well as monitoring the providers’ performance and the individual’s well-being. Rhode Island’s Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH) designates “Authorized Placement Agencies for Shared Living Arrangements.” These entities manage and contract with shared living providers, recruit and match families with individuals, furnish training and on-going support to providers and submit payment invoices. In **Massachusetts**, the Department of Developmental Services (DDS) Area Offices contract with provider agencies to ensure all aspects of the shared living service take place including, recruiting, screening, matching, training and ongoing case management/monitoring. The Area Offices are reimbursed for activities including matching, training and follow-along in the service payment rate.

Paying for Shared Living Services. Shared living is not a specific support “model,” but rather an “approach” that can take many forms. Not every shared living arrangement requires compensation to the individuals providing support. Many people freely choose to share their lives without compensation although, typically, the individual(s) providing support receive some type of compensation. There are a variety of ways to finance shared living—from paying a “live-in” care giver to using a traditional licensed host home or foster home model. Most states finance shared living with Medicaid funds under the Section 1915(c) Home and Community-Based Services (HCBS) waiver program. Other funding sources include services covered under the Medicaid State Plan and new HCBS options including Medicaid State Plan services offered through Sections 1915(i) and 1915(k) Community First Choice which covers personal care-type services.⁷ These options allow shared living to be funded in different ways as companion services, live-in-caregiver payment, personal care, residential supports (sometimes known as residential habilitation), foster care, or host homes. States also can define their own shared living service under these programs. Typically, states use the host

⁵ Unlike some group homes in a few states, no Shared Living arrangements for adults, to our knowledge, are directly operated using state employees.

⁶ These agencies are also responsible for managing and overseeing other services as well.

⁷ Information on 1915(i) can be found at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html>. Information on 1915(k) can be found at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Community-First-Choice-1915-k.html>



home or adult foster home approach to providing shared living⁸ with the individual moving into the home of the person providing support. This approach can enable the home provider to take advantage of financial incentives under provisions in the federal income tax code that permit qualified foster care payments to be excluded from the provider's calculation of gross income for tax purposes.⁹ The provision offers a considerable benefit to states interested in expanding this option.

Although, no national studies appear to have directly compared the costs of shared living for individuals with I/DD against those of other residential options such as group homes with staff available 24 hours per day, 7 days per week, published reports of the costs of different residential options do highlight differences. A 2006 University of Minnesota study, for example, reported that "Persons living in host family or companion arrangements had average social support and medical expenditures (\$44,112) that were 71.4% of the average costs for all HCBS recipients and 34.4% of the average for ICF/MR residents."¹⁰

MANAGING QUALITY IN SHARED LIVING

Assuring the quality and outcomes for people with disabilities in shared living has many components:

Provider Qualifications. The most basic element in assuring support quality and responsiveness is the presence of providers with the skills, attitudes and abilities necessary to deliver shared living supports.

- Some states require that a shared living provider obtain specific licensing, for example, as a foster care home, while others have certification standards but do not require licensing.
- Maine's application is clear, "In order to be considered as an independent contractor to provide services, it will be necessary to answer some very personal questions regarding yourself and members of your household."¹¹
- Georgia's Support Coordination Agency inspects the home using the approved State Division of Developmental Disabilities Site Inspection tool prior to an individual with developmental disability living or receiving care in the home. The home study assesses the physical characteristics of the home as well as the provider's family dynamics, past experience and expectations. The home study gathers information on the provider's motivation and attitudes towards people with disabilities across a range of topical areas including dating and information on how other family members might react to an individual with disabilities.

⁸ For a detailed review at these options see, Cooper, R., "Shared Living Guide", NASDDDS, June, 2011, pp.38-46.

⁹ H.R. 3090 [107th]: Job Creation and Worker Assistance Act of 2002, SEC. 404. EXCLUSION FOR FOSTER CARE PAYMENTS TO APPLY TO PAYMENTS BY QUALIFIED PLACEMENT AGENCIES. a. (1)(A)

¹⁰ "Medicaid Home and Community-Based Services for Persons with Intellectual and Developmental Disabilities: Background and Findings from Consumer Interviews and the Medicaid Statistical Information Systems, Final Report", Prepared for: Centers for Medicare & Medicaid Services Submitted by: The University of Minnesota Research and Training Center on Community Living, September, 2006, p. vii.

¹¹ "Shared Living Handbook", Maine Office of Adults with Cognitive and Physical Disability Services, Effective October 1, 2010, p.3.

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- Pennsylvania uses an application that seeks information about the physical aspects of the home, the neighborhood, and the background and experience of the potential life sharing provider and their family (if applicable). Pennsylvania, like most states, also requires references and criminal background checks as a routine part of the application. Once an application is accepted, the state performs an actual on-site home study that reviews critical safety issues, comfort and neighborhood characteristics.

Robust person-centered planning: Person-centered planning has been a part of DD service system expectations since the early 1980's. Currently, most systems engage in one or another form of person-centered planning. Done correctly, person-centered planning is a commitment to much more than the planning process, it is a way of doing business throughout the system. The recent experiences of six states that embarked on a journey to person-centered systems is instructive (see the pieces cited in the footnote)—and can guide states through their person-centered planning efforts.¹² A companion to person-centered planning is self-advocacy training and participation in self-advocacy groups, empowering and providing people with the skill to speak for themselves. Making sure the voice of the individual is being heard clearly *and acted upon* is critical to the quality and outcomes of shared living.

Competent, well-resourced case management. The role of the case manager is important to assuring quality services and outcomes while minimizing risk. Frequent and casual communication with the consumer as well as the shared living provider increases trust and openness. The consumer and the shared living provider must each know that they can tell the coordinator or case manager if there are problems and if they need assistance.

CONCLUSION

Shared living offers an alternative approach to supporting individuals with I/DD. It is not a specific model of service, but an approach to creating individualized, customized living situations, based on relationships. Shared living presupposes that people choose to live together, mutually exploring and agreeing upon how they wish to share their lives. With careful attention to matching individuals and good supports to providers, shared living can be a successful alternative to “traditional” residential services.

¹² See, Michael W. Smull, Mary Lou Bourne, and Helen Sanderson, “*Becoming a Person Centered System-A Brief Overview*”, 2009 and, “*Best Practice, Expected Practice, and the Challenge of Scale*”, April 2010, found at: http://www.nasddds.org/Publications/special_pubs.shtml



SELECTED RESOURCES

State Materials

GEORGIA

Georgia Department of Behavioral Health and Developmental Disabilities, “*Host /Life-Sharing Home Guidelines*,” found at

http://mhddad.dhr.georgia.gov/DHR-MHDDAD/DHR-MHDDAD_CommonFiles/Host%20LifeSharing%20Home%20Guildelines.pdf

MAINE

Maine Office of Adults with Cognitive and Physical Disability Services “*Shared Living Handbook*,” Effective October 1, 2010, found at

http://www.maine.gov/dhhs/OACPDS/DS/protocol-guidelines/shared_living.html

NEW YORK

New York: “*Creating Innovative, Individualized Living Options For Persons with Developmental Disabilities: It’s not about a model, it’s about an approach*,” New York State Association of Community and Residential Agencies, Prepared for: New York State Developmental Disabilities Planning Council, December, 2009.

PENNSYLVANIA

Pennsylvania Office of Developmental Programs, “*FY 2008-09 Lifesharing Through Family Living Directory Lifesharing Agency Survey Results*,” PowerPoint Presentation, found at

http://odpsrv.tiu11.org/alfresco/d/d/workspace/SpacesStore/dd889686-076a-4c40-9554-92ac2fed35c3/Lifesharing_Agency_Survey_Results_2008-2009.pdf

RHODE ISLAND

Rhode Island’s description of shared living found at
<http://www.mhrh.state.ri.us/about/pdf/sharedLiving.pdf>

“*Standards for Authorized Placement Agencies for Shared Living Arrangements*,” State of Rhode Island, Department of Mental Health, Retardation and Hospitals, Division of Developmental Disabilities, August 23, 2007, found at <http://www.bhddh.ri.gov/ddd/pdf/SLAFinalAugust2307.pdf>

VERMONT

Vermont Division of Disability and Aging Services, Department of Disability, Aging and Independent Living “*Shared Living in Vermont: Individualized Home Supports for People with Developmental Disabilities*,” 2010, found at

<http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/dd-publications-other/shared-living-individual-home-supports>



Other Resources

CMS, “*Application for a §1915(c) Home and Community-Based Waiver [Version 3.5], Instructions, Technical Guide and Review Criteria*,” Release Date, January, 2008, found at <http://www.hcbswaivers.net>.

Cooper, Robin, “*Caring Families, Families Giving Care: Using Medicaid to Pay Relatives Providing Support to Family Members with Disabilities*,” NASDDDS, Inc. June 2010, found at http://www.nasddds.org/Publications/special_pubs.shtml

Lakin, K. Charlie, “*Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009*,” University of Minnesota, 2010, found at <http://rtc.umn.edu/docs/risp2009.pdf>

Mollica, Robert, et al., “*Building Adult Foster Care: What States Can Do*,” AARP Public Policy Institute, September, 2009, p. 35. Full document found at http://assets.aarp.org/rgcenter/ppi/ltc/2009_13_building_adult_foster_care.pdf

O’Brien, John and O’Brien, Connie Lyle, “*Assistance with Integrity: The Search for Accountability and the lives of People with Developmental Disabilities*,” Responsive System Associates, 1993 found at <http://www.eric.ed.gov/PDFS/ED369219.pdf>

Smull, Michael W., Bourne, Mary Lou, and Sanderson, Helen “*Becoming a Person Centered System-A Brief Overview*,” (April 2009), <http://www.nasddds.org/pdf/BecomingaPersonCenteredSystem-ABriefOverview.pdf> and, “*Best Practice, Expected Practice, and the Challenge of Scale*,” (April 2010), <http://www.nasddds.org/pdf/BestPractice&ExpectedPractice.pdf>

Smull, Michael, PowerPoint Presentation: “*Becoming a Person Centered Organization*” found at <http://www.unc.edu/depts/ddti/powerpoint/ot10-05.ppt>