



Issue Brief

Respite Care

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Introduction

Proposals submitted to the Missouri Foundation for Health (MFH) have requested funding for respite care services either as an auxiliary component of the application or as a complete program. At the October 7, 2003 peer review staff meeting, a discussion arose concerning the need for, and benefits of, respite care services in Missouri. At the request of the MFH Program Group, the MFH Policy Group has produced this issue brief on respite care to broaden the knowledge base of both the MFH staff and the Program and Grants and Project Review Committees (PGC/PRC).

The MFH Policy Group has examined the subject and offers this document which includes:

- Definitions, background information and statistics relating to respite care
- Key elements for successful programming and
- Examples of model programs.

Overview

Respite care can be defined as a service that “provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs, or who may be at risk of abuse or neglect.”¹ Those who receive respite services include: children with cerebral palsy or muscular dystrophy, adults with brain injuries, individuals suffering from Parkinson’s or Alzheimer’s disease and persons afflicted with AIDS. Caregiver respite has two primary purposes: 1) to decrease caregiver stress and 2) to delay or eliminate the need for the institutionalization of, or foster care services for, the person receiving care. The core principles connected with this type of assistance include support and preservation of caregiving or family relationships.²

Respite services can typically be split into one of two categories: 1) short-term or regularly planned episodes that permit caregivers to perform routine errands and/or take time out from caregiving or 2) infrequent or longer periods of time that give caregivers the opportunity to go on vacation or attend to a family crisis.³ Additionally, the setting for a respite care program can vary from a family's home to a residential facility to a senior day center to a children's crisis nursery.

The term informal or family caregiver refers to any unpaid individual that provides care including:

- **Parents**
- **Neighbors**
- **Grandparents**
- **Friends**
- **Spouses/Partners**
- **Siblings**

Informal Caregiver Statistics

A survey conducted by the National Family Caregivers Association in 2000 showed that 26.6% of the adult population had cared for a chronically ill, disabled or aged individual.⁴ This means that more than 50 million people a year act as informal caregivers to a family member or friend. Of these individuals, parents represent the largest group (38%), followed by non-related persons (24%), then other relatives (20%), spouses (11%) and children (7%).⁵

While many caretakers report a dedication to attending to a loved one, they also experience financial, emotional and physical health problems as a result of caregiving. A recent study found that in comparison to the general population 27% of caregivers reported having more headaches, 24% described stomach disorders, 41% expressed additional back pain, 51% more sleeplessness and 61% reported depressive symptoms.⁶ High levels of depression among caregivers stand as a significant concern because depression has been cited as a key risk factor for chronic conditions such as coronary heart disease, cancer and diabetes.⁷ The effect of these health concerns is evident in that elderly caregivers who report stress due to caregiving have a 63% higher mortality rate than their non-caregiving peers.⁸

The hours spent as a caregiver combined with the physical and mental health effects of caregiving results in a huge financial burden for these individuals. Nearly two-thirds of caretakers participate in the workforce. Estimates reveal that U.S. businesses lose

“If institutionalization of individuals with Alzheimer’s disease could be delayed even one month, it would mean a savings of \$1.2 billion annually.”¹¹

between \$11 billion and \$29 billion per year because of caregiving responsibilities and increased caregiver health concerns.⁹ Additionally, the stress, burnout and depression associated with caregiving results in earlier institutionalization for many care recipients. Research has clearly shown that home care costs significantly less than care in long-term care facilities (i.e. nursing homes, residential care, etc.).¹⁰

Benefits of Respite Care Services

Respite care alone can not effectively address all of the needs of caregivers. As discussed above, considerable diversity exists among the population receiving care, as well as among the caregivers themselves. No single type of program can adequately fit the various caregiving situations. However, respite care does offer an array of benefits for both the caregiver and the care recipient. When surveyed, caregivers name respite as their highest priority need among auxiliary services.¹²

In general, studies show that respite care benefits the caregiver by decreasing emotional and physical stress, by increasing quality of life and by postponing the costly and painful decision to utilize a long term care facility.¹³

Respite services also benefit care recipients by:

- preventing abuse or neglect,
- delaying or averting institutionalization (the vast majority of care recipients prefer to remain in their home) and
- providing opportunities to build new relationships and feel a sense of independence.¹⁴

Furthermore, avoiding early institutionalization saves taxpayers money (i.e. 58% of nursing home costs are picked up by the publicly funded programs of Medicare and Medicaid).¹⁵ Respite care not only saves money, but it provides a break for caregivers to tend to their own needs and come back healthy and reenergized.

A 1999 study estimated that the national economic worth of informal caregiving for ill or disabled adults was \$196 billion in 1997. This figure would currently exceed \$200 billion.¹⁶

Philosophical Debate on Respite Services

The issue of respite services covers an extremely diverse target population, and includes an assortment of agencies that provides care to these clients. Therefore, debate exists on how these services should be structured on a systemic level. Current legislation under consideration at the federal level, the Lifespan Respite Care Act, would create “coordinated systems of accessible, community-based respite care services for all caregivers of individuals regardless of the individual’s age, race, ethnicity or special need.”¹⁷ This type of system has been enacted in several states, one of which will be detailed later in this paper.

Having coordinated respite care services for all populations creates a seamless structure that prevents individual groups from falling through the cracks of a fractured system. However, respite care is only one of many auxiliary services that works to support informal or family caregivers. Some believe that instead of building a system of comprehensive respite care, that the construction of a system of ancillary services (e.g. transportation, case management, respite, meal delivery, etc.) focused on a specific target population would be more reasonable. This type of coordinated system would link all of the needs for that target population and offer a less complicated transition between home-care and placement in a long-term care setting. To date, Missouri has not coordinated its respite services into a broad system of care.

Key Components for Effective Programming

Although Missouri has not developed a comprehensive structure for respite care services, the inclusion of certain elements in existing programs could contribute to future coordination efforts. The following describes essential elements of a successful respite care program.

1) Family-Centered Framework

Respite care allows informal caregivers a “mental” break from the stress and responsibilities of caregiving. Research shows that physical separation from a care recipient does not automatically equate to respite if a caregiver continues to worry about the level of care received by their loved one.¹⁸ Providers of respite should proactively

involve the caregiver and care recipient in as many aspects of the respite process as possible. Often formal (professional) caregivers feel that they know the needs of the client better than the family caregiver. However, the respite provider should not only respect, but utilize the intimate and in-depth knowledge that the care recipient and informal caregiver bring to the given situation.¹⁹

2) Flexibility and Accessibility

A recent literature review found that the top concerns of in-home respite care users revolved around scheduling complications (e.g. too few hours, not enough providers or inconvenient hours of service).²⁰ This concern illustrates the need for respite care programs to respond to caregiver needs in terms of scheduling and hours of assistance. Most of the time families who access respite care can plan ahead for when they will require services. However, respite care must be easily accessible for an informal caregiver during a crisis situation. If a family can not access services at these vital times the consequences could include abuse, neglect or early institutionalization of the care receiver, and increased caregiver illness, stress or lost wages.²¹

3) Broad Array of Respite Options

An essential component of a respite program involves offering a wide range of options in order to support the diverse needs of the target population. Respite projects should ideally include choices for care both in the home (i.e.: home health aides, volunteer companions, nurses, etc.) and out of the home (i.e.: nursing facilities, social or medical day services, residential homes, etc). Although it may be difficult for a smaller agency to provide both types of services, organizations within a community can collaborate to create an array of easily accessible options for informal caregivers.²²

Studying Respite Care

A 2002 study of HIV-positive individuals found that a client engaged in ancillary services such as respite care is more likely to be engaged in, and continue to receive, primary care services.²³

4) Cultural Competence

In the last ten years participants in the U.S. health care system have become acutely aware of the need for culturally competent services. Currently, “over 300 different languages are spoken in the U.S., and nearly 47 million people (almost 18 percent of the nation’s population) speak a language other than English at home.”²⁴ The health consequences of language and cultural barriers include: decreased health access, poor patient understanding, low client satisfaction, diminished quality of care and increased health costs.²⁵ Respite care providers must train workers (whether paid or volunteer) in order to offer culturally appropriate services to all members of the target population in their community.²⁶

5) Outreach/Consumer Awareness

A respite care program should contain a strategy for conducting outreach to its target population to increase awareness of community services. In many instances, individuals most in need of respite care may be unaware of the existence of local programs. Respite services delay the institutionalization of care recipients more effectively if a caregiver accesses this type of assistance at an earlier stage of disease or disability. Additionally, consumers must have prior knowledge of available respite services in order to effectively utilize them during a crisis situation.²⁷

Outreach Strategy

Example components of consumer awareness:

- Community Presentations
- Health Fairs
- Radio Spots
- Websites
- Brochures/Posters
- Hotlines
- Newspaper Ads

6) Training and Support for Caregivers

Organizations can enhance the respite care experience by offering workshops and instruction to informal caregivers to increase their caregiving skills or update their knowledge of specific diseases or disabilities.²⁸ Furthermore, linking respite services with counseling is very valuable because caregivers often experience stress or guilt when placing a loved one in another’s care. This strain on the relationship between caregiver and care recipient can actually counteract the positive benefits of respite care. Support services such as counseling can not only reduce the anxiety and tension associated with utilizing respite, but can also assure positive outcomes for both the caregiver and care receiver.²⁹

7) Eligibility for Middle and Low-Income Families

Many of the funding streams for respite programs revolve around income eligibility requirements. While vitally important to serve those with low incomes, many middle income families may not qualify for assistance, yet can not afford to pay for respite care out of pocket (i.e. if they are uninsured or if their private insurance does not cover the service). Assuring access to respite services for middle income families through the use of options such as sliding fee scales creates an equitable system of care.³⁰

8) Quality Improvement and Evaluation

Agencies that provide respite care services should build mechanisms into the program that work to enhance the quality of care. A systematic evaluation plan will not only measure program objectives and supply outcomes, but will also account for feedback from the actual consumers. Involving clients in the organization's efforts to improve services supports a family-centered framework and drives progress within the program.³¹

Incorporating Feedback

Possible ways to obtain consumer input:

- Surveys
- Focus Groups
- One-on-One Interviews
- Planning Teams
- Client Representation on Board or Committees

Respite Care Programs

As mentioned earlier, a diverse group of individuals comprises the target population for respite care services. Many programs that provide respite serve a particular subgroup such as older adults or children at risk of abuse or neglect. Although a comprehensive system that ties together agencies and resources that provide respite would be ideal, the individual agencies serving a specified population can still work to incorporate many of the eight essential elements discussed above.

The following examples illustrate both a comprehensive state program that links respite services within a community and two model programs that serve specific target populations. Although differing in their approaches, all three represent cases that combine many of the crucial components that result in effective programming. At the end of each example, a bulleted list ties the program back to the eight essential components for effective programming.

Oregon Lifespan Respite Program

In 1997 Oregon became the first state to create a Lifespan Respite Care Program, which now exists in three other states. This approach has been introduced on the federal level as the Respite Care Act of 2003. Traditionally, respite care in Oregon and throughout the nation has consisted of unaffiliated agencies that serve targeted populations, each with their own eligibility criteria. Often families find these decentralized services difficult to navigate.³²

The Oregon Lifespan Respite System establishes “access networks that serve all families and individuals regardless of age, income, race, ethnicity, special need or situation.”³³ These local networks serve as a central point of coordination for individuals seeking respite care resources and information. The community-based networks:

- “Maintain a database of trained in-home providers, volunteers and facilities that provide respite services;
- Help connect families to services and payment options;
- Give information on provider’s skill levels and backgrounds
- Provide referrals and related services and
- Identify gaps (for certain populations) in services available in communities.”³⁴

To create consumer control, leadership councils comprised of at least 51 percent caregivers run each local network. The partners of the community networks include caregivers, providers, federal and state government agencies, faith-based and non-profit organizations and Native American tribes, as well as others. These community level systems each received start-up funds in the amount of \$15,000 from the state. In the period 2001-2003 the state has budgeted \$30,000 to \$50,000 per group for biannual ongoing operating costs. Funds from the Oregon state government also go towards technical assistance and resource coordination. Many of the networks also supplement funding through donations, agency contracts and solicitation of grants.³⁵

A 2001 survey listed the Oregon Lifespan Respite Program as one of the top five model respite care programs in the nation.³⁶ This comprehensive system meets all of the key factors that lead to a successful respite care program.

- The establishment of a **family-centered framework** stemming from consumer controlled leadership councils and a comprehensive, easily navigated, system of care.
- The construction of a local network for caregivers to contact, regardless of their need, offers both **flexibility and accessibility** of services.
- The development of a community-based respite care database means a **broad array of respite options** for caregivers to access.
- Oregon requires that network providers “be sensitive to the unique needs, strengths and multicultural values (**cultural competence**) of an individual, family or caregiver.”³⁷
- The Lifespan program provides **outreach/consumer awareness** (listed as a guiding principle) through such things as media articles and community presentations.
- Another guiding principle calls for the network to coordinate community respite and health related workshops in order to **train and support caregivers**.
- Lifespan offers respite services to individuals **regardless of income**.
- Key **evaluation** outcomes drive the Oregon program, including working to **improve the quality** of services through gathering and compiling data and collecting customer satisfaction surveys.³⁸

The Oregon Lifespan Respite Program presents an example of a model system of coordinated and comprehensive respite services. The structure builds upon existing community resources and provider organizations. Furthermore, the locally based networks decrease the fragmentation of services while also working to fill identified gaps.

Respite Care—Older Volunteer Service Bank

The Older Volunteer Service Bank (OVSB) administered out of the Missouri Department of Health and Senior Services (DHSS) provides in-home respite through the use of volunteers. These volunteers benefit not only from filling an important role in the community, but also by earning “credit” for each hour served. These “credits” can later be accessed for respite services by the volunteer, their families or a designated individual.³⁹

DHSS locates community agencies willing to locally sponsor the OVSB program. These agencies recruit, train and assign volunteers to informal caregivers that request respite services. Volunteers can provide up to six consecutive hours of respite for the caregivers of dependent older or disabled adults. The staff of DHSS’s Division of Senior Services maintains a computerized registry that tracks the hours of respite provided and used by each volunteer.⁴¹

Examples of Local Sponsoring Agencies for the OVSB Program⁴⁰

- Hospice Programs
- Senior Centers
- Area Agencies on Aging
- Home Health Providers
- Hospital Auxiliaries
- Churches & Civic Groups

Current literature on the topic of respite care refers to the Missouri OVSB as an innovative model program.⁴² However, as revealed by National Public Radio’s (NPR) “This American Life” low levels of funding for the OVSB has resulted in inefficient programming. Nonetheless, the OVSB model meets at least five of the eight key components to a successful program.

- The program offers a certain amount of **flexibility and accessibility** in scheduling respite services by using mostly retired or non-working volunteers.
- The OVSB program, in conjunction with other DHSS and local sponsoring agency services, offers the target population a **broad array of respite options**.
- The community organizations train the OVSB volunteers in order to have **culturally competent** services for the populations served.
- DHSS conducts **outreach/consumer awareness** through the use of their website, a hotline, brochures, posters and the local sponsoring agencies.
- Finally, eligibility for the OVSB program does not have an earnings requirement which makes respite services available to all families **regardless of income**.⁴³

This innovative program clearly demonstrates many of the components that produce effective respite services for this specific population.

Saint Louis Crisis Nursery

The St. Louis Crisis Nursery, a MFH grantee funded in January 2003, provides respite services to families experiencing overwhelming stress in order to prevent child abuse and neglect. The agency also offers immediate shelter and safety for children escaping an abusive environment. The population served by the crisis nursery includes: minority clients (77%), low-income families (87%), single parent households (88%) and families that have a child with a disability (15%). The program provides 24-hour care for children, a medical exam by a physician, medication, a developmental assessment and access to a helpline for families in crisis.⁴⁴

The St. Louis Crisis Nursery presents a highly regarded example of a program that prevents child abuse and neglect and also meets many of the key components for effective respite services, including:

- The Crisis Nursery has a reliable reputation with the community it serves. This **family-centered framework** decreases the caregiver stress and anxiety that comes from being physically separated from their children.
- Offering 24-hour, 365 days a year of service, and a crisis hotline, the agency provides **flexibility and accessibility** in respite care.
- The organization has many credentialed staff, and all staff receive initial, as well as on-going, training that assists in providing **culturally competent** services.
- The St. Louis Crisis Nursery promotes **outreach/consumer awareness** of their services through radio and television interviews, press releases, a hotline, community presentations, flyers, conferences, workshops and an agency newsletter.
- The agency **supports caregivers** through family counseling, the crisis hotline and referral services.
- The organization serves all families **regardless of income**.
- Through the use of client surveys and follow-up interviews with the families, the Crisis Nursery can **evaluate** the program and **improve the quality** of services.⁴⁵

The St. Louis Crisis Nursery effectively incorporates the essential components that produce a successful and beneficial respite care program for their targeted population.

Conclusion

Respite care benefits a diverse population of both caregivers and care recipients. This valuable tool reduces the early institutionalization of care recipients, and also decreases the stress and anxiety associated with caregiving. Respite programs promote both the physical and mental health of family caregivers. Additionally, informal caregiving saves billions of dollars each year nationally by decreasing institutionalization and placement in foster care services. While a coordinated and inclusive system of respite may be ideal, individual organizations or collaborating agencies can work to develop the efficacy of their own activities through meeting the preceding key elements to successful programming. Respite services can both maintain and improve the health of many of Missouri's informal caregivers and care recipients.

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