Volunteer Respite Programs
Resources to Establish and Sustain Volunteer Respite Programs

Overview

This document is designed to assist ADDGS grantees in establishing and sustaining volunteer respite service programs. It presents information in three sections. These sections are:

- General principles for establishing and sustaining volunteer respite programs
- Nationally Recognized Volunteer Respite Programs and Related ADDGS Examples
- Publications outlining steps for establishing voluntary in-home caregiver support and respite services

The online links in this document are designed to direct the reader to key pieces of information about the programs described.

General Principles for Establishing and Sustaining Volunteer Respite Programs

Several organizations, including the Robert Wood Johnson Foundation, Oregon’s Lifespan Respite Program, and the ARCH National Resource Centers have published guidance about establishing and sustaining voluntary programs to provide in-home services. For example, these organizations recommend that programs have paid supervisors, ongoing recruitment efforts, and solid base funding. Examples of key pieces of guidance are provided below.

- Faith in Action. Key principles for establishing and sustaining in-home volunteer services are outlined in the executive summary of a report evaluating the Robert Wood Johnson Foundation’s *Faith in Action* program prepared by Public/Private Ventures (P/PV). Grantees may find the information on survival and recruiting and retaining volunteers on pages iii to vi of particular interest.

- Oregon’s Lifespan Respite. Oregon’s statewide *Lifespan Respite* program has published a list of guiding principles on page seven of “Building Oregon’s Lifespan Respite Care System.”

- ARCH (Access to Respite Care and Health) National Resource Center. Guiding principles published by the ARCH National Resource Centers can be found in the “ Volunteers: A Valuable Resource” Fact Sheet.

Nationally Recognized Volunteer Respite Programs and Related ADDGS
Examples

This section describes three nationally known volunteer respite programs and provides related ADDGS project examples. The three nationally known programs described are:

- Brookdale Foundation’s National Group Respite Program
- Robert Wood Johnson Foundation’s Faith in Action Program,
- University of Alabama’s “Support Teams

The Brookdale Foundation’s National Group Respite Program

The Brookdale Foundation’s National Group Respite Program is a social adult day care model that provides dementia-specific group activities for participants and respite time for caregivers. The Brookdale Foundation funds 15 programs annually. Grants are for $7,500 in the first year, and $3,000 in the second year. Applicants must be non-profit organizations seeking to provide dementia specific day services. Programs must be based on a social day service model and must provide caregiver services. Services must be available for at least four hours a week. Programs must be staffed by at least one paid professional staff member who is responsible for the supervision of program assistants, including volunteers and students. Sponsoring organizations must provide 100% matching funds either in cash or in-kind support. Applicant organizations must demonstrate that a concrete fundraising plan has been established to sustain ongoing services. Most programs operate on annual budgets of $15,000 to $20,000. Information about delivering a package of core services using the Brookdale model and the grant application process can be found on the Brookdale National Group Respite Program website.

Contact Information: For additional information contact Carmen Mendieta at (510) 540-6734.

ADDGS Example: During the 1990s, Florida’s Department of Elder Affairs implemented the Florida Alzheimer’s Volunteers Offering Respite (FAVOR) program. With funding from the Brookdale Foundation and the state’s ADDGS grant, project FAVOR supported group volunteer respite activities at three multi-purpose organizations in Palm Beach, Miami and Liberty City and six respite specific sites in St. Petersburg, Jacksonville, Orlando, Tampa, Clearwater, and Bradenton. Project staff from the respite specific sites were sent to annual trainings in New York conducted by the Brookdale Foundation.

ADDGS Contact Information: For further information contact Dawn Lynch at the Florida Department of Health (850) 245-4444 ext. 2270. One of the respite specific sites still operating is the Share the Care Inc. in Orlando. Mary Ellen Ort-Marvin at Share the Care, Inc. can be reached at (407) 423-5311 or www.helpforcaregivers.org.

Robert Wood Johnson Foundation’s Faith in Action Program

Faith in Action is an interfaith volunteer caregiving initiative supported by of The Robert Wood Johnson Foundation (RWJF). Local Faith in Action programs bring together multi-faith volunteers to work together to provide in-home care for their neighbors who have long-term health needs. Faith in Action has hundreds of program sites nationwide. On average, more than 100 care recipients are served by each Faith in Action site. Typically, volunteers provide...
services three hours a week.

RWJF established programs based on the proven success of the *Faith in Action* caregiving model that is based on the following five *Building Blocks*: 1) interfaith 2) use volunteers, 3) provide help with caregiving, 4) assist people with long-term illness and disability; and 5) provide home-based services.

In 2003, The Robert Wood Johnson Foundation released a study titled, “*Faith in Action: Using Interfaith Coalitions to Support Voluntary Caregiving Efforts*” conducted by Public/Private Ventures (P/PV) that identified program characteristics associated with interfaith volunteer caregiving program survival. *Key sections of the report* related to: 1) practices associated with successful programs and 2) critical issues facing interfaith voluntary caregiving programs can be found.

**ADDGS Example:** In January of 2004, Idaho’s Commission on Aging began working with a new Boise Faith in Action site to provide volunteer in-home and respite services to families identified by ADDGS project staff. AAA III located in Boise (which participates in the ADDGS program) has referred participants to the Faith in Action program and the Boise Faith in Action staff has referred participants and their caregivers to the AAA/ADDGS program. Faith in Action volunteers provide two forms of volunteer respite services: in-home services, and walking companions for people with Alzheimer’s disease. Additionally, Faith in Action staff has recently received dementia care training.

**ADDGS Contact Information.** For additional information contact ADDGS Project Director Pam Catt-Oliason at (208) 334-3833 or the Boise Faith in Action Director Abby McLean at (208) 333-1363.

**University of Alabama’s Support Teams**

Support Teams are groups of volunteers organized to provide practical, emotional, and spiritual support to persons with health concerns or other special needs. Using a team approach, volunteers pool their talents, creativity, time, and leadership abilities to offer much more support than one volunteer can provide alone. Services vary based on individual/family needs and the interests and availability of Support Team members. Teams may provide transportation to appointments, run errands, prepare meals, visit, calls, provide respite for the caregiver, yard work or shopping. Teams may also offer music, social outings, help with computer needs, or help with patient advocacy. Team empower Friends (recipients) do what they enjoy doing, focusing on improving quality of life.

Support teams are organized around four major principles. Volunteers are asked to: 1) do what they enjoy doing, 2) when they are able to do it, 3) in a coordinated way, 4) with a built-in support system. These principles recognize that: 1) different volunteers have different talents to contribute to people who need help; (do what they enjoy doing); 2) people can only provide assistance to others when it makes sense within the context of the rest of their schedule (when they can do it); 3) supporting individuals in need requires an organized and coordinated approach (in a coordinated way); and 4) volunteers and care recipients may need assistance in confronting end-of-life and other issues (with a built in support system).

The size of the Support Team varies based on the situation and the need. Teams average 6-12 members. Each Support Team has its own volunteer leader or co-leaders and its own volunteer coach. Following an orientation, each Support Team meets monthly for 59 minutes and actively
participates in ongoing communication, education and coordination. Support Teams have been successfully created through a wide range of organizations including congregations, retirement communities, civic groups, neighborhood groups, schools and businesses and hospice volunteer programs to provide volunteer in-home services including respite services.

The Support Team Network is a national organization based at the University of Alabama at Birmingham. Developed by Rev. Malcolm Marler, the Support Team Network provided education and support for organizations, groups and communities seeking to create Support Teams. Through Leadership Training Conferences, the Support Team Network has empowered more than 3,000 persons from 40 states to start Support Teams that have served more than 5,000 persons since 2000.

The Support Team Network has partnered with Project Compassion in Chapel Hill, NC to provide Support Team materials and leadership trainings in communities across the country. Please visit the Support Team Network for more information. You may also view a presentation by Dr. Marler titled, “A Support Team Initiative: A Plan for Caring for Persons with Health Concerns or Other Special Needs” about Support Teams.

Contact Information: For additional materials or information about Support Team Leadership Training, contact James L. Brooks, M.Div., Director of Team Development and Leadership Development, The Support Team Network, (919) 402-1844 or www.project-compassion.org.

**ADDGS Example:** Alabama’s ADDGS project uses Support Teams or “Caring Teams.” Caring Teams provide in-home and community based care to support caregivers and persons with Alzheimer’s disease (and other related dementias) through shared community volunteer Caring Teams. A Caring Team is a group of six or more individuals that offer practical, emotional, and spiritual support to help caregivers maintain their family member or friend in his or her own home. The members of the Caring Teams are required to commit to the Team for one year.

The Caring Teams have monthly meetings in order to coordinate the time and tasks of the team, and for the team to reflect on their experiences with the client. Each team has a Team Leader, and a Co-Captain of the week who is responsible for checking in with other team members to assure visits are being completed. Each of the four piloted AAAs in Alabama is responsible for recruiting volunteers and providing them with Caring Team training. Additionally, the Southern Alabama Regional Planning Commission, in Mobile has provided the AAA Alzheimer program directors the training needed to implement the Caring Teams in their local communities.

Contact Information. For additional information contact Alabama’s ADDGS Project Director, Bettina Schmid at (334) 850-3006.

**ADDGS Example:** North Carolina’s ADDGS, Family Caregiver Support programs and community-based organization have partnered together to implement Support Teams as part of their outreach to community organizations. Support Team Leadership Trainings have been held in the following areas: Asheville, Chapel Hill/Durham, Charlotte, Fayetteville, Greenville, Shelby, and Wilmington.

**ADDGS Contact Information:** For information on the “train the trainer” session sponsored by the Northwest Piedmont AAA, the Western Carolina chapter of the Alzheimer’s Association, Senior Services of Forsyth County, Hospice and other community
organizations contact **Dottie Lyvers** at (336) 725-3085. For information on the emerging NC Support Team Network and information about creating a regional or statewide Support Team Initiative, contact **James Brooks** at (919) 402-1844.

**Regional Example:** Project Compassion, an organization that creates community and provides support for people living with serious illness, caregiving, end of life and grief based in Chapel Hill, NC has partnered with a wide range of organizations, including faith communities, retirement communities, civic organizations, hospices, hospitals, businesses and schools to create a regional Support Team Initiative. Since 2002, Project Compassion has created over 125 Support Teams with over 900 volunteers in partnership with more than 60 community groups and organizations. These teams have provided caregiving support for more than 350 individuals, including more than 25 of teams for individuals and families living with Alzheimer's. For more information about creating a regional initiative, contact **Sonia Norris** at (919) 402-1844.

*Publications outlining steps for establishing voluntary in-home caregiver support and respite services*

The resources below are online publications with pertinent information on volunteer respite programs.

- **Caring to Help Others: A training manual for preparing volunteers to help caregivers of older adults.** *AARP, Interfaith Caregiver Alliance, United Way of America, Hospice Association of America, Alzheimer's Association.* 2000. This training manual is designed to help community-based organizations prepare volunteers to more effectively assist primary caregivers of older adults. Includes tips on volunteer management.

- **Building a Volunteer Respite Care Program: A “How To” Manual Especially for Churches.** *Alzheimer's Association.* Ver Hoef, Judy and Diana Findlay. 1993. This training was written to implement volunteer respite programs administered through rural and metro churches. The manual presents material on volunteer respite programming.

*For More Information*

AoA's ADDGS National Resource Center is operated by RTI International and the Alzheimer's Association.

- For further information about the ADDGS program, please contact **Lori Stalbaum**, AoA Project Officer for the ADDGS program.

- For additional information about this document, please contact **Kate Gordon** or **Natalie Kelly**.