

The Technical Assistance Center for Lifespan Respite Fact Sheet Number 53, May 2010

Respite and the Faith Community

Introduction

Historically, faith communities in the United States have been vital in shaping and supporting the larger community of which they are a part. In the early years of our nation, faith communities often provided the only existing social services, such as education and healthcare. They also provided significant input into the social concerns of the day, with the meeting house often doubling as a place for political assembly. Over time, however, this social involvement slowly diminished. As government increasingly met society's social and economic needs, faith communities began to limit their focus to society's spiritual needs.

Today that focus is changing again, as a growing number of faith communities seek to serve not only the spiritual needs of their congregations but also the many different social needs in the larger community to which they belong. Congregations wanting to improve their communities, however, may not know how to meet this goal. At the same time, programs that provide direct services may be reluctant to tie into the vast network of resources within a faith community for fear of offending nonmembers.

This is a real concern but one that can be addressed with good communication. Respite programs, especially those in rural settings, often find themselves with limited resources. Faith communities, on the other hand, have resources such as facilities, volunteers and, in some cases, expertise that should no longer be ignored. As a parent in need of respite, a pastor, and a respite coordinator, the author has found that with clear dialogue respite programs and faith communities can come together, and that in doing so they can meet the needs of families better than if they had remained apart.

Why the Faith Community?

Typically, those who participate in the activities of a faith community do so to better themselves and their community, and they have long-standing relationships with others who are likeminded. Active members of a faith community usually form a strong foundation that has stood the test of time and is community-based; their contacts and sphere of influence go far beyond the facility within which they meet. Tapping into these resources can be a great benefit in expanding a respite program.

Compassion

While many people may feel sympathy for individuals who are less fortunate than they are, compassion implies much more than sympathy. It is sympathy combined with action, or as some have said, "come-passion," to come alongside with a passion. Often, members of faith communities have a desire to improve themselves, and for many that is done by helping others. A volunteer who truly wants to help is quite different from an employee just doing a job. People inspired to serve without personal gain are a very strong resource. For those in the faith community, it is their heart, not a paycheck, that often motivates them.

Volunteerism

Most faith community programs or ministries are volunteer-based and volunteer-led, and, in many cases, these volunteers have a long history of working together on various other activities. This can help maintain a community-based focus. Young people have proven to be open and enthusiastic volunteers in respite programs, while mission groups or members with health or human service backgrounds are a tremendous resource as well.

Once volunteers are trained and providing respite, they often build lasting relationships with the families and individuals in their care. It is not uncommon for a volunteer to offer respite outside the scheduled respite program. Because families often develop close relationships with these volunteers, they may feel more comfortable using volunteer providers in other settings, especially in emergencies.

Community

Although faith communities are focused around philosophical or theological beliefs, most are strongly rooted within their social community and therefore are a wealth of information and resources.

Stability

Partnering with a faith community willing to help carry some or all of the administrative responsibilities can give a respite program or support group the stability to survive. Some security is assured when a congregation can provide a constant supply of volunteers, and even a somewhat secure source of charitable giving. However, one of the major lessons learned from the Robert Wood Johnson Foundation's (RWJF) Faith in Action national volunteer caregiving programs was that it was best to develop interfaith volunteer projects under the aegis of health and social agencies, in partnership with an interfaith coalition, to reduce the challenges of maintaining financial stability beyond grant funding.'

Family Caregiver Trust

For many families, their place of worship is often the first place they turn to for help, especially when they have no idea of where else to go. Studies have documented that family caregivers are especially reluctant to ask for help. Family caregivers needing respite may not be as willing to ask for help from outside agencies, but may be more accepting of help from people they know at their church, synagogue or mosque. The involvement of a faith community in respite provision may offer the trusted environment these family caregivers prefer.

Philanthropy

For small respite programs the daunting task of becoming incorporated and applying for federal non-profit status can be overwhelming. However, many faith communities are willing to use their non-profit status to give individual donors or corporate sponsors a tax-deductible receipt. In these situations, donations must be "at the discretion of the faith community" to use as the "ministry of that faith community."

Benefits of a Respite Ministry to the Faith Community

The benefits to a faith community of providing respite are numerous, not only for the family and the respite provider, but for the congregation as a whole. These include:

- increased family participation in congregation activities
- increased awareness by members of the needs of families
- increased sense of belonging for families
- increased awareness by members of the barriers to participation by people with disabilities in the congregation and how to remove those barriers
- new skills for caregivers and volunteers
- a positive image in the community and a sense of pride among the congregants of the valuable service they are providing.

Respite programs have often been the catalysts for opening faith communities to true inclusion. Once staff and volunteers are trained, any fears they may have had about inclusion or serving those with special needs are usually eliminated. When fear is replaced with compassion and love for an individual or a family, many faith communities have made programming shifts and used their trained respite volunteers and staff to shadow children with special needs in typical church school classes and activities or offer their

National Model: Interfaith CarePartners®

Interfaith CarePartners was founded in 1985 in Houston, TX, by Earl E. Shelp, Ph.D. (professor of medical ethics) and Ronald H. Sunderland, Ed.D. (professor of pastoral theology and pastoral care) who began by providing hands-on care for people with HIV/AIDS utilizing a team methodology. New caregiving projects were added to the AIDS Care Team, including an Alzheimer's Care Team® for individuals with dementia or other cognitive impairment and their caregivers; Second Family Care Team for individuals with physical impairments due to disease, trauma, or advanced age; and Kids' Pals Care Team for families with a child with a disability. From 1986 to 2009, 1.85 million hours of volunteer service were provided in the Houston area. Over 12,000 Care Team members provided services to over 7,600 individuals. In addition to respite, congregation-based teams of intergenerational volunteers provide individualized social, emotional, practical, and spiritual support to individuals and families. The formation of mutually caring relationships is the basis of the Care Team program. The activities of team members are coordinated by team leaders and supervised by professional staff of Interfaith CarePartners. The program has been replicated nationally and has received numerous national awards, including the President's Service Award from President Clinton, the Rosalynn Carter Caregiving Award, 1997, Older Volunteers Enrich America Award program of the MetLife Foundation and the National Association of Area Agencies on Aging (2006), and many others. Guidance and instruction for replicating the caregiving concept and methods are available in three publications: **Caregiving Team Ministry: A Manual for** Congregations, Caregiving Team Toolkit, and **Caregiving Team Curriculum: Education for** Caregiving Teams. On-site and telephone consultations may be scheduled. For more information, visit http://interfaithcarepartners.org/, call 713-682-5995, or for general information, e-mail at info@interfaithcarepartners.org.

support in other ways to families caring for an aging family member. This helps break down fears in others, so that friendships often develop naturally between those providing respite and those receiving care.

For many faith communities, serving their older members already is a major focus, and developing programs to help families who are caring for an elderly family member with special needs may be part of their strategic plan. Although they may not identify it as such, this is a "respite ministry."

Creative Faith-based Models

The respite examples described in this factsheet can be provided either voluntarily or for pay through any faith-based community, regardless of whether it is centered around a church, synagogue, mosque, temple, or other religious structure. The best faith-based supports are developed through collaboration between families in need of respite and the congregation, or members of the faith-based community. Together they determine what respite supports are needed and how the congregation can respond, given its vision and resources. The following list does not include all possible options, but reflects successful efforts that presently exist, ranging from the least to the most involved by the faith community.

Financial Support

Some faith communities may not be willing or have the resources to initiate a respite program, but may want to help fund an existing program. For example, a faith community may be willing to pay for a "provider," someone who provides respite service to families, if the need among families who are members of their congregation or community is clearly presented. The question to consider is, "Does the congregation have a benevolence or home mission fund that could support programs serving individuals, families and/or the local community?"

Respite Site

Although a faith community may not be ready to start a respite program, it may be willing to allow others to use their facility as a place to provide respite. Many faith communities have outstanding childcare facilities that are used only in the morning. The same may be true of the community's space for adults and seniors. If the congregation can be shown that there is a need, then it is often willing to open its facility for others to use.

Support Group Respite

Some faith communities sponsor parent or caregiver support group meetings in their facilities. During the meetings, a youth or adult group from the congregation provides childcare or eldercare in the same facility. This gives the respite providers the opportunity to develop a rapport and become comfortable with those they are caring for while their families are in a nearby room. It also gives the families and those with special needs time to become comfortable with the new care providers, so that after a while the support group could meet at another site.

Respite Vouchers

In respite voucher programs, the congregation provides no direct services, but helps pay the family or caregiver's cost of hiring the provider of their choice. Actual payment may be made to the family or directly to the respite provider. One church set up a benevolence fund to which anyone could contribute and any family needing respite could apply for grants of \$50 or more.

Adopt-a-Family Program

The title of this program is self-explanatory. Parents or guardians with typically developing children who are members of a congregation agree to care for the children of families needing respite. The arrangement is scheduled and carefully monitored so as not to overwhelm either family, and the family providing respite is reimbursed for incidentals such as mileage.

Family Caregiver Cooperatives

In a cooperative, two or more families needing respite trade off care for each other's child, children, or the adult or aging family member who is the care recipient. In a site-based cooperative, parents of children with special needs or family caregivers of adults with

disabilities or chronic conditions or aging family members, work alongside congregational volunteers to provide quality care. In one cooperative of eight families, for example, two parents provided care so the other six families could get a break. They were helped by a coordinator and additional volunteers, or shadows, recruited from the faith community. In this way, both the family caregiver and the volunteer respite providers learn about the care recipients from the experts, the family caregivers or parents who provide full-time care. Faith communities wanting to begin a respite cooperative may easily recruit interested families through local parent-to-parent groups, support groups, school districts, Area Agencies on Aging, and disability groups, or through their own community contacts.

Inclusion

Congregations often have a myriad of existing programs: mother's morning out, child development center programs, vacation Bible school, church school or youth programs, or social programs for seniors. Inclusion, or opening these programs to children or adults with special needs, gives families another option for respite on a regular or as needed basis. The staff and volunteers of these programs may be willing to be inclusive, but may not feel adequately trained. Offering workshops and training about disabilities, inclusion strategies, and respite can do much to develop a few well-equipped staff or volunteers and open up existing programs. As these programs become more inclusive, other community settings may follow, enabling family caregivers to tap into numerous options.

Trained Respite Providers

A faith community may decide to create a provider registry by training members of the congregation to provide direct respite services, either for pay or as volunteers, to individuals or in group settings, for children or for adults. Training curricula exist specifically for working with the faith community, including a manual produced by the National Council of Catholic Womenⁱⁱ. ARCH also maintains a library of respite provider training curricula that might be useful to prepare

paid or volunteer providers to work with special populations.

Collaborative Respite, Faith & Community Programs

Some faith communities have acted as catalysts to bring families, community programs, state agencies and other congregations together to provide respite for families of children and adults with special needs. One collaborative network brought together a congregation, a community recreational program, and a university in order to create a respite program.

Findings from the RWJF Faith in Action Program, which funded over a thousand interfaith coalitions nationally over a 25-year period to provide caregiving services, found that it is most helpful when recruiting volunteers, to think beyond congregations for a pool of volunteers, including campus ministries, high school and college organizations, such as the Key Club, and employers in town. iii

Enlisting the Faith Community

Faith communities are typically relationshipbased, so when a respite program initiates contact it is helpful if the program already has a relationship with someone in the faith community. This could be a family in the faith community who needs respite or a member interested in or already involved in providing respite. Either is a great place to start. Congregants are also helpful because they can explain the typical working structure of the faith community, and a clear understanding of this structure and how decisions are made is advantageous. Knowing the faith community's calendar and its program start-up time is also strategically important. For example, youth groups often initiate new efforts at the beginning of a school year or start mission projects over spring or summer breaks. In addition, understanding the current focus of the faith community's ministry enables a program to correlate its own cause with the faith community's vision. For example, if one focus of its ministry is mentoring youth, a respite program

National Model: Faith In Action

The Robert Wood Johnson Foundation (RWJF) funded a number of faith-based initiatives between 1983-2008, in order to support interfaith volunteer caregiving. The project brought together congregations, social service organizations and others to engage and organize volunteers to provide services. Among the volunteer services provided were friendly visitors, shopping, transportation, home repair and respite. Individuals assisted included the frail elderly, those with physical disabilities, Alzheimer's or dementia, the terminally ill and people with developmental disabilities and mental illness. As a result of the RWJF funding the *Faith In Action model* emerged. Coalitions made up of groups of congregations representing the communities' various faiths came together to establish a single caregiving program, drawing their volunteers from participating congregations. The key to their success was having a paid coordinator to administer the program. In order to maintain the interfaith character of the program the model required that there be no religious proselytizing by the volunteers thus making services more acceptable to those in need of care who might not share their beliefs. During the course of the initiative projects were established in every state, Puerto Rico and the Virgin Islands. Even though RWJF funding has ended, over 670 local Faith in Action programs continue to provide volunteer caregiving services for their neighbors in need. Many of these programs have created a national membership network that has a Web site indicating where you can find local Faith in Action programs. For more information about the Faith in Action National Network, call 866-**839-8865**, or visit

www.fianationalnetwork.org.

National Model: The Gathering

Lyngblomsten, organized in 1906 by Norwegian women, is a nonprofit social ministry organization with the Evangelical Lutheran Church in America, providing quality care through its healthcare, housing and outreach programs. *The Gathering* is one of the outreach programs in Home- and Community-Based Services. The Gathering was developed in partnership with Como Park Living at Home Block Nurse and Lyngblomsten Care Team Ministry at St. Timothy Lutheran Church in St. Paul, MN in 2000 to support respite for caregivers. Lyngblomsten was awarded an Age Odyssey Policy Award for *The Gathering* from the Governor of Minnesota for its creative approach to meeting the needs of the frail elderly through agency and community group collaboration. Since then, *The Gathering* has grown to multiple church sites and church partners of eight denominations. Many sites have waiting lists to get in to the programs. Churches are waiting to work with the program. In the Twin City area, The Gathering has 200 volunteers with varied backgrounds. Lyngblomsten trains and mentors the volunteers. The volunteers plan and run the 5 hour respite day for 8 to 10 participants with early to mid- stage memory loss. Each church hosts twice a month. Where there are churches working together, families can attend weekly by going to two sites if they desire. The load is shared with welltrained volunteers. Volunteers are trusted by the community and do not share their faith beliefs with families in the program. The Gathering has been a Brookdale grant recipient since 2005. Lutheran Services in America, based in Baltimore, MD, plans to expand "The Gathering" nationwide through its "Caregiver Suite" initiative. For more information, see

http://www.lyngblomsten.org/support services/gathering.php and http://www.lutheranservices.org/lsaTogether_feb10_feature2 may want to tailor its approach to training and overseeing young people in providing respite.

The decision-making process is different within each faith community. Some are "top-down," in other words, permission from the priest, rabbi, bishop or imam is needed before the congregation gets involved. Some are "bottomup," so that decisions start with members of the congregation and work up through committees of the faith community.

In either case, a clear proposal is helpful. This should include:

- the mission statement of what the respite program proposes to do;
- the resources the respite program is requesting, such as financial help, staffing, volunteers, and/or space within a facility;
- the extent to which the program needs these resources (for example, the first and third Saturday of each month from 1–4 P.M.);
- a clear statement of preliminary policies and procedures if a site or staffing is being requested^{iv}; and
- the resources the respite program has to offer.

After an initial personal contact, a written proposal is the first formal step in the process of soliciting help from the faith community. This process may take some time depending on the structure of the faith community. Often a proposal will have to pass through several committees before a decision can be rendered. Keep yourself available to meet with these committees if questions arise.

Summary

The faith community has a wealth of resources, and its congregation can significantly influence the larger, social community by developing a respite program. With clear dialogue, respite programs and faith communities can effectively

work together to meet the respite needs of their families—better than if they remained apart.

References

Montgomery, B., Risk Management, Fact Sheet 17. ARCH National Respite Network & Resource Center, 1992.

Robert Wood Johnson Foundation. May 2009. Grant Results from the Faith in Action(R); Faith in Action: Replication of the Interfaith Volunteer Caregivers Program; Interfaith Volunteer Caregivers Program, retrieved at http://www.rwjf.org/reports/npreports/faithinaction.htm#OverallProgramResults, May 2010

Resources

For more information about how to talk to your local faith community or for a *Respite*Cooperative Start-up Manua, contact W.C.

Hoecke, Special Connection of Family Connection of South Carolina, 2712 Middleburg Drive, Suite 103-B, Columbia, SC 29204, (800) 578-8750

For more information about starting respite activities in your congregation, visit the SC Coalition website at www.screspitecoalition.org

For copies of Caregiving Team Ministry: A
Manual for Congregations, Caregiving Team
Toolkit, and Caregiving Team Curriculum:
Education for Caregiving Teams contact:
Interfaith CarePartners®

701 N. Post Oak Rd. Suite #330 Houston, TX 77024 Phone 713-682-5995 · Fax 713-682-0639 e-mail: info@interfaithcarepartners.org

For **Lessons Learned** about interfaith coalitions, including a *Faith Based Outreach Tool Kit*, see Faith In Action National Network at http://www.fianationalnetwork.org/resources/resources-category-list.cfm

For more information about accessible congregations, contact:

Pathways Awareness Foundation 150 N. Michigan Ave., Suite 2100 Chicago, IL 60601 Toll-free: 1-800-955-2445 (or 1-800-955-CHILD) e-mail: friends@pathwaysawareness.org

Union of Reform Judaism

How to Start a Disability Inclusion Program

Within Your Congregation

http://urj.org//life/community/disabilities//?sysp
age=document&item id=11643

For more information on training volunteer respite workers in faith communities:

National Council of Catholic Women 200 N. Glebe Road, Suite 703 Arlington, VA 22203 703-224-0990 nccw01@nccw.org

ARCH National Respite Network and Resource Center: *Training Ideas*http://chtop.org/ARCH/Training-Ideas.html

About the Authors

Rev. W.C. Hoecke (pronounced "heck-uh"), M.Ed., is spouse of Catherine and father of three children, one with special needs. He coordinates Special Connection, a project of Family Connection of South Carolina, and works to find respite solutions for South Carolina families. He coordinates *Up on Downs*, a Mid-lands parent support group and served as a founding board member of the SC Respite Coalition.

Kathy Mayfield-Smith, M.A., M.B.A., is a research associate professor at the University of South Carolina, Institute for Families in Society, chair and co-founder of the South Carolina Respite Coalition, and former project director of Project Helping Hand, a respite initiative working with faith communities. Kathy is the parent of three children, two with special needs.

The update of **Respite in the Faith Community** was prepared by Maggie Edgar and Jill Kagan of ARCH, May 2010, with assistance from W.C. Hoecke and Carolyn Klaver, RN, of Lyngblomsten, St. Paul, Minnesota.

This factsheet was originally produced by the ARCH National Respite Network and Resource Center, which was funded in part by the U.S. Department of Health and Human Services, Administration for Children, Youth and Families, Office of Child Abuse and Neglect. The fact sheet was updated by the ARCH National Respite Network. This project is funded, in part, under a grant from the U.S. Department of Health and Human Services, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal Government should not be assumed.

This information is in the public domain. Readers are encouraged to copy and share it, but please credit the ARCH National Respite Network and Resource Center. i Robert Wood Johnson Foundation. May 2009. Grant Results from the Faith in Action(R); Faith in Action: Replication of the Interfaith Volunteer Caregivers Program; Interfaith Volunteer Caregivers Program, retrieved at

http://www.rwjf.org/reports/npreports/faithinaction.htm#OverallProgramResults, May 2010.

ii National Council of Catholic Women, *Respite*Manual, 2nd edition

Robert Wood Johnson Foundation. May 2009. retrieved at

http://www.rwjf.org/reports/npreports/faithinaction.htm#OverallProgramResults, May 2010.

Montgomery, B. Risk Management, Fact Sheet 17. ARCH National Respite Network & Resource Center, 1992.





