



Louisiana Lifespan RESPITE COALITION

Background

In 2006, President Bush signed the Lifespan Respite Care Act into law (P.L. 109-442). The Lifespan Respite Care Program (LRCP) provides grants to state agencies to maximize existing resources and ensure that respite is available and accessible to family caregivers by establishing or enhancing statewide respite systems. DHH received a small three-year planning grant of \$200,000 in 2010 to coordinate the coalition through the Aging Disability Resource Centers of Louisiana/LouisianaAnswers.com.

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I am my brother's keeper: Respite and Louisiana's Faith Community

The need

An estimated 337,500 working Louisianans face the challenges of family caregiving as they struggle to balance job responsibilities with caring for a relative aged 50 or older or a child with a disability. In 20 years, we're going to have twice as many older people as we have now, so the average employee is going to be a caregiver. Today's average caregiver is a 49-year-old woman caring for their aged parent in their home. This employee has a lot of value in the workplace, but there is only so long they can do two full-time jobs.

The call

Historically, faith communities have stepped up when the private marketplace or public service arena fails to meet the social service needs families. In Louisiana, waiting lists for respite services, whether private pay or public service, are high. Further, when people have to leave their jobs to care for a relative, they lose on average about \$325,000 in lifetime income - from lost wages, lost Social Security and lost pension. More than one-third of all working caregivers will quit their jobs or reduce their work hours to care for a loved one.

A trusted place for rest

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 and may be more accepting of help from people they know at their church, synagogue or mosque. Church communities are the trusted environment these family caregivers prefer.

A special ministry

Respite programs rely on volunteers. 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. 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.

A faith-based respite ministry or support group can also give the stability a respite program needs to survive. A congregation can provide a constant supply of volunteers, and even a somewhat secure source of charitable giving. To maintain the financial stability of such a program, it is best to develop respite volunteer projects under the aegis of health and social agencies. Contact Tammy LeBlanc with the Louisiana Lifespan Respite Coalition to continue this discussion.

Benefits of a Respite Ministry

The benefits to a faith community of providing respite are numerous:

- 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.

For more information contact the Louisiana Lifespan Respite Coalition:

LouisianaAnswers.com or
Tammy LeBlanc, (225) 219-0223 or
tammy.leblanc@la.gov

Resources

Caregiving Team Ministry: A Manual for Congregations, Caregiving Team Toolkit, and Caregiving Team Curriculum: Education for Caregiving Teams.

visit <http://interfaithcarepartners.org>,
call (713) 682-5995, or e-mail at
info@interfaithcarepartners.org

For more information about the Faith in Action National Network, call (866) 839-8865, or visit www.fianationalnetwork.org

For more information about how to talk to your local faith community or for a Respite Cooperative Start-up Manual, 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.scredspitecoalition.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 www.fianationalnetwork.org/resources/re-sources-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](http://urj.org/life/community/disabilities/?sysp%20age=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://chttop.org/ARCH/Training-Ideas.html>

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. Fear is replaced with compassion and love.

Types of ministry

Respite Site

Allow others to use the church facility as a place to provide respite.

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.

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

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. 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.

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.

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 Women. 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.