Q&A from Participants in the Webinar “Respite in the Faith Community”
June 3, 2010

Questions directed to W.C. Hoecke, consultant/trainer of faith-based respite programs, Columbia, South Carolina and Carolyn Klaver, The Gathering Coordinator, St. Paul, MN, regarding their individual programs and faith-based respite in general and their responses.

Q: Did you spend time getting local social service/health providers’ buy-in?

W.C. Hoecke: Not all of them, but that would not be a bad idea. We did get buy in from our local Disability and Special Needs Boards and did use their training material in starting Respite co-ops.

C. Klaver: Thank you for this very important question. Yes, we especially worked with one metro county government agency and they have been fabulous! Every time we have an opening, I send an email to them and they shoot it out to their Public Health Nurses and Social Work case managers. They tell us how important we are to them and we feel the same of them. The other two counties where we have respite programs are very large metropolitan areas and it is harder to work in their very large systems. Here, we have been working with the health plan providers per recommendation from the MN Dept. of Human Services. I also attend professional meetings to get the word out - (e.g., memory care professionals, metropolitan caregiver support collaborative, Senior workers, Faith Community nurse network, CareOptions - a local network of service providers).

Q: I am currently trying to get my own wife’s buy-in. She is a local united Methodist pastor who is a transplant from Minnesota. I think a program like this would strengthen our mission and ministry in the united Methodist church and wondered if you or know of someone who does presentations or webinars upon requests from churches? The United Methodist Church may also already be doing similar ministries that I do not know about.
C. Klaver: I work with two Methodist churches currently as we are very ecumenical in working with each community's churches. We also have Parish Nurses from Lyngblomsten in one of these Methodist churches. This particular church had a retired Parish Nurse who started the Methodist Parish Nurse/Faith Community Nurse group at least in the state of MN. Lutheran Services in America (LSA) might be able to work with churches in the future for First Circle Friends national respite. For the first year of our project with LSA I think the plan is that LSA is working with their over 300 agencies across the country to get them started doing this as well. The webinar on Faith-Based Respite is available for viewing at http://chttop.org/ARCH/Lifespan-T/TA.html and can be used with acknowledgement of ARCH.

Q: Could you repeat the place to find the risk information given by WC please.

ARCH has several fact sheets that WC was referring to on Risk Management and Liability Issues. We also have fact sheets on using volunteers that address these issues. We plan to update these in the very near future, but they are still useful.

Volunteers: http://www.archrespite.org/archfs16.htm
Risk Management: http://www.archrespite.org/archfs17.htm

Q: Could you go back over family cooperatives?

W.C. Hoecke: You can view the Manual for setting up family cooperatives at http://www.familyconnectionsc.org/public/files/docs/manual_Document_10_2006.pdf. Go to page 11 for a time line. Sorry this is from 2006 and a bit dated but the basics are all there.

Q: What resources do you access for persons who need respite who may have other disabilities: low vision, Braille, ASL interpreters?

W.C. Hoecke: We always started within the faith community to see what resources individuals in that community have that we could pull into this new program. When they felt they had exhausted their resources, we then would encourage them to partner with local agencies and organizations for additional supports.

C. Klaver: This is a very good question. We have not used these resources for our group respites as of yet. When the needs are greater than what we can manage, we refer folks on to Adult Day Centers and other possibilities. We want to make
certain our volunteers can provide for our attendees. We are a low cost group respite that provides services to a certain clientele who fit our criteria. Due to our lengthy waiting lists, we have felt that we are serving many who need this type of service. I know we have not turned away any with people with disabilities if they have fit our criteria. And since we pride ourselves on looking at the individual’s needs and trying best to address it within our abilities, I know we might have stepped up had this become a question/need from a family. So far, we have only had one care recipient with low vision and we have taken the lead from his wife and her guidelines. We could maybe be doing better in this arena. Thank you for helping me to realize something we may have unintentionally overlooked.

Q: We are a supported living environment for adults with disabilities and we offer day and overnight respite in our community room. Could we look into the benevolence respite policy for our Christian organization? Alternatively, does this just have to be offered in a church setting?

W.C. Hoecke: No, we would love to see any non-profit use this benevolence strategy.

Q: Have any of the churches found an increase of attendance by the caregivers?

W.C. Hoecke: Yes, we have even seen families switch denominations because the respite congregation has been welcoming to their child.

C. Klaver: Increase in attendance would be a complicated question. Caregivers may not be able to attend due to the caregiving role and their loved one’s inability to sit through a service. Their indebtedness to the congregation and the volunteers, however, is evident. The tears, the appreciation, feeling supported in their very serious role - this is very strong in the caregivers attending group respite. The observation from their friends, family and neighbors on the impact this group has to help the caregiver and participant is profound. We have received 2- $1,000 donations due to what this ‘word of mouth’ proved to these bystanders or secondary caregivers. How these folks (secondary caregivers or bystanders) in turn advertise your program is significant. Many respite participants will come from the community at large- the word of mouth about what that congregation is doing for the community cannot be easily measured, but it is great, I guarantee you.

Q: How much is a church charged to participate in the respite program?
W.C. Hoecke: We have never charged a congregation to help them start up a respite co-op in South Carolina. However, we welcome and accept donations to offset our expenses for a 4 hr training and ongoing technical assistance.

C. Klaver: Our corporate congregations (they make up our board) are charged $400/year. The non-corporate congregations are charged $600/yr. This fee does not pay for the services - in fact it hardly covers one day of training, let alone all the mentoring support, admit/discharge of participants, professional guidance to the caregivers. However the fee is intended more to set the tone for the partnership. When even a small fee is charged, there is a different/better level of commitment. Both entities give a lot 'in kind' but it is easy to overlook how much the agency is contributing because so much is behind the scenes - similar to a Parish Nurse/Faith Community Nurse. The fee helps to make the value more evident.

Q: Do elders count the monies raised for the benevolent fund as part of the church/congregation's percentage of contribution back to the community?

W.C. Hoecke: If I understand your question correctly, yes. Most faith communities have checks and balances that have two people counting any offerings received. Those funds would then be designated to the respite benevolence fund to be provided for "local missions". A separate account could also be created if the Church was concerned that a large gift could skew the portion they are responsible to give back to their denomination. That second account would still have to be managed by the churches board as a non-profit.

Q: Is there a site we can access for interview questions for volunteers, both for their skills and concerns about their integrity (liability)?

W.C. Hoecke: "Finding Respite Caregivers" [http://www.archrespite.org/docs/Faith-Based_Caregivers_SC.pdf](http://www.archrespite.org/docs/Faith-Based_Caregivers_SC.pdf) was developed for parents and caregivers to interview their in-home providers, but the questions on page 10 and 13 should be helpful.

C. Klaver: Lyngblomsten was trained by Befriender Ministry in Minneapolis on the interview process. You may wish to contact Befriender Ministry to learn more about their excellent one-day training.

www.befrienderministry.org
1301 American Boulevard East
Minneapolis, MN 55425-1988
Q: One speaker mentioned a “respite notebook”. Please clarify.

W.C. Hoecke: Please see http://www.familyconnectionsc.org/public/files/docs/Respite_Book_word.pdf This notebook was designed to be used with parents of special needs children in respite cooperatives: pre-scheduled, non-emergency cooperations for respite service between families. This notebook probably provides more information than you’ll ever need, but it is intended to be all-inclusive so parents’ minds will be at ease when leaving their child(ren) for respite care. Any pages that are not applicable to your child or family may be removed. This is simply a tool to help parents find compatible and caring matches with other parents.

Q: Who or how is it determined which family receives priority...specifically related to the statement that the presenter from the Gathering has a wait list?

C. Klaver: Priority is given to those who are members of that congregation - this is done loosely enough to include a relation of a member (a member’s father, etc). Churches very much appreciate this for all the effort they put in to the respite program.

Q: Is there a criteria to indicate that the individuals needs are too great to benefit from the respite...specifically related to the caregiver presenter stating she is interviewing for in home support services?

C. Klaver: Eligibility Criteria for Participants in the Gathering:
1. Early to mid-stage dementia/memory loss
2. Ambulatory, with no assistance to be in a bathroom stall alone. Can use an assistive device, walker, cane or wheelchair otherwise
3. Able to toilet themselves and manage incontinence products alone
4. Does not need medications during program. Cannot bring any medications to program
5. Does not display aggressive or inappropriate behavior
6. Caregiver needs the break
7. Ability to stay the duration of the day (10 a.m. to 3 p.m.)
8. If vulnerable adult, cannot be living alone or returning to residence without supervision

Q: How is this service advertised among the faith community?
C. Klaver: Brochures, tri fold board, bulletin notices, pulpit talks, ministeriums, professional groups - Public Health Nurses and Social Workers (case managers). Word of mouth is the best.

Q: Is there a certification or documentation to demonstrate the volunteer has successfully acquired the skills and knowledge being trained?
C. Klaver: No, they are all required to go through the training and all required to do quarterly training. Working in a group allows for great accountability and mentoring. The R.N. mentors while observing each respite day as well.

Q: Obviously, the focus here is faith-based involvement, but are there any models whereby corporations are blending in as part of wellness programs?
W.C. Hoecke: A faith-based program in upstate South Carolina began with one offering to put in a respite fund for one member of their local church. This member told her girlfriend what her church had done for her and that women’s husband donated $5,000 from his company to support that church’s efforts. He then went on to solicit an additional $5,000 from a fellow businessman and their respite voucher program was up and running. It is rare that a company can donate funds and know that 100% will go directly to support families. The key is that the company trusts the 501(c)(3), in this case a church, and the 501(c)(3) is willing to distribute benevolent gifts.

C. Klaver: I know of some employers that are seriously looking at the impact of caregiving on their employees 'sick and away' time because it is costing them a lot of dollars. Because of this, some have had a wakeup call to do NOON caregiver education over their staff’s lunch breaks. They see this as part of their “wellness programming” to help support employees in the double role of employee at work and caregiver at home. Local businesses in Minnesota, including Sam’s Club and Costco, have donated for Volunteer Appreciation events and local Gatherings. Donations include gift cards to help an individual site with some expenses (maybe a $50 or $100 gift card on occasion).

I want also to encourage you to continue to run with your desire to make this work. Thinking outside the box is exactly what it takes to get a feel for what your community/businesses are willing to consider. From my experience, however, businesses
are more willing to fund something already showing an impact, instead of a vision - grants seem to work similarly. Never give up on your dream to get funding from other larger potential sources. Use that passion to fuel your work and keep the fire going as you grow/strengthen.

Q: How many paid staff do each of your programs have and where does the funding come from pay those salaries?

W.C. Hoecke: My organization is a Parent to Parent and a Family Voices chapter for South Carolina. We have 75 employees (some part time) with approximately 570 volunteers, six regional centers and an annual budget of 1.4m. But respite currently has only a $10,000 budget, and this is for dissemination of information and technical assistance for those in SC who want to develop respite programs. This comes through federal Lifespan Respite grant to the SC Respite Coalition and the state Office on Aging and I am the only employee providing respite support.

We started our funding through the Governor's Developmental Disabilities Office, which awarded us $78,000 for three years to create a Parent-to-Parent respite program that morphed into our respite Co-op program. We then received funding from the Faith in Action program -- $35,000 over three years. We have also received funding from private family foundations.

C. Klaver: 2.25 FTE staff. Full time Coordinator (R.N.), 26 hour/wk Site Liaison (R.N.) and 24 hour/wk Business Specialist. The Lyngblomsten Foundation pays most of the salaries. We have a few grants - Anderson Foundation and Brookdale Foundation. We charge $45/person/site. We also charge the churches a yearly partnership fee $400 for corporate congregations belonging to Lyngblomsten, $600 for non-corporate congregations.

Q: At my church in Norfolk, VA, our "Living in Holland Ministry" provides a support group with child care available for children with special needs. We are also beginning a monthly respite afternoon next year. We have found that our teenage youth are great volunteers to work alongside the children that come with special needs (with adults helping too). Do any of the programs talked about today use teenage volunteers and what does that look like?

W.C. Hoecke: The Rave program in Reno, Nevada, while not a faith-based effort, used two special education teachers and student volunteers for respite for children 6 months to 7-8 years of age. It was a phenomenal program, but it may have run out of funding. We have also used teen volunteers very effectively at our respite co-ops. We always keep them in teams of two with plenty of adult supervision.
C. Klaver: We do not have any teens currently working in our respite program. We have had college students that we have precepted. We would consider internships with college/post college students. Here are my thoughts on using teen volunteers: I would partner the teen with an adult for a certain amount of time to monitor their ability to judge their understanding of working with children with special needs. You may want to create a ‘checklist’ of what you need them to demonstrate before they are paired individually. This would assist in your risk management.

You could encourage teens through this process by also offering them an incentive - you would be willing to be a reference for them for a future job application. Teens will have a different relationship with your special needs children than your adult volunteers so your time with them will be a win for them and a win for your children.

Since I have a 21 year old and 17 year old - I know that teens can be fabulous volunteers when they come with the right heart. They don’t have the checks and balances that adults hopefully do - they are more impulsive. If you have a training to offer, I would ensure they go through this training. Or if you don’t train, you may want to come up with a simple training just for the teens. What we consider ‘common sense’ is not common knowledge across the board. A 50 year old volunteer will come with different common sense than a 14 year old. Think of the ‘rules’ of the work you do and write them down. At least verbally mention them but of course, a handout helps those who learn better by reading- you will ensure they ‘got it’. Also a list of “what would be important to mention regarding the teenage volunteer” to provide to the coordinator or leader for that session - otherwise they may feel they should have known and be embarrassed to mention a problem they weren’t sure how to solve.

Q. How did and does the Gathering get the word out/market the program? Has there always been a waiting list or did it build?

C. Klaver: We utilize a brochure with photos for volunteers and participants at all sites in three counties. We provide one phone number for an intake for a potential participant, to sign up for volunteer training, to receive directions to the class, and to answer other questions as well. We have a display tri-fold board that has a calendar and is scheduled to go out to places including senior centers. We encourage churches to put it up at least twice a year with the brochures, including the job descriptions and application in each brochure. We advertise our web site to link them to details from Lyngblomsten’s perspective and it provides information on all our sites. We belong to professional groups where we can email the group with openings (e.g., memory care professionals, metropolitan caregiver support collaborative, senior workers, faith community nurse network, etc). We work with county agencies to advise them when we have an opening. The waiting list built over time.
We have done this for 10 years. Once word of mouth starts spreading information about the program, you will be surprised at the response. In the beginning, we tried to sell the program as a benefit for the caregiver, but you have to sell it also for what it can do for the person with the special need. Then family caregivers are more likely to come to the program.

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Caregiver Programs & Lifespan Respite:  
Technical Assistance Centers  

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