



Respite Review

December 2011

LIFESPAN GRANT TO PROVIDE RESPITE

GREAT NEWS! South Carolina was granted additional funds to provide respite to unserved and underserved populations. All the respite hours are required to be provided by September 30 next year.

In October 2009, South Carolina was one of the first 12 states to receive Lifespan funds from the Administration on Aging (AOA). Earlier this year, SC was among 24 states invited by AOA to apply to expand the grant for the 3rd and final year. We took a leap and were 1 of only 8 states to receive it!

While this is a *small* grant, it *will* provide respite. The focus is on family caregivers caring for adults between 18 and 60 years old and are not receiving respite now. The SC Respite Coalition will work with SC Autism Society, local faith communities, and the SC Adult Day Services Association and Adult Day Service providers across the state to serve families.

See “Expanded Grant” page 2

RESPITE SOLUTIONS CONFERENCE

The SC Respite Coalition will hold its 5th Annual Respite Solutions Conference on Thursday, February 16, 2012 at St. Andrews Baptist Church in Columbia.

The keynote speaker is **Mary Tutterow**, mother of an adult daughter with quite involved autism. Mary struggled with the idea that “God never gives us more than we can bear” until she realized that God intends our fellow humans to help us. Her bible study has helped family caregivers of all ages realize that asking for help is a strength and not a weakness.

See “Conference” page 2

REGIONAL ADVISORY COUNCILS TO START

The SC Respite Coalition will convene its first two Regional Advisory Councils in January. With the leadership of Gail Marion, Director of Rhodes Respite Program in Anderson and SCRC Board member (below R), the Upstate Council will meet 1/23/12 in Easley.



Peg Lahmeyer (above L) will help convene the Low Country Respite Advisory Council. Peg is Director of The Ark Alzheimer’s Family Support Services in Summerville, and serves on the conference planning task force each year. This photo was with Respite Coalition Executive Director, Susan Robinson (center) who is back with us again full time.

See “Advisory Councils” page 2

LIFESPAN RESPITE ACT TO EXPIRE

The national legislation, passed in 2006 to create more respite for family caregivers in the US, must be re-authorized in 2012 or it will expire. Except for the Family Caregiver Support Program, also a target

See “Lifespan Act” page 3

EXPANDED GRANT (CONT. FROM PAGE 1)

In collaboration with CLTC (Community Long Term Care), the Respite Coalition will offer respite to some of the family caregivers whose loved ones are on the waiting list (over 3,000 people statewide.) The SC Autism Society will subcontract to provide special respite events for waiting list families of SCDDSN (SC Department of Disabilities and Special Needs).

This grant also will enable the Respite Coalition to develop the infrastructure for a respite voucher program. Additionally, 10 mini-grants of about \$500 will be awarded to faith communities on the verge of starting a respite ministry. Ideally, we can demonstrate to Congress how much respite can be generated with small amounts of money and its impact of family well-being.

The Respite Coalition is most indebted to Denise Rivers and the LGOA for their flexibility and partnership in applying for this funding on very short notice. The funding is for the entire lifespan and will strengthen the work of the Aging and Disability Resource Centers, serving seniors and adults with disabilities statewide.

CONFERENCE (Continued from front page)

The conference is planned for faith-based and community leaders. It brings people together to learn about respite opportunities in faith communities and elsewhere in the community. It also addresses how to prepare and motivate family caregivers to develop and make use of respite resources.

Workshop sessions will address resources for funding respite programs, how to use volunteers, risk management, using bible study to lead family caregivers to accept offers of help and even ask for it. Go to www.screpitecoalition.org for details.

Again this year, the conference is partially funded by the Center for Medical Excellence and the Administration on Aging. We also are very grateful to St. Andrews Baptist Church for the donation of their facilities. **SEE YOU FEB. 16th!**

US Administration on Aging



St. Andrews Baptist Church, Columbia

HELP US RAISE \$500 - ONE VOTE A DAY!

In January 2012, one daily vote will help the S.C. Respite Coalition earn \$500. Or you can authorize us to vote for you and use your e-mail address. If you do, e-mail us by December 30 and give us all the information we need to represent you.



Daybreak Adult Care Services, in the Midlands, donates \$500 monthly to the organization that has the most votes. YOUR CONTACT INFORMATION WILL BE USED BY THEM ONLY FOR YOUR VOTE.

**EACH DAY OF JANUARY, VOTE FOR SC
RESPITE COALITION at
<http://www.daybreakcare.com/>**

We're counting on your votes!!

ADVISORY COUNCILS (CONTINUED FROM PAGE 1)

The Regional Respite Advisory Councils will collaborate and share information about family respite across the lifespan. They will strive to strengthen the network of organizations serving family caregivers in their region. Ideally the exchange of information across disciplines, age groups, and varying populations served will, at the least, maximize existing respite resources.

They will help the Respite Coalition Board of Directors and other regional Respite Advisory Councils to increase flexibility in respite service delivery and reach un-served and underserved populations, create volunteer-based respite, draw in and educate faith communities, and teach family caregivers to make use of respite.

To join a regional Respite Advisory Council or form one in your region, please e-mail or call Susan Robinson at the Respite Coalition office.

Mission of the SC Respite Coalition:

To expand quality respite opportunities in South Carolina throughout the lifespan for families having a member with special needs.

LIFESPAN ACT (Continued from page 1)

for elimination, this is the only legislation with a total focus on family caregivers.

In October 2011, Reps. McMorris Rodgers (R-WA) and Langevin (D-RI) introduced the Lifespan Respite Care Reauthorization Act of 2011 (HR 3266) in the US House of Representatives. It has been referred to the House Energy and Commerce Committee. It is easy to think you can not make a difference, but remember that legislators need to hear from just a few voters to learn that this issue matters.

Please Express Your Opinion. Call the capital switchboard at 202-225-3121 & ask for your Senator or Representative OR go to:
<http://www.archrespite.org/national-respite-coalition/reauthorize-lifespan-respite> to send an online message.

LIFESPAN RESPITE PROGRESS REPORT

Guided by the State Advisory Committee of respite providers, advocates and consumers, the Lt. Governor's Office on Aging (LGOA) is partnering with the **SC Respite Coalition** and Family Connection for the 3rd year of the Lifespan grant.

This grant recognizes that families do not operate in defined age and disability categories. Multi-generational families (3.8% of U.S. families house 3 generations per the 2010 census) are increasing. Resources for one age group might not be appropriate for another.



When the Respite Coalition and LGOA displayed at the Family Connection and SC Autism Society conferences, traffic was brisk, as parents of children with special needs explored eldercare resources for their parents or grandparents.

Cross-training is on-going between the staffs of the 10 SC Area Agencies on Aging (Aging and Disability Resource Centers and Family Caregiver

Support Programs) and the Family to Family Health Information Center which communicates with family caregivers whose children have special needs. Referrals back and forth are being made and we can document more discussion with callers about the issue of respite. Often this is simply not on the radar of many family caregivers, as their need for other resources has taken precedence for so long.

Statewide, four work groups are meeting to recommend how to improve coordination of existing respite services, identify gaps in them and work to build capacity at both state and local levels.

1. Gaps and obstacles to service

- Needs assessment
- Identification of what exists already
- What is missing?
- Barriers to using respite

2. Provider network development

- Recruitment strategies
- Type, cost and availability of respite services
- Training – how do we create a workforce?
- Models of respite (incl. Volunteer models)
- Adequacy/appropriateness of respite services
- Planned vs. emergency respite

3. Education and Outreach

- Understanding caregiver needs
- Education of caregivers re: benefits of respite, options for and strategies to develop respite networks/resources (as early as possible)
- Outreach and public awareness

4. Legislative and Policy Issues

- Funding streams - barriers and opportunities
- Policy and other barriers
- Policies to encourage use of respite

The Statewide Advisory Committee is composed of family caregivers as well as leaders from AARP, Alzheimer's Association, Aging and Disability Resource Centers (ADRCs), Family Connection, SC Autism Society, Family Caregiver Support Programs, SCDDSN, Veterans Administration, SC Department of Health and Human Services, SC Commission for Minority Affairs, Voices for the Voiceless, SC Department of Mental Health, SC Department of Social Services, SC DHEC Division of Children with Special Needs, Senior Corps Volunteer Programs, MS Society, Silver-Haired Legislature, SC Developmental Disabilities Council, Federation of Families, and Brain Injury Association of SC.

For more information visit the Coalition website at www.screstitecoalition.org



Allison Poole (L) is the part time Program Coordinator for the Lifespan Respite project. She is an experienced legislative advocate. Here she is with Board President, Kathy Mayfield-Smith (R).

Let your search engine give back!

While you search the internet, use “GOODSEARCH” as your search engine. When you choose your cause, put “ARCH National respite network” or “Federation of Families, S.C.” and a small donation goes to them!

CHECK OUT OUR WEBSITE

www.screpitecoalition.org has links to respite resources, materials for families and about the , conference, and information on respite in faith communities. The “What You Need to Know About Me” notebook for family caregivers to give their respite providers is also there.

Your feedback is not only welcome, but solicited!
What else do you need to know?

RESOURCES

For links to presentations at National Respite Conferences and webinars, go to www.archrespite.org

Create a calendar list of your needs at www.lotsahelpinghands.com. This is a great tool for a family caregiver, friend or social worker willing to coordinate help for a family caregiver.

Executive Director Back Full time

With the award of the expansion funds, Susan Robinson (previously Carlton) took a leap of faith. She left a secure hospice position to resume full time duties at SCRC. Though Lifespan funds are only for 1 more year, it is a major opportunity for SCRC. She brings fresh knowledge of direct work with family caregivers and is pleased to use it for the good of SC

THANKS, MADAM PRESIDENT!

It is to the credit of our tireless and gifted Board President, Kathy Mayfield-Smith, that the Lifespan and recent expansion grants were secured. A multi-talented person, Kathy gives countless hours of volunteer service a year to promote respite. For two years, she has served on the National Respite Conference planning committee and this year was a keynote panelist with Denise Rivers from LGOA.

Kathy helped to found the SC Respite Coalition with W.C. Hoecke and Connie Ginsberg of Family Connection of SC, Inc. She works full time as Research Associate Professor at the Institute for Families in Society USC and parents 3 children, two of whom have special needs. Her professional interest in respite pre-dates their arrival from work at USC Dept. of Pediatrics Center for Disability Research.

We are very grateful for her continued support.



Kathy, her husband, Bryan, and Susan’s son, Blake, helped Susan to move the Coalition office in 2010.



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