

TAKE A BREAK SC!



SUSTAINING SOUTH CAROLINA'S FAMILY CAREGIVERS THROUGH RESPITE

**Report of the Lifespan Respite
State Advisory Committee**

In Memoriam

Craig Stoxen, President and CEO of the SC Autism Society and a valued member of our Lifespan Respite State Advisory Committee, passed away unexpectedly. Craig was an innovative and insightful director and a tremendous asset to our lifespan respite endeavors. He will be greatly missed.



Transmittal Letter

To Members of the S.C. Senate and House of Representatives

In 2009 the Lieutenant Governor’s Office on Aging, in partnership with the South Carolina Respite Coalition and Family Connection SC, submitted a grant to the U.S. Administration on Aging to fund a Lifespan Respite Care Program. The purpose of the project was to establish a state and local lifespan respite system to improve access to respite services in South Carolina for all family caregivers of people of any age with any special need. Respite is defined as regular, temporary breaks from caregiving for a person of any age with a disability, special need or chronic illness. This initiative established a State Advisory Committee to guide the development of the coordinated lifespan respite system. In furtherance of the quest to coordinate and sustain lifespan respite in South Carolina we are pleased to submit “Take a Break SC! Sustaining South Carolina’s Family Caregivers through Respite”, a state plan to guide implementation of sustainable lifespan respite. The State Advisory Committee adopted a multi-disciplinary approach, through representation from the public and private sectors as well as consumers, to formulate recommendations in a holistic approach.

This project is the first of its kind in South Carolina and targets the following activities in furtherance of the objective: provide outreach, information and screening for respite services through the Aging and Disability Resource Centers and the Family-to-Family Health Care Information and Education Center to encourage use and connect family caregivers with respite options as early as possible; disseminate information and reach out to family caregivers across the state, providing information and training materials in support of respite usage; and build networks and capacity at the local level.

In light of the current economic situation the State Advisory Committee is offering several recommendations that we believe can be carried out through existing infrastructure, thus lessening the fiscal impact to those involved. Full implementation of all of the recommendations in the report, however, will certainly require additional funding. This funding will enable local

and statewide activities in furtherance of the objective to establish a state and local lifespan respite system. The South Carolina Respite Coalition, as the only statewide non-profit organization working with families across the lifespan to increase awareness of the need for respite, will serve as the facilitator for fulfillment of the recommendations and will utilize the collective expertise of stakeholders to provide guidance.

The State Advisory Committee members brought a wealth of knowledge and experience to this vital undertaking. The combined efforts of the aging community with the disability community have resulted in a roadmap for respite that will coordinate previously fractured systems into a cohesive initiative blanketing the state.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Tony Kester". The signature is written in a cursive style with a large initial "T".

Tony Kester
Director, Lieutenant Governor's Office on Aging

FOREWORD

The Encarta Dictionary defines a caregiver as “somebody who has the principal responsibility for caring for a child or dependent adult, especially in the home.” These eighteen words explain, but cannot express, what it means to be a caregiver. Our parents, children, siblings, and partners are the roots of our family trees. They are what give us our foundation, make us strong, and enable us to thrive. When a loved one is unable to live independently, we as caregivers become a new support for the family tree. Whether we have a medically fragile child or a parent with Alzheimer’s, our role becomes a lifeline. Our view of the world is forever changed when we become a caregiver.

My brother, sisters, and I could never have imagined the change in our lives when our mother was diagnosed with Alzheimer’s disease. Over a span of five years, we learned the challenges of this long farewell and the importance of family caregivers. We were fortunate to have home-based care for Mama for most of this journey. Respite serves not only the caregivers but the care recipients, as well.

This State Plan represents an opportunity to make critical changes in our efforts to ensure respite for South Carolinians who serve as caregivers for loved ones of any age or disability. I encourage you to read the plan and take steps to help all caregivers and care recipients receive what they need. If you are a caregiver, learn what is available for you and your loved one. If you are interested in advocating or volunteering, consider becoming involved in implementation of the recommendations put forth in the plan. Our family trees are always strongest when we have sturdy roots and an environment that makes it possible for all of us to age in place where we are planted.

A handwritten signature in black ink, appearing to read "Alan McConall". The signature is written in a cursive style with a large initial "A" and "M".

South Carolina's Respite for the Lifespan System

In 2009 the Lieutenant Governor's Office on Aging, in partnership with the South Carolina Respite Coalition and Family Connection SC, submitted a grant to the U.S. Administration on Aging to fund a Lifespan Respite Care Program. The purpose of the project was to establish a state and local lifespan respite system to improve access to respite services in South Carolina for all family caregivers of people any age with any special need. This initiative built on the infrastructure in place and established a State Advisory Committee to guide the development of the coordinated lifespan respite system.

The proposed project targeted the following activities in furtherance of the objective: provide outreach, information and screening for respite services through the Aging and Disability Resource Centers and the Family-to-Family Health Care Information and Education Center to encourage use and connect family caregivers with respite options as early as possible; disseminate information and reach out to family caregivers across the state, providing information and training materials to aid in mobilizing supports for respite and to encourage earlier and increased use of respite; and build networks and capacity at the local level to recruit and train volunteers to fill gaps in respite services, particularly in rural areas and through the faith based communities.

About the Partners:

The **Lt. Governor's Office on Aging (LGOA)** is the designated State Unit on Aging (SUA) and administers federal funding received through the Older Americans Act. The LGOA works with a network of regional and local organizations to develop and manage programs and services to improve the quality of life of South Carolina's older citizens, and to help them remain independent in their homes and communities.

The **SC Respite Coalition** is the only statewide non-profit organization working with families across the lifespan to increase awareness of the need for respite and to expand quality respite services for family caregivers of all ages. Begun through meetings with partners in 1999, a formal coalition was formed and thirty agencies agreed to be partners in the task of creating a statewide organization for respite. In 2001 incorporation papers were filed for the SC Respite Coalition and subsequent non-profit status was granted the same year.

Family Connection of South Carolina, Inc. is a community-based, family-focused organization that provides a support network to families who have children of all ages with disabilities, developmental delays and chronic illnesses. Founded in 1989 by a group of parents who have children with disabilities and special needs, Family Connection of South Carolina is based on the principle of parent-to-parent networking. Its primary purpose is to provide emotional support, assurance and information, with emphasis on matching a referred family with a trained, veteran support parent who has faced similar problems. The goal is to strengthen families through connections with parents who have faced, or continue to face, similar circumstances.

Vision: All South Carolina caregivers will have the respite services they need in order to have the strength to care for their loved ones of all ages.

Mission: The mission of the South Carolina Respite for the Lifespan project is to promote and support a statewide coordinated network of quality intergenerational respite care, ensuring seamless provision of respite services and training across populations.

South Carolina's Respite for the Lifespan System will work to achieve the vision and mission by:

- establishing a coordinated network that meets the respite needs of families, caregivers, and individuals across the lifespan
- ensuring seamless provision of respite services and training across populations
- creating opportunities for new respite services to fill identified gaps in service
- facilitating access to quality training for respite providers and families
- promoting awareness about respite care
- preserving and promoting respite in policy and programs at the national, state and local levels.

An integral component of the Lifespan Respite initiative was the creation of the Statewide Advisory Committee. It represents the collaborative effort which is a vital part of creating a statewide network of respite services. This multidisciplinary approach, through representation from the public and private sectors, enabled recommendations through a holistic approach to truly address respite needs across the lifespan.

The Committee worked diligently toward their determined mission and vision. Quarterly statewide meetings were held as well as numerous subcommittee meetings over the course of the endeavor.

S.C. Respite for the Lifespan Project
State Advisory Committee

Cindy Alewine, CEO/President
Alzheimer's Association – South Carolina
Chapter

Michele Armstrong
Mother of child with Down Syndrome

Teresa Arnold, Associate Director for State
Advocacy
AARP

The Honorable Lamar Bailes, Speaker
Silver Haired Legislature

Eve Barth, Program Manager
Lt. Governor's Office on Aging

Valarie Bishop, Executive Director
SC Developmental Disabilities Council
Office of the Governor

Patricia Brown
Consumer

Jeanne Carlton
SC Department of Health and Human
Services

Joyce Davis, Executive Director
Brain Injury Association of SC

Jocelin Dawson
SC Department of Health and Human
Services

Erin Donovan
SC Department of Health and Human
Services

Christina Emrich
Mother of two children with autism
christinaemrich@bellsouth.net

Diane Flashnick, Executive Director
The Federation of Families for Children's
Mental Health

Rachal Hatton, LMSW
Senior Resources, Inc.
Director of Foster Grandparent and Senior
Companion Programs

Wilfried (WC) Hoecke, Director of Family
Information
Family Connection of South Carolina, Inc.

Shawn V. Keith, Aging Director
Santee-Lynches Regional Council of
Governments
slaging@slcog.org

Kathy Mayfield-Smith
Institute for Families in Society
University of South Carolina

Lee S. McElveen, Program Coordinator
Hispanic/Latino Affairs
The South Carolina Commission for Minority
Affairs

Charles McLafferty, Board Member
Voices for the Voiceless

Anne McLean, Director of Advocacy and
Adult Services, ID/RD Division
SC Department of Disabilities and Special
Needs

Mallory Miller, Program Coordinator
HomeShare/Crisis Stabilization
SC Department of Mental Health

Sheila L. Mills, MPH, CPM
SC Department of Mental Health

Glenn Niske, Geriatrics Administrator
Officer
Williams Jennings Bryan Dorn
Veterans Administration Medical Center

Joe Ritchey, Family Caregiver Advocate
Central Midlands Council of Governments

Denise Rivers, Deputy Director
Lt. Governor's Office on Aging

Susan Robinson, Executive Director
SC Respite Coalition

Liz Smith, Project Manager
Child Care Services
SC Department of Social Services

Craig Stoxen, President and CEO
South Carolina Autism Society

Sam Waldrep, Bureau Chief
Bureau of Long Term Care and
Behavioral Support
SC Department of Health and Human
Services

Cheryl Waller, Director
Division of Children with Special Health
Care Needs
SC Department of Health and Environmental
Control

Marsha Ward, Social Work Supervisor
Geriatrics and Extended Care
Williams Jennings Bryan Dorn
Veterans Administration Medical Center

Anne Wolf, Assistant Deputy Director
Lieutenant Governor's Office on Aging

Table of Contents

Executive Summary	1
The Faces of Respite	4
Chapter 1 – Introduction to Respite and Extent of Need	8
Chapter 2 – Respite in South Carolina: Challenges and Opportunities	11
Chapter 3 – Recommendations of the State Advisory Committee	15

Appendices:

A. Text of the Lifespan Respite Act	24
B. Lifespan Respite Subcommittees	30
C. Adjunct Contributors	31
D. References	32
E. Credits	33

EXECUTIVE SUMMARY

South Carolina, like all states, faces an impending crisis -- how to care for a growing aging population as well as children and adults of all ages with disabilities and special health needs. Current estimates place the number of family caregivers nationwide at over 50 million. The number of family caregivers is anticipated to increase in the upcoming years, and so too will the physical, emotional and financial burden on caregivers. Unpaid family members provide 80% of long term care for people with special needs. The availability, accessibility and affordability of respite care are essential as we seek ways to sustain these family caregivers, keep families together and avoid costly institutional placements of loved ones.

Respite is regular, temporary breaks from caregiving for a person of any age with a disability, special need or chronic illness. It is the number one need identified by family caregivers; it is an essential service that keeps families together by protecting the physical and mental health of the caregiver and providing relief from the ongoing responsibilities that caregiving entails. Not to be confused with hiring a provider who handles the full time responsibilities of caregiving, respite offers a much needed break and some “me time” for a caregiver. Breaks can be provided for as little time as an hour or two or as long as a couple of weeks. Respite care can be provided in-home or in the community, by paid providers, volunteers, family members or friends, all of whom should have appropriate training and supervision. The term lifespan respite refers to care that is available and accessible to all family caregivers of individuals of any age with any disability.

In recognition of the significant contributions and needs facing America’s caregivers, Congress authorized the Lifespan Respite Care Act (Appendix A) in 2006. In 2009, the US Administration on Aging made funds available to enable states to establish, enhance and expand lifespan respite systems. Although \$94.8 million was originally proposed in the authorization bill, \$2.5 million per year was actually allocated. South Carolina was one of the first 12 states in the country to receive a modest 3 year grant through this program. Awarded to the SC Lieutenant Governor’s Office on Aging, in partnership with the SC Respite Coalition (SCRC) and Family Connection of SC, South Carolina’s Lifespan Respite program has worked to increase public awareness and the understanding of what respite is and why it is so vital. The grant has provided outreach to family caregivers by encouraging the use of respite, by connecting those in need with respite options and working to improve information dissemination to caregivers through existing state resources such as SC Access, Aging and Disability Resource Centers and the Family-to-Family Health Care Information and Education Center. Over the past 3 years, partners have coordinated existing respite services, identified gaps in service provision and worked to build capacity at both state and local levels by cross training existing providers for all ages. This program has also worked to mobilize respite volunteers within community and faith based organizations across the state.

The following recommendations were generated by four subcommittees within the State Advisory Committee, which focused on Gaps and Obstacles, Education and Outreach, Legislative and Policy Issues, and Provider Network Development. The recommendations are divided by the suggested time frame for implementation.

The SC Respite Coalition will serve as the overall facilitator for the recommendations, with key participants proposed under each recommendation. The term “Responsible Party” identifies suggested agencies or entities that may be appropriate for assuming responsibility for implementation of these recommendations. The parties identified are by suggestion of the Advisory Committee, and the agencies or entities named have not provided a formal review or approval of the recommendations.

For full details and rationale, please view Chapter 3 of this report.

For Implementation in 1-2 years:

Recommendation 1: Modify SC Access website to create a user-friendly resource for caregivers.

Recommendation 2: Generate more public awareness about the role and utilization of respite.

Recommendation 3: Disseminate comprehensive respite information to diverse populations through multiple venues, to include social networks/computer technology.

Recommendation 4: Create a lifespan respite brochure to educate legislators.

Recommendation 5: Create a lifespan respite toolkit.

Recommendation 6: Obtain proclamation either from the Governor’s Office or the House/Senate recognizing Lifespan Respite (for a set time to be determined).

Recommendation 7: Continue to strengthen the SC Respite Coalition as the lead advocacy group for respite in the state by developing an accurate e-list of respite advocates to whom time sensitive information can be distributed in a quick and efficient manner.

Recommendation 8: A comprehensive list of respite and/or caregiver training resources, including local and national, should be listed on the South Carolina Respite Coalition website.

Recommendation 9: Add a respite provider self-assessment tool on the South Carolina Respite Coalition website.

Recommendation 10: Recruit faith communities to develop respite programs and sustain seed funding to support the development and implementation of these services.

For Implementation in 3-5 years:

Recommendation 11: Assemble existing information resources and establish a centralized access point. Utilize established libraries as part of the infrastructure.

Recommendation 12: Create a dedicated website for respite.

Recommendation 13: Expand training on special needs populations and respite providers to first responders (i.e. EMS, firefighters, law enforcement and the medical community).

Recommendation 14: Generate innovative respite programs for persons who do not meet the requirements for participation in existing programming.

Recommendation 15: Establish a respite assessment tool to provide universal foundational material and which is all-inclusive, i.e. caregivers, care recipients and families.

Recommendation 16: Advocate for state funding to continue activities included in the Lifespan Respite Expansion grant.

Recommendation 17: Solicit technical colleges and universities to approve respite provision by their students as part of a curriculum and/or individual course.

Recommendation 18: Encourage development of emergency respite options in existing skilled nursing and assisted living facilities, hospitals, respite homes, or among private providers OR develop plan to create a statewide system or build facilities to meet family respite needs at time of crisis.

For Implementation in 6-10 years:

Recommendation 19: Create a centralized toll-free number/clearinghouse for access to emergency resources for caregivers and care recipients.

The Faces of Respite

When you have children with autism, respite can often be difficult to come by. As a family, we continue to struggle with respite options. Sometimes respite is as simple as being able to attend adult Sunday school at church or have coffee with a friend, but very rarely are we able to enjoy respite as a couple.

We have been very fortunate to be able to take advantage of the local Family Connection and SC Autism Society respite opportunities. The best respite experience we ever had was during one particular Valentine's Day. The SC Autism Society sponsored a respite event for children on the autism spectrum and their siblings at a bounce house. For the first time in over six years, we were able to go out to dinner, just the two of us. The last time we had been out as a couple was when I was pregnant with our youngest child.

Our boys can be so unpredictable, and even relying on family for childcare seems unfair to them, particularly our older parents who have an increasingly difficult time managing two rough-and-tumble, very strong boys. It was such a relief just to be able to spend a quiet dinner together and not worry about whether the boys would be taken care of, or whether they would throw a tantrum or display unusual or quirky behavior that would baffle or frighten a typical sitter.

Because the event included staff from the SC Autism Society, we knew they would know how to manage typical issues that could arise and were able to enjoy a memorable Valentine's Day dinner without feeling the need to call and check in every two minutes. Our older daughter was also able to enjoy herself with some of the other older siblings without feeling pressured to have to watch after her little brothers.

Just those two hours of being able to re-connect as a couple made such a difference! It reduced our stress level and made it easier to manage challenges later on in the week. It also helped us to be more of a 'united front' on parenting issues, and helped us to draw closer as a couple. It

helped to bring down the stress level of the family in general by allowing the kids some great play time and helping us as Mom and Dad to unwind.

Even a few hours of respite can have a huge impact on us as a family, as it truly helps us as parents to recharge so that we can better manage the challenges of raising special needs children.

~ Adam and Christina E. are the parents of two children with Autism

I had the best vacation with my husband thanks to you. It was so relaxing, fun and restful. We even took two afternoon naps! I was in desperate need of a break. Now I feel rejuvenated, willing again to do those tasks that are expected of me. It is very important for a caregiver to have some relief. Knowing that there are people that understand and can provide this keeps me going! God Bless You All.

~ Donna E. is caring for her adult sister with intellectual disabilities



My wife is in the latter stages of Alzheimer's and I have been keeping her at home. Her social worker suggested that I apply for a \$500 voucher from the SC Respite Coalition. I applied and was approved. I decided to go fishing with some family and old friends. The day before I was leaving, I felt like was deserting my wife and thought I wouldn't go. However deep down inside, I knew that I was just digging myself deeper into a hole every day. So I went anyway.

My kin and friends felt like I needed to stay busy. Well, I guess maybe they were right. I was tired but it was a different kind of tired. This kind of tired comes from day after day of constant caregiving with no end in sight, with no hope and no one to care. This kind of tired feels like tiredness from working even though I hadn't been doing any real demanding physical work. I felt weak and dizzy and not able to concentrate. It seemed that no one had any time to spare to help. Respite allowed me to be with people who care, and realize that some people understand what caregivers are going through. My fishing trip reminded me that I could still have a life when all this is over, and I got to be the kind of tired that a little rest would cure.

~ Henry G. is taking care of his wife Brenda who has Alzheimer's Disease



I have provided care for my son Eric 24 hours a day, 7 days a week since his birth 37 years ago. I don't get Christmas, Thanksgiving or any of the holidays that working people outside of the home get. I love my son and I want what's best for him and I'm not trying to be a martyr. It's a matter of doing God's work but even God had to take a break and rest from it all. Respite has given me a chance to take a break, take a breath and catch a second wind so that I can keep caring for my son at home.

~ Brenda S. is taking care of her adult son Eric with Rubenstein-Taybi Syndrome



I can't begin to describe the blessing of free time that respite has given me. It is wonderful that I can choose a good friend or family member to spend time with my mother while I take a break and know that she enjoys that time as much as I do. Mama is 93 years old and I have been with her for 14 years and I feel so blessed to be able to keep her at home where she is happiest.

~ June R. cares for her elderly mother Minnie



Respite has been a huge benefit to our family. Our son also benefited because he got to spend some quality time away from us and with new faces. Respite is a great relief and we would love to continue to receive this service if it is still available in the future. We plan to contact our state legislators and let them know how much respite means to our family.



~ James and Inez I. care for their adult son, Trey, who is living with congenital hydrocephalus

We were able to get respite through our church (Columbia 1st Church of the Nazarene). This was the first time our family has ever used respite and it was a much appreciated gift! In the distant past, we had always relied on extended family members to step in to give us a break, but we no longer live near these family members, as we had moved to Columbia over 5 years ago, so with this program, my husband and I were able to use the respite money to actually pay for a caregiver to come and take care of our 14 year old son, Matthew, who has PDD, moderate cerebral palsy and epilepsy. We took this opportunity of the respite to celebrate our wedding anniversary and were able to enjoy an entire day away, eating a nice meal and going to a movie. We had so much extra time, that we added some errands and were able to go to a local bookstore, where we perused books at our leisure, topping it off with coffee at Starbucks. How nice it was, just taking our time, instead of feeling panicky over getting back at a certain time, so we didn't have to pay out money we didn't have; having the funds to pay a caregiver for as many hours as we needed and more, and not having to worry about rushing back in a smaller time frame, gave us time to just relax and really enjoy each other's company, and we cannot even express when we were last able to do that. The respite money paid for the caregiver at the amount the caregiver needed to be paid. Usually, when we can budget for some time away from home, leaving our son in the hands of a caregiver, we've only been able to grab about 2 hrs, which does not allow time to relax and really enjoy anything, much less each other's company, because what money we have, has to be split frugally between paying for a caregiver and then either a meal for us somewhere or just running errands. The respite grant money opportunity made available through our church, made it easy for us to access the funds and we were able to take a much needed break, our son was able to spend time with someone other than his parents, and we could go out with peace of mind, knowing that everything was handled, and with less stress involved, and that's key to the whole opportunity, having less stress.



~ Randy and Beth B. care for their 14 year old son who has various special health care needs

As parents of a daughter with mixed quad cerebral palsy who requires total care for all areas of daily living, the respite program at Epworth Early Intervention Center has been a blessing. Adia, who is 11, has attended respite since she was 2 years old. Although Adia was our only child at

the time, the respite program provided my husband and I with time to relax, reconnect, and often just allowed us time to breath, which surprisingly was sometimes difficult when caring for a two year old 24/7, who for all intents and purposes was more often than not like a newborn. Today we have three children in total, 3 year old and 6 year old sons, plus Adia. Respite still provides us a much needed outlet where we can go to dinner or a movie or just run errands, but it also allows our children to interact with other kids, special needs and typically developing, while doing fun activities. Our sons get to talk with other siblings of kids with special needs so that they can see that they are not unique. But best of all respite provides Adia with an opportunity to hang out and play with persons who don't just see a little girl in a wheelchair, but see Adia. We all look forward to our monthly respite and our thankful that Epworth is there for us.



~ Aisha and Kedrick L. are the parents of an 11 year old daughter with cerebral palsy

People who are not living this nightmare have no idea what it means to have a break. And most don't realize how many people are helped by just one of the SC Respite Coalition vouchers. Not only did it give our son and me 50 glorious hours of freedom but it helped the lady who cared for my husband and her family of six in which she is the only one working now. She only has a part time job so to get extra hours here and there help not only to keep their home from going into

foreclosure it keeps food on the table and gas in their 1996 car. And as for our getaway trip to Conway, the respite voucher helped even more people by enabling us to pick up a van full of adult diapers that are desperately needed here in the Upstate. So for those who are blessed enough in their lives not to know anything about these precious respite vouchers, they touch more lives than you know. Thank you so much and may God bless you for all you do.

~ Linda B. is caring for her husband David who suffered severe brain damage following oxygen deprivation during a cardiac arrest



I wish my family had known about respite care five years ago, when my 81-year-old father-in-law was caring for my mother-in-law, who was battling Alzheimer's. We knew he was struggling, never getting a break, but we didn't know there were options. I truly believe that if he had had more help, his health would not have declined so quickly, and he would still be able to live at home, puttering around having enough money for them to live out their years at an assisted living facility and memory care facility.

~Debbie H.

CHAPTER 1

Introduction to Respite and Extent of Need

Background

According to the US Department of Health and Human Services, over 50 million people provide care each year for family members who are chronically ill, disabled or aged. In South Carolina, it is estimated that approximately 770,000 South Carolinians are serving as family caregivers at any given time and that 1.13 million individuals are caring for an adult with limitations of daily activities at some point during the year. The estimated economic value of this unpaid care to South Carolina is over \$7.4 billion annually (Valuing the Invaluable: The Economic Value of Family Caregiving; AARP, 2011 Update). Moreover, based on the 2010 census an additional 200,000 residents are caregivers for other populations not enumerated in the AARP report. Often, family caregivers do not define themselves as such. They simply identify as mothers, fathers, daughters, sons, siblings, spouses or friends who have an obligation to care for their ailing loved one. They may not realize the importance of, or feel guilty about, “taking a break” and underestimate the impact that caregiving can have on their own health. According to a survey conducted by Caring Today (www.CaringToday.com; Caring Today Magazine, LLC), 4 out of 10 family caregivers reported increased feelings of depression since becoming a caregiver while 3 in 10 feel that their personal health is suffering. In addition, many studies on caregivers demonstrate that:

- Family caregivers suffer a chronic condition at more than twice the rate as non-caregivers
- Divorce rates among parents of children with special needs are double that of parents with typical children, particularly in the first several years after birth and/or diagnosis
- Family caregivers who provide more than 36 hours of care weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For adult children caring for a parent, it is twice as high; for a spousal caregiver, the rate is six times higher
- Elderly spousal caregivers with their own history of illness, and who are experiencing care-related stress, have a 63 percent higher mortality rate than non-caregiving peers (www.CaringToday.com; Caring Today Magazine, LLC)
- The National Alliance on Caregiving (NAC) and Evercare (2009) recently showed that the economic crisis in the US has resulted in 6 out of 10 family caregivers feeling less comfortable with taking time off to care for a loved one. In addition, 51% of those surveyed said that they feel an increased amount of stress in caring for a loved one due to the current economic climate

“I love my son and I want what’s best for him and I’m not trying to be a martyr. It’s a matter of doing God’s work but even God had to take a break and rest from it all.”

Respite is an essential service that provides family caregivers with the relief necessary to maintain their own physical and emotional health, thereby allowing families to successfully

continue caring for their child or adult family member in the home. By improving family relationships and stability, respite also helps families to delay, and in many cases avoid altogether, costly hospitalization, residential or nursing facility care. For example, studies have shown that children with special health care needs whose parents utilize respite not only require fewer doctors' visits, but are hospitalized less frequently (Benefits and Costs Savings Due to Respite, National Respite Coalition, 2009). Chronically ill elders whose families use respite also are hospitalized less frequently and respite use has been shown to decrease the probability of nursing home admissions (Benefits and Costs Savings Due to Respite, National Respite Coalition, 2009).

As little as 4 hours a week has been shown to make a significant difference in the lives of caregivers. At an average cost of \$17 per hour, the cost for a year's respite would be less than \$3600 per year per family. In contrast, a year of residential or nursing home care costs in excess of \$71,000 annually.

“Just those two hours of being able to re-connect as a couple made such a difference! It reduced our stress level and made it easier to manage challenges later on in the week.”

(MetLife Mature Market Institute Survey, 2011) The estimated 50 million caregivers nationwide provide at least \$375 billion in uncompensated care services, amounts which are approximately the combined annual costs of Medicare and Medicaid. U.S. businesses also incur high costs due to decreased on the job productivity by working caregivers.

MetLife estimates the dollar amount lost to employers to be between \$17.1 and \$33.6 million per year, including the costs of absenteeism, interruptions during the workday and costs to hire new employees for those who quit due to caregiving responsibilities (MetLife Mature Market Institute, 2006; cited from Lifespan Respite Task Force, National Respite Coalition).

It is also important to note that respite benefits both the family caregiver and the care recipient. Not only does the loved one benefit from a rested and renewed caregiver, but many studies show that recipients of care need a break from their primary caregiver and that affirmation from a different person and exposure to new faces and new environments is good for them as well.

Caregiver Population and Extent of Need for Respite

In South Carolina, the number of people with disabilities and special needs in all age brackets continues to grow. Estimates for 2015 are that just over 900,000 South Carolinians will be age 62 and over (Census, 2010). Additionally, the SC Budget and Control Board Office of Research and Statistics (2007) reports that there are over 387,000 children and youth with one or more special health care needs “requiring extraordinary care above what a typically developing child would require.” Census estimates from 2009 show that among South Carolinians age 5 and over, 15%, or 638,000 individuals, have a disability of some form. From 2000 to 2010, the number of people known to have Alzheimer's and related dementias in the state increased by 19%. By 2015 it is expected that new cases will increase by another 49%.

It is difficult to determine the true unmet need for respite in South Carolina. In a 2011 survey of providers, we (the Lifespan Respite Program) found that the vast majority of providers document only the respite they provide, not the requests they are unable to serve. Many families

who need it do not ask for it and others are resistant to use it. From the research and surveys we conducted, we know that families having a member with higher care needs (e.g., behavioral health, medically complex, severe physical challenges) have more difficulty finding respite services. We also know that families caring for a young adult have high unmet respite needs and are at greater risk for out-of-home placement. Given the level of care requirements for Medicaid waivers, people on those waiting lists are more likely to have more complex care needs, and currently, are not getting much needed home and community based services including respite. As of the end of 2011, the numbers of people on waiver waiting lists are as follows:

- Community Choices, formally elderly and disabled (3975)
- HIV/AIDS (83)
- ID/RD (2,300)
- Medically Complex Children (128)
- Head and Spinal Cord Injury (402)
- Community Supports (3500)
- Pervasive Developmental Disabilities (502), and
- Psychiatric Residential Treatment Facility alternative (3).

“For the first time in over six years, we were able to go out to dinner, just the two of us.”

“Mama is 93 years old and I have been with her for 14 years and I feel so blessed to be able to keep her at home where she is happiest.”

“Our son was able to spend time with someone other than his parents, and we could go out with peace of mind, knowing that everything was handled, and with less stress involved, and that’s key to the whole opportunity, having less stress.”

CHAPTER 2

Respite in South Carolina Challenges and Opportunities

Respite Infrastructure, Funding and Service Delivery

In both research and practice, nationally and in South Carolina, respite care is still the need most frequently identified by family caregivers (Brigel & Ethridge, 2010; Singer et al, 2010; NAC/AARP, 2009; Evercare, NAC, 2006; Brazil, K, et al, 2005; Plauche Johnson, et al, 2005; Family Connection of SC, 2009; Continuum of Care, 2001, 2005). Although on the surface, South Carolina appears to have numerous respite services, these resources are critically inadequate to meet the needs of most families. Some population groups are served better than others; but in general, respite is in short supply, inaccessible or unaffordable. It is significantly underfunded for those who need subsidy and difficult, if not impossible, in some places and for certain populations with particularly complicated physical and mental conditions, to find trained respite providers. The recent recession and state budget deficits have exacerbated the problem.

According to 2012 SC Access data, there are 310 in-home and 346 out-of home respite services for persons with disabilities and special needs in South Carolina. The majority of funding for respite flows through four major agencies and two private, non-profit organizations. These entities are, therefore, responsible for most of those providers and the respite provided by them throughout the state, leaving major gaps for families not eligible for services via those agencies. The S.C. Department of Disabilities and Special Needs (DDSN) provides respite vouchers with state appropriated funding through 39 local Boards representing 46 counties and through the state Autism Division, although as noted, DDSN has significantly reduced its support for respite care as a result of multi-year budget cuts. Respite is available through three Home- and Community-Based Care Service (HCBS) waivers operated by DDSN (i.e., ID/RD, Head and Spinal Cord Injury and Community Supports). In addition, DDSN operates a respite initiative, The Caregiver Relief Program, through grants awarded in eight areas of the state to fund innovative relief programs for people who are on the waiting list for services. Various services provided via the HCBS waivers also give caregivers a break; i.e., attendant care, companion, adult day health, day activity, support service centers and personal care services. S.C. Medicaid's Community Long-Term Care Division provides various forms of respite (e.g., in-home respite, adult day health care, companion services, institutional respite, Pediatric Medical Day Care) for people who meet an institutional level of care and are in five HCBS waivers: Community Choices (Elderly/Disabled -18+); HIV/AIDS (any age); Ventilator Dependent (ages 21+), Psychiatric Residential Treatment Facility alternative (ages 4-19) and Medically Complex Children (0-18 years old). In 29 of 46 county offices, the Department of Social Services provides some respite to families who are at risk for abuse and neglect including children with disabilities. The Department of Social Services also provides respite to its foster families by paying them to give each other breaks.

“We knew he was struggling, never getting a break, but we didn’t know there were options.”

It is important to note that because of the great demand for respite services, many of these programs must place applicants on waiting lists. A population which is particularly underserved is that of families with young adult family members who are disabled. Through a one year grant, the LGOA and the SCRC are currently providing respite to this group; specifically to adults with disabilities who are on a waiting list for services. This limited funding will provide respite to approximately 120 family caregivers. This represents less than eight percent of the waiting list for the Community Choices waiver.

The LGOA, partnering with the SC Area Agencies on Aging, provides respite vouchers and other services through the Family Caregiver Support Program (FCSP) to four groups of caregivers: (1) unpaid caregivers of frail or disabled older adults; (2) caregivers of someone with Alzheimer's disease or other dementia; (3) grandparents caring for an adult with disabilities 19-59 years; or (4) seniors raising a child 18 or younger. Through this consumer-directed program, ten regional Family Caregiver Advocates work one-on-one with caregivers providing counseling, assessment, training and help finding resources. Eligible caregivers may receive a mini-grant to purchase respite or other services from the provider of their choice (neighbor, agency, or family member). In 2010, 1,853 caregivers purchased 194,240 hours of respite with a grant averaging \$538. Making careful choices the average caregiver was able to purchase 105 hours of respite at an average cost of \$5.14 per hour. Also, 3,794 family caregivers participated in more than 11,216 caregiver training programs, counseling and support sessions. Also through the LGOA, the Alzheimer's Resource Coordination Center (ARCC) awards grants to communities to develop respite programs. In FY 2011, the ARCC respite grantees provided 33,850 hours of respite to 57 families.

The Alzheimer's Association of SC also provides vouchers (up to \$500 per year) for respite to families caring for a loved one with Alzheimer's. During Fiscal Year 2011, 3320 families received vouchers through this state funded program. Other providers include adult day care programs, private home health providers and sitter services in many areas of the state; however, respite is not covered by most insurance and most families in South Carolina cannot afford private providers on an ongoing basis, if at all.

“My fishing trip reminded me that I could still have a life when all this is over, and I got to be the kind of tired that a little rest would cure.”

Faith and community based organizations are also a source of respite care in the state. Over the three years of the Lifespan Respite Grant, the SCRC has begun cataloguing faith based respite programs, as well those operated by community and private organizations around South Carolina. To date, we have identified over 30 such respite programs serving children with special needs, adults with special needs and individuals with Alzheimer's, statewide. It is likely that more programs exist, both formally and informally, and the SCRC continues to pursue information for referral purposes and to stimulate the development of such programs. Sustaining these programs is difficult due to their reliance on volunteers and the need for continual reinforcement.

The Veterans Administration recognizes care giving places high burden on caregivers of seriously injured veterans. Respite care is designed to give primary family and other family caregivers temporary relief from the demands of the daily care, thereby supporting the veteran's

desire to remain in the home. The VA currently has authority to provide respite care for up to thirty days annually and additional days may be approved by the VA medical center director. The VA has approved additional respite care for the purpose of caregiver training for the Comprehensive Assistance for Family Caregivers Program (seriously injured post 9/11 Veterans). The VA is committed to providing clinically appropriate respite care services through the use of VA and non-VA programs and contracts. Because military families are so mobile, self-help techniques to build a “circle of support” around them are not as effective as among families that stay in one community. Solutions for serving military families, however, are important in a state with as many military bases as ours. South Carolina is one of five states working with the Army’s “Give Army Parents a Break” pilot respite program targeting families of active duty reserves, National Guard and recruiters. See Appendix B for more information and statistics on *Where Families Find Respite in SC*.

Other creative sources of respite include “respite events” sponsored by the South Carolina Developmental Disabilities Council and carried out by organizations such as the SC Autism Society and the SC DDSN. These events offer a periodic respite afternoon or evening for families who are not currently receiving respite services but are on an agency’s waiting list. Events have taken many forms, ranging from fun nights at “bounce house” facilities for children with autism and their siblings to evenings of food, massages and the provision of resource information for families having a member with special needs. Several such events have taken place over the past year and more are currently scheduled around the state during the second half of 2012. The South Carolina Developmental Disabilities Council has approved a new grant that will fund Family Connection to hold five events in targeted counties across the state in conjunction with DDSN that will offer a night of fellowship, food and relaxation for families and offer parents/caregivers information on community and statewide resources. Respite will be provided at each event. These events will be held between July 2012 and June 2013. The SC Respite Coalition, through a grant with the LGOA, is partnering with the Autism Society to sponsor respite events in four areas of the state for families of individuals currently on waiting lists for care. In many instances, these “respite events” are public-private partnerships as private businesses provide the venue for the event. Some private businesses also are beginning to recognize the need for respite care in their respective communities and open their doors to families. One example in the Columbia area is *Monkey Joes*, an indoor recreation facility that offers a “Special Needs Night” once a month, free of charge, for children with special needs and their siblings. While parents are required to stay on site, comfortable seating, flat screen televisions and computer stations are available to enjoy.

“But best of all respite provides Adia with an opportunity to hang out and play with persons who don’t just see a little girl in a wheelchair, but see Adia.”

Although South Carolina is finding some creative ways to provide this vital service, most families in need are still falling through the gaps in terms of funding streams and eligibility criteria and are either receiving no respite or receiving much less respite than they need. The Lifespan Respite Program continues to strive to fill these gaps by creating a seamless system of care in South Carolina that addresses the needs of families of all ages, with all diagnoses and disabilities.

Barriers to Respite

Overall, there are too few resources or options for respite. Family caregivers identify two major barriers to obtaining respite:

- lack of financial resources (Family Connection, 1998, 2009; SCRC, 2008; FCSP, 2008; Casado, B, 2008), and
- lack of qualified providers (Family Connection, 1998; NAMI, 2002; Continuum of Care, 2001).

Some agencies provide vouchers to pay for respite identified by the family. Many families use vouchers successfully; however, the limited resources (less than \$500 per year) often do not meet the total need. Other families have difficulty finding a respite provider due to the level of care that is required and limited social supports. Although a variety of formal respite programs exist, restrictive eligibility criteria excludes many families based on category of special need/disability, age, location, lack of transportation as well as other criteria. Legal constraints such as the Nurse Practice Act and tuberculosis regulations in residential facilities severely limit flexible options for emergency respite or respite for individuals with medically complex conditions.

The need for coordinated efforts and innovative solutions for families is more critical than ever. Fostering public/private partnerships to build community and family capacity, mobilizing volunteers, promoting respite to caregivers as a health promotion activity, providing flexible funding for consumer directed respite and training families to build circles of support that encourage relationships for respite are among the options to be considered.

“Respite has been a huge benefit to our family. Our son also benefited because he got to spend some quality time away from us and with new faces.”

A major barrier lies within families themselves. Despite the need and known benefits, many families do not recognize the need; and even when they do, do not readily leave their loved one with someone else (Family Connection, 1998; Rudin, J, 1994; Strain, et al, 2002; Friends FS#14, 2007). Due to this family resistance, some respite services that do exist are underutilized. The rural nature and high illiteracy rates in South Carolina complicate service delivery and exacerbate the problem of finding respite providers. According to the US Census Bureau (2010), 16.4 % percent of the population in South Carolina lives below the poverty level. Twenty two (22%) percent of SC children live in poverty (US Bureau of the Census 2006) and 38% live in single parent homes (SC Kids Count Report, 2005). Caregivers are ill-prepared for their role, often receive little or no support and have few central contact points through which to find respite. There are inadequate resources to meet the needs of most families and resources are, in

fact, shrinking due to state and local budget cuts, growth of the elderly population, high unemployment rates and increased costs of health care services. State and federal governments cannot meet all the respite needs of all families, but must partner with private resources in order to promote the development of creative solutions, such as volunteer-based programs, public-private partnerships and faith based respite programs essential to providing care for all those in need.

“Now I feel rejuvenated, willing again to do those tasks that are expected of me. It is very important for a caregiver to have some relief”

CHAPTER 3

South Carolina Lifespan Respite System State Advisory Committee (SAC) Recommendations

Consensus was reached among the SAC members on the creation of subcommittees to address the four aspects critical to providing respite across the lifespan. The subcommittees created were Gaps and Obstacles, Education and Outreach, Legislative and Policy Issues, and Provider Network Development. SAC members chose their respective subcommittees and each was responsible for bringing recommendations before the full body.

The following recommendations, with their accompanying rationale, are the product of the four subcommittees with input from the full State Advisory Committee. The recommendations are divided by the suggested time frame for implementation. Where available, possible action steps have been included for their respective recommendations.

The SC Respite Coalition will serve as the overall facilitator for the recommendations, with key participants proposed under each recommendation. The term “Responsible Party” identifies suggested agencies or entities that may be appropriate for assuming responsibility for implementation of these recommendations. The parties identified are by suggestion of the Advisory Committee, and the agencies or entities named have not provided a formal review or approval of the recommendations.

For Implementation in 1-2 years:

Recommendation 1:

Modify SC Access website to create a user-friendly resource for caregivers.

Rationale:

1. SC Access is a known tool for many professionals who can serve to introduce its availability to consumers.
2. SC Access can serve as an entry point to respite services and information while a dedicated website is being developed.

Responsible Party:

Lt. Governor’s Office on Aging

Recommendation 2:

Generate more public awareness about the role and utilization of respite.

Rationale:

1. Research shows that respite decreases the risk to caregivers, reduces the risk of acute hospital admissions and helps prevent or delay costly placements in assisted living facilities or nursing homes.
2. Unpaid family caregivers provide 80% of all long term care in the U.S. Most of the 770,000 family caregivers in South Carolina receive little or no support and are unaware of the benefits of respite.
3. Family caregivers in SC provide 737 million hours of ‘free’ care for their loved ones each year and are at higher risk for stress, depression, physical and financial problems and early death.

Responsible Parties:

South Carolina Respite Coalition and community partners; appropriate government entities; medical community

Recommendation 3:

Disseminate comprehensive respite information to diverse populations through multiple venues, to include social networks/computer technology.

Rationale:

1. Increased availability of information will empower caregivers and care recipients.
2. Multiple venues for disbursement enhance the reach of information.

Responsible Parties:

Public Libraries; South Carolina Hospital Association; South Carolina Medical Association; South Carolina Chapter of the National Association of Social Workers; faith based communities; appropriate government entities

Recommendation 4:

Create a lifespan respite brochure to inform legislators.

Rationale:

1. Increased awareness and understanding of the issue of lifespan respite is vital to the well-being of caregivers.
2. Distribution of information to legislators and subsequent discussion will lead to finding champions for lifespan respite.
3. The brochure will give all respite advocates/partners a focal point and help them deliver the same message.
4. Listing the partners that have more legislative visibility will give the issue more visibility and credibility.

Action Steps:

Include personal stories from families that have experienced and know the benefits of respite.

Utilize the brochure to explain the concept and importance of lifespan respite for family caregivers.

Hand deliver brochures to the state legislators' offices.

Responsible Parties:

South Carolina Respite Coalition; respite advocates

Recommendation 5:

Create a lifespan respite toolkit.

Rationale:

1. The toolkit will provide additional information including real life stories about the benefits of respite, additional statistics, etc. (above that provided in the brochure) further increasing awareness of the issue.
2. This detailed information will keep all interested parties (agencies, non-profits, individuals) on the same page in terms of advocacy and understanding of the issues involved.

Action Steps:

Distribute the toolkit to state agencies and nonprofit organizations to enhance education about lifespan respite and provide the tools necessary to promote it within their organizations and legislatively.

Responsible Parties:

South Carolina Respite Coalition; respite advocates

Recommendation 6:

Obtain proclamation either from the Governor's Office or the House/Senate recognizing Lifespan Respite (for a set time to be determined).

Rationale:

1. More publicity and legislative awareness reinforces the foundation for lifespan respite.
2. A rally would allow more families to come out, be heard and speak with their legislators.
3. Possible champions could be identified to speak.
4. A rally could serve to highlight the completed lifespan respite plan submitted by the State Advisory Council.

Action Steps:

Utilize a proclamation to establish a Lifespan Respite for Family Caregivers day or week.

Plan a Lifespan Respite rally at the State House in conjunction with the signing of the proclamation.

Responsible Parties:

South Carolina Respite Coalition; State Advisory Council member organizations

Recommendation 7:

Continue to strengthen the SC Respite Coalition as the lead advocacy group for respite in the state by developing an accurate e-list of respite advocates to whom time sensitive information can be distributed in a quick and efficient manner.

Rationale:

1. The more “go to” advocates an issue has, the better the chances of it being heard and getting crucial attention from legislators.
2. Legislation and policy issues move and change quickly; advocates need to be able to be reached in a timely manner.

Action Steps:

Clearly identify methods for recruiting advocates including at the respite awareness event, conferences and other appropriate venues.

Encourage utilization of e-lists and contact lists by the State Advisory Council to distribute information about the South Carolina Respite Coalition.

Responsible Parties:

South Carolina Respite Coalition; State Advisory Council member organizations; respite advocates

Recommendation 8:

A comprehensive list of respite and/or caregiver training resources, including local and national, should be listed on the South Carolina Respite Coalition website.

Rationale:

1. Currently, there is no one place in the state where respite provider/family caregiver training opportunities and resources are catalogued.
2. Providers and family caregivers will benefit from an increased awareness of available training.
3. Providers need to be able to access a variety of training resources in order to meet the diverse needs of those receiving respite across the lifespan.

Action Steps:

Include contact information and/or links for available resources.

Connect providers with training opportunities.

Responsible Party:

South Carolina Respite Coalition

Recommendation 9:

Add a respite provider self-assessment tool on the South Carolina Respite Coalition website – this short survey will help individuals interested in becoming providers identify whether or not they have a proclivity toward the profession.

Rationale:

1. Now and in the future, more and more individuals will need to enter into caregiving careers in order to meet the growing need.

Responsible Party:

South Carolina Respite Coalition

Recommendation 10:

Recruit faith communities to develop respite programs and sustain seed funding to support the development and implementation of these services.

Rationale:

1. Family caregivers in the state desperately need affordable respite.
2. Faith Communities serve as a trusted focal point within the larger community.
3. Faith Communities are historically flexible and mobilize volunteers for most of their work. They also have facilities, thereby reducing costs of respite provision.

Action Steps:

Continue the annual “Respite Solutions” conference with consideration given to holding conferences/trainings outside the capital city.

Pursue a formal endorsement from the Christian Action Council as well as the Interfaith Council of South Carolina.

Support increased funding for Alzheimer’s respite programs through the Alzheimer’s Resource Coordination Center at the Lieutenant Governor’s Office on Aging.

Create an awards process in concert with faith community leadership to recognize accomplishments and encourage more participation.

Responsible Party:

South Carolina Respite Coalition; governing/organization faith community bodies; South Carolina Legislature; SC Department of Disabilities and Special Needs (DDSN); SC Department of Health and Human Services (DHHS) Community Long-Term Care; Lt. Governor’s Office on Aging

For Implementation in 3-5 years:

Recommendation 11:

Assemble existing information resources and establish a centralized access point. Utilize established libraries as part of the infrastructure.

Rationale:

1. Caregivers will have access to publications and resources not limited to internet availability.
2. A single access point serves as an intermediate bridge to consolidating information while working on a dedicated website for respite.
3. Consolidated access ensures that all respite questions are addressed, thereby closing the gaps in accessing information and services.

Responsible Parties:

Area Agencies on Aging/Aging and Disability Resource Centers; Family Connection of South Carolina, Inc.; South Carolina Respite Coalition; colleges and universities

Recommendation 12:

Create a dedicated website for respite.

Rationale:

1. A single access point is easier to market, remember, and use.
2. Streamlining respite information enables greater ease of sharing.
3. A dedicated website consolidates maintenance to one site.

Responsible Parties:

South Carolina Respite Coalition; Lt. Governor's Office on Aging; philanthropic organizations

Recommendation 13:

Expand training on special needs populations and respite providers to first responders (i.e. EMS, firefighters, law enforcement and the medical community).

Rationale:

The needs of caregivers and care recipients can create special circumstances which may impact interactions with emergency personnel.

Responsible Parties:

South Carolina Technical College System; South Carolina Respite Coalition; South Carolina Criminal Justice Academy; South Carolina Fire Academy; USC School of Medicine; Medical University of South Carolina (MUSC)

Recommendation 14:

Generate innovative respite programs for persons who do not meet the requirements for participation in existing programming.

Rationale:

1. South Carolina spends more than \$40 million annually to remove, house and stabilize individuals with emotional disorders and then bring them home to their families.
2. Gaps currently exist for populations in need of respite: to include but not limited to people with disabilities or special needs who are post-education but unable to “mainstream” and those who do not meet other eligibility requirements.
3. Those caring for individuals with emotional disorders experience high stress and tend to keep their situation private due to stigma.

Responsible Parties:

Public and private schools; faith based communities; Family Connection of South Carolina, Inc.; South Carolina Autism Society; SC Legislature; appropriate government entities

Recommendation 15:

Generate respite assessments that provide universal foundational material and are all-inclusive, i.e. caregivers, care recipients and families.

Rationale:

1. Maintains continuity across multiple agencies.
2. Enhances the assessment based on current needs.

Responsible Parties:

Area Agencies on Aging/Aging and Disabilities Resources Centers; Veterans Administration; Family Connection of South Carolina, Inc.; South Carolina Department of Disabilities and Special Needs; South Carolina Department of Health and Human Services – Community Long Term Care

Recommendation 16:

Advocate for state funding to continue activities included in the Lifespan Respite Expansion grant.

Rationale:

1. These funds will reach families in crisis who are not currently receiving any respite services. Adults with disabilities are a chronically underserved population in South Carolina.
2. Money could be allocated in mini-grants to other organizations wishing to conduct similar events (in addition to the South Carolina Autism Society and Department of Disabilities and Special Needs). Events can be inexpensive, offer

great opportunities to educate families about resources and can be targeted to all ages and disabilities.

Action Steps:

Include care for adults with disabilities currently on DDSN/DHHS waiting lists.

Continue mini-grants to faith communities to begin respite programs.

Conduct events modeled after those held by DDSN and the SC Autism Society and provide resource information on-site.

Pursue funding for expansion to other underserved populations across the lifespan.

Responsible Parties:

South Carolina Respite Coalition; South Carolina Autism Society; SC Department of Disabilities and Special Needs; other respite advocates and interested organizations

Recommendation 17:

Solicit technical colleges and universities to approve respite provision by their students as part of a curriculum and/or individual course.

Rationale:

1. Family caregivers in the state desperately need affordable respite.
2. Students will gain valuable and real experience of family life.
3. Students will gain an understanding of the need for and required skills to provide respite care.
4. The experience may help students in selecting their career paths.

Responsible Parties:

Technical colleges and universities in collaboration with South Carolina Respite Coalition

Recommendation 18:

Encourage development of emergency respite options in existing skilled nursing and assisted living facilities, hospitals, respite homes, or among private providers OR develop plan to create a statewide system or build facilities to meet family respite needs at time of crisis.

Rationale:

1. Increased emergency respite will ease the stress and burden of family caregivers.
2. Quality, affordable care will be available for care recipients, potentially minimizing unnecessary hospitalization.

Responsible Parties:

South Carolina Respite Coalition; Community Long-Term Care; South Carolina Department of Mental Health; Skilled Nursing Facilities; South Carolina Hospital Association; South Carolina Medical Association; South Carolina Chapter of the National Association of Social Workers; South Carolina Department of Health and Environmental Control; faith based communities

For Implementation in 6-10 years:

Recommendation 19:

Create a centralized toll-free number/clearinghouse for access to emergency resources for caregivers and care recipients.

Rationale:

1. There are currently insufficient resources for emergency respite needs.
2. Rural consumers face limited transportation availability and respite options.

Responsible Parties:

South Carolina Respite Coalition; Lt. Governor's Office on Aging; emergency services responders (criminal justice system, EMS, firefighters)

Appendix A
Text of the Lifespan Respite Act

H.R.3248

One Hundred Ninth Congress
of the
United States of America
AT THE SECOND SESSION

Begun and held at the City of Washington on Tuesday,
the third day of January, two thousand and six

An Act

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the 'Lifespan Respite Care Act of 2006'.

SEC. 2. LIFESPAN RESPITE CARE.

The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following:

'TITLE XXIX--LIFESPAN RESPITE CARE

'SEC. 2901. DEFINITIONS.

'In this title:

'(1) ADULT WITH A SPECIAL NEED- The term 'adult with a special need' means a person 18 years of age or older who requires care or supervision to--

'(A) meet the person's basic needs;

'(B) prevent physical self-injury or injury to others; or

'(C) avoid placement in an institutional facility.

'(2) AGING AND DISABILITY RESOURCE CENTER- The term 'aging and disability resource center' means an entity administering a program established by the State, as

part of the State's system of long-term care, to provide a coordinated system for providing--

`(A) comprehensive information on available public and private long-term care programs, options, and resources;

`(B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and

`(C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient point of entry for such programs.

`(3) CHILD WITH A SPECIAL NEED- The term `child with a special need' means an individual less than 18 years of age who requires care or supervision beyond that required of children generally to--

`(A) meet the child's basic needs; or

`(B) prevent physical injury, self-injury, or injury to others.

`(4) ELIGIBLE STATE AGENCY- The term `eligible State agency' means a State agency that--

`(A) administers the State's program under the Older Americans Act of 1965, administers the State's program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State's programs under this title;

`(B) is an aging and disability resource center;

`(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and

`(D) demonstrates--

`(i) an ability to work with other State and community-based agencies;

`(ii) an understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

`(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

`(5) FAMILY CAREGIVER- The term `family caregiver' means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.

`(6) LIFESPAN RESPITE CARE- The term `lifespan respite care' means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.

`(7) RESPITE CARE- The term `respite care' means planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

`(8) STATE- The term `State' means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

`SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

`(a) Purposes- The purposes of this section are--

`(1) to expand and enhance respite care services to family caregivers;

`(2) to improve the statewide dissemination and coordination of respite care; and

`(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

`(b) Authorization- Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which an application is submitted pursuant to subsection (d).

`(c) Federal Lifespan Approach- In carrying out this section, the Secretary shall work in cooperation with the National Family Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

`(d) Application-

`(1) SUBMISSION- Each Governor desiring the eligible State agency of his or her State to receive a grant or cooperative agreement under this section shall submit an application on behalf of such agency to the Secretary at such time, in such manner, and containing such information as the Secretary shall require.

`(2) CONTENTS- Each application submitted under this section shall include--

`(A) a description of the eligible State agency's--

`(i) ability to work with other State and community-based agencies;

`(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

`(iii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients;

`(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of--

`(i) the population of family caregivers;

`(ii) the extent and nature of the respite care needs of that population;

`(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

`(iv) existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;

`(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

`(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;

`(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;

`(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, other forms of reimbursements, personnel, and facilities;

`(ix) respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;

`(x) the criteria used to identify family caregivers eligible for respite care services;

`(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and

`(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating those results;

`(C) assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and

`(D) a memorandum of agreement regarding the joint responsibility for the eligible State agency's lifespan respite program between--

`(i) the eligible State agency; and

`(ii) a public or private nonprofit statewide respite coalition or organization.

`(e) Priority; Considerations- When awarding grants or cooperative agreements under this section, the Secretary shall--

`(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or enhancing lifespan respite care statewide; and

`(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents.

`(f) Use of Grant or Cooperative Agreement Funds-

`(1) IN GENERAL-

`(A) REQUIRED USES OF FUNDS- Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds--

`(i) to develop or enhance lifespan respite care at the State and local levels;

`(ii) to provide respite care services for family caregivers caring for children or adults;

`(iii) to train and recruit respite care workers and volunteers;

`(iv) to provide information to caregivers about available respite and support services; and

`(v) to assist caregivers in gaining access to such services.

`(B) OPTIONAL USES OF FUNDS- Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for--

`(i) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services;

`(ii) other services essential to the provision of respite care as the Secretary may specify; or

`(iii) training and education for new caregivers.

`(2) SUBCONTRACTS- Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities.

`(3) MATCHING FUNDS-

`(A) IN GENERAL- With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

`(B) DETERMINATION OF AMOUNT CONTRIBUTED- Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

`(g) Term of Grants or Cooperative Agreements-

`(1) IN GENERAL- The Secretary shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

`(2) RENEWAL- The Secretary may renew a grant or cooperative agreement under this section at the end of the term of the grant or cooperative agreement determined under paragraph (1).

`(h) Maintenance of Effort- Funds made available under this section shall be used to supplement and not supplant other Federal, State, and local funds available for respite care services.

Appendix B Lifespan Respite Subcommittees

Gaps and Obstacles: Areas of focus included needs assessment, environmental scan of respite providers/services, what is missing, barriers to using respite.

Rachal Hatton
Anne McLean
Glenn Niske
Denise Rivers
Liz Smith
Facilitator: Anne Wolf

Education and Outreach: Areas of focus included understanding of caregiver needs, knowledge and education of caregivers regarding the benefits of respite, options and strategies for respite including early development of respite networks/resources.

Michele Armstrong
Eve Barth
Janet Lawrence
Christina Emrich
Shawn Keith
Lee McElveen
Marsha Ward
Facilitator: Anne Wolf

Legislative and Policy Issues: Areas of focus included identifying funding streams with their barriers and opportunities, policies to encourage use of respite, general policy initiatives, and dovetailing endeavors with education and outreach.

Teresa Arnold
Valarie Bishop
Erin Donovan
Diane Flashnick
Craig Stoxen
Facilitator: Allison Poole

Provider Network Development: Areas of focus included recruitment strategies, type, cost and availability of respite services, training, models of respite, volunteer models of respite care, adequacy and appropriateness of respite services, and planned versus emergency respite.

Wilfried Hoecke
Kathy Mayfield-Smith
Mallory Miller
Sheila Mills
Tammy Quarles
Cheryl Waller
Facilitator: Allison Poole

Appendix C

Adjunct Contributors

The following individuals played vital roles in the formation of this state plan:

Brandon Crawford
University of South Carolina

Erin Donovan
SC Department of Health and Human Services

Sarah Eason
SC Autism Society

Angela Johnson
University of South Carolina

Kathi Lacy, Ph.D.
SC Department of Disabilities and Special Needs

Charles Lang
SC Developmental Disabilities Council
Office of the Governor

Margie Moore-Williamson
SC Autism Society

Allison Poole
SC Respite Coalition

Janet Priest
SC Department of Disabilities and Special Needs

Tammy Quarles
Columbia Adult Care, Inc.

Joyce Romero
DayBreak Adult Care Services

Rebecca Smith
Senior Resources, Inc.

Appendix D References

1. Feinberg, L., Reinhard, S. C., House, A., & Choula, R. (2011) *Valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving* (July 2011 ed., pp. 28). AARP, Washington, DC
2. Silverman, F. (2010). Caregiver Survey. *Caring Today*. Retrieved from Caring Today website: <http://www.caringtoday.com/>
3. The Evercare Survey of the Economic Downturn and its Impact on Family Caregiving. (2009). Minnetonka, MN and Bethesda, MD: Evercare and National Alliance for Caregiving.
4. National Respite Coalition (2009). Benefits and Cost-Savings Due to Respite. In National Respite Coalition (Ed.), (pp. 3). Annondale, VA: National Respite Coalition.
5. MetLife Mature Market Institute. (2011). The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services and Home Care Costs. New York, NY
6. Bureau, U. C. (2010). 2010 US Census Population Estimates: State Tables. Retrieved 4/19/2013, 2013, from <https://www.census.gov/2010census/data/>
7. SC Budget and Control Board, Office of Research and Statistics. (2007). South Carolina Kids Count. Columbia, SC
8. SC Respite Coalition (2011). Lifespan Respite Program Survey of Respite Providers in SC. Columbia, SC
9. Singer, G. H. S., Biegel, D. E., & Ethridge, B. L. (2010). Trends impacting public policy support for caregiving families. *Journal of Family Social Work*, 13, 191-207.
10. Brazil, K., Bedard, M., Krueger, P, Abernathy, T., Lohfield, L., & Willison, K. (2005) Service preferences among family caregivers of the terminally ill. *Journal of Palliative Medicine*, 8(1), 69-78
11. Johnson, CP. (2005). Helping Families Raise Their CWD At Home. *Pediatrics*, 115(2), 507-511
12. Family Connection of SC, Inc. (2009). Summary of Family Connection's Parent Survey, Columbia, SC
13. Continuum of Care (2001, 2005). Needs Assessment of Families Caring for Children with Serious Emotional Disorders. Columbia, SC: SC Governor's Office of Continuum of Care.
14. SC ACCESS Program. (2012). Listing of Respite and Related Services. South Carolina Lt. Governor's Office on Aging, Columbia, SC
15. Family Connection of SC, Inc. (1998). Family Connection of SC 2012 Annual Report, from www.familyconnectionsc.org/uploads/1/7/2/7/17273542/annual_report_2012.pdf
16. Casado, B. L. (2008). Sense of need for financial support and respite services among informal caregivers of older Americans. *Journal of Human Behavior in the Social Environment*, 18(3), 269-287
17. NAMI. (2002). NAMI Annual Report 2002. Arlington, VA.
18. AARP, N. (2009). Caregiving in the U.S. - A Focused Look at Those Caring for the 50 +. Bethesda, MD.
19. Rudin DJ. (1995). Caregiver Attitudes Regarding Utilization and Usefulness of Respite Services for People with Alzheimer's Disease. *Journal of Gerontological Social Work*, 23(1-2) 85-108
20. National Resource Center for CBCAP. (2007). Friends Factsheet #14: Respite and Crisis Care (pp. 7). Chapel Hill, NC: Chapel Hill Training Outreach Project, Inc.

Credits

Authors

Kathy Mayfield-Smith

Allison Poole

Anne Wolf

Contributors

Lifespan Respite State Advisory Committee

South Carolina Respite Coalition

Family Connection of South Carolina, Inc.

Cover design by Brandon Crawford

Special Recognition goes to Angela Johnson, a University of South Carolina graduate student who undertook work with the Lifespan Respite program as part of her studies. Her contributions to the project are greatly appreciated.

This project was supported, in part, by grant number 90LI0007 from the Administration for Community Living/U.S. Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.