

# Take Another Break SC!



## AN UPDATE ON SUSTAINING SOUTH CAROLINA'S FAMILY CAREGIVERS THROUGH RESPITE

Report of the Lifespan Respite  
State Committee on Respite  
February 14, 2018





### **Transmittal Letter**

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

In 2013 the Lieutenant Governor's Office on Aging, in partnership with the South Carolina Respite Coalition and Family Connection of SC, published "Take a Break SC! Sustaining South Carolina's Family Caregivers through Respite". Respite is defined as regular, temporary breaks from caregiving for a person of any age with a disability, special need or chronic illness. This state plan served as an implementation guide for sustainable lifespan respite. It was made possible through a federal grant award from the U.S. Administration on Aging (now under the Administration for Community Living) under the U.S. Department of Health and Human Services. South Carolina has been the recipient of multiple Lifespan Respite grant awards since 2009, which have enabled growth and progress in support of our family caregivers. "Take Another Break SC! An Update on Sustaining South Carolina's Family Caregivers through Respite" is submitted today to provide the status on the recommendations proposed in the 2013 Lifespan Respite State Plan, and offer new recommendations to further the objective of establishing a comprehensive statewide system of respite for caregivers of persons of any age or any disability.

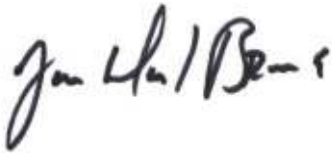
Throughout the project the State Committee on Respite has maintained the multi-disciplinary approach and brought together diverse stakeholders from the public and private sectors to support work on fulfilling the recommendations of the original state plan and promulgating new recommendations in furtherance of the mission to establish a coordinated system of respite in South Carolina. While great accomplishments have been made, including securing recurring state appropriations for lifespan respite vouchers for caregivers, increasing awareness and exchanges across the state about respite, both with providers and family caregivers, and laying the foundation for a more coordinated system of respite among diverse populations of family caregivers, there is still work to be done to ensure that South Carolina's more than 770,000 family caregivers are supported along their caregiving journeys.

Always mindful of the economic impact of recommendations being made, the State Committee on Respite 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.

South Carolina is recognized nationally as a leader in the Lifespan Respite initiative, and was cited in 2017 as a best practice for collaboration by the ARCH National Respite Network. It is our goal, in conjunction with our partners and stakeholders to continue to make South Carolina a statewide community of available resources for family caregivers.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Darryl Broome". The signature is written in a cursive, slightly slanted style.

Darryl Broome  
Director, Lieutenant Governor's Office on Aging

## FOREWORD

Serving as Lieutenant Governor of South Carolina has taken me on a wonderful journey across our state. One of the blessings of this journey is the opportunity to meet and learn about the more than 770,000 fellow South Carolinians who are family caregivers for their loved ones. They are our neighbors, our friends, our community leaders; they are us.

They are the single mom dropping her child off at school, and then rushing home to her aging mother, and then to work. They are your friends who have not been to a dinner party in months, because they cannot hire a high school student to babysit their child with a special need. They are the cashier at the grocery store and the accountant at the bank. They are every race, every age, and every story.

Respite is the lifeline for these South Carolinians. Respite provides a break so that the single mom can keep her own doctor's appointment or your friends can have a date night. Respite also provides their loved ones with more socialization and more access to skilled care. The combination of caregivers and respite is vital to keeping our loved ones at home where they want to be and where their families want them.

This State Plan makes critical updates to our efforts to ensure respite for South Carolinians who serve as caregivers for loved ones of any age or need. Please 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 this plan. Our communities are strongest when we help our neighbors and friends to live their lives to their fullest. Respite helps achieve that goal.



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# South Carolina's Lifespan Respite System

## Where Were We?

In 2009, South Carolina, like all states, faced an impending crisis about how to care for a growing aging population as well as children and adults of all ages with disabilities and special health needs. The system of care and delivery of respite services was fragmented with different agencies having different eligibility criteria and operating in silos. Although on the surface, South Carolina appeared to have numerous respite services, these resources were critically inadequate to meet the needs of most families. Some population groups were served better than other groups; but in general, respite was in short supply, inaccessible or unaffordable. It was underfunded significantly for those who needed subsidy and difficult, if not impossible, in some geographical areas or for certain populations with particularly complicated physical and mental conditions to find trained respite providers. Having recently gone through a national recession, the state budget deficits exacerbated the problem.

In that same year, the Lieutenant Governor's Office on Aging, in partnership with the South Carolina Respite Coalition and Family Connection of SC, was awarded a grant from the U.S. Administration on Aging (now the Administration for Community Living) to fund a coordinated 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. This initiative built on the infrastructure in place and established a State Committee on Respite to guide the development of the coordinated lifespan respite system.

With the support of multiple Lifespan Respite grants from the federal Administration for Community Living, South Carolina continued the journey of building a more coordinated Lifespan Respite System. These projects targeted the following activities in furtherance of the objective: provide coordinated outreach, information and screening for respite services through the Aging and Disability Resource Centers, SC Respite Coalition, 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 encouraging earlier and increased use of respite; develop and provide training for respite providers; provide respite through vouchers; 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 as a grassroots effort in 1999, a formal coalition was formed through incorporation as a non-profit in 2001 with thirty agencies agreeing to partner in creating a statewide organization for respite. The SC Respite Coalition works to support families and providers through a coordinated respite information resource, to provide respite care opportunities for family caregivers through vouchers for respite, education and training for caregivers and providers, and working with communities to develop local respite options. It also educates the general public and specific groups about the need for respite care and strategies to provide and improve respite services for families.

**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.

**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.

**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 Lifespan Respite 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 Lifespan Respite System** is working 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 State Committee on Respite. 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.

Addressing the needs of family caregivers across the lifespan is an ongoing and evolving effort. The purpose of this update is to report on the progress to date of the original State Respite Plan recommendations and to share the updated and new recommendations resulting from the continued work of the State Committee on Respite. The Committee has continued to work diligently toward their determined mission and vision. We would like to thank those individuals and their organizations for their dedicated service as members of the State Committee on Respite and their continuing support of family caregivers and efforts to improve respite across the lifespan in South Carolina.

### **S.C. Lifespan Respite Project State Committee on Respite**

Janet B. Altman, Executive Director  
SC Respite Coalition

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Senior Resources, Inc.

Christina Emrich  
Parent of two special needs children

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Lt. Governor's Office on Aging

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SC Department of Mental Health

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National MS Society

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Family Connection of SC, Inc.

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National Alliance for Mental Illness

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University of South Carolina

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SC Department of Disabilities and Special  
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HomeShare/Crisis Stabilization  
SC Department of Mental Health

Reyhan Miller, Program Coordinator  
SC DD Council  
SC Department of Administration

Sheila L. Mills, MPH, CPM  
Program Manager Integrated Care Policies  
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SC Department of Mental Health,  
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Santee-Lynches Area Agency on Aging  
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Dr. Nathaniel Patterson, former Director  
SC Institute of Medicine and Public  
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Alzheimer's Association, South Carolina  
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Anne W. Wolf, Community Resources  
Divisional Manager  
Lt. Governor's Office on Aging

## Where Are We Now?

Recently, South Carolina was highlighted as one of three states demonstrating successful collaboration across state lead agencies, state respite coalitions and community partners to provide a coordinated system of community-based respite for all family caregivers regardless of age or disability. In their recently published “Tools for Collaboration”, the ARCH National Respite Network stated, “The cornerstone of the South Carolina lifespan respite grant efforts has been ongoing partnerships between the SC Respite Coalition (SCRC), the Lieutenant Governor’s Office on Aging (LGOA), Family Connection of SC’s Family to Family Health Information Center (F2FHIC), and the Aging and Disability Resource Centers (ADRC). The strength of these partnerships is in how collaboration has enabled them to leverage other partners (formal and informal), including statewide representation of agencies, organizations and families through state and regional respite councils, as well as diverse funding sources.” The most profound impact has been from the state legislative appropriation of respite funds that are used for respite across the lifespan. This was a combined effort of the partners over a period of several years, during which the funding went from one-time to a recurring line item and from serving seniors only to serving across the lifespan. In addition to increasing respite for families, these efforts have laid the foundation for broader partnerships with families, providers, higher education, and the medical and business communities.

Because of the success of far-reaching collaboration throughout the lifespan respite project, partners and stakeholders shared that work was being done simultaneously on updates to the Long Term Care Task Force Report of the SC Institute of Medicine and Public Health, the Alzheimer’s State Plan, a collaborative publication of the Lt. Governor’s Office on Aging and the Alzheimer’s Association, South Carolina Chapter, and the Lifespan Respite State Plan. From this nexus grew the Bridge Group, with representatives from each of the above groups who meet to coordinate efforts in achieving overarching goals of the respective plans. The first inroad was realized in 2017 when a representative from each segment of the group was invited to do a joint presentation on family caregiving and its impact on the workforce to the Board members of the SC Business Coalition on Health.

With continued grant support, this collaborative effort continues to expand its partnerships across the state and makes significant progress toward implementation of the original recommendations.

### **UPDATE OF STATUS ON ORIGINAL RECOMMENDATIONS:**

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

**Status:** Complete

**Summary:** With additional support from the Duke Energy Settlement, the LGOA established a stakeholder advisory committee to guide redesign and development of GetCareSC.com, an on-line database of aging and disability related information and

referral resources. Unveiled in the fall of 2017, GetCareSC.com is a more comprehensive and user-friendly resource for caregivers.

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

**Status:** In-process and on-going

**Summary:** A number of activities have been implemented that have increased the public awareness about the role and utilization of respite. The SC Respite Coalition hosts Respite Awareness Day every February 14<sup>th</sup> (Valentine's Day) at the SC Statehouse with increased attendance each year. Educational materials are provided to family caregivers, legislators and the general public in print and via news outlets before and during this event. Targeted outreach has been conducted through newsletters, presentations at conferences, civic groups, and on radio shows. Working with Regional Councils in the Upstate and Low Country is increasing awareness across the state. The availability of funds for respite vouchers and significant increased awareness has afforded the opportunity to educate family caregivers about the role, importance and utilization of respite.

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

**Status:** In-process and on-going

**Summary:** Building on current social networks and available computer technology, several mechanisms have been developed for dissemination of comprehensive respite information. SC Respite Coalition developed, and regularly posts to its Facebook page and Twitter feed, and utilizes Constant Contact for wide scale dissemination of respite information.

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

**Status:** Complete

**Summary:** LGOA developed an educational Rack card (oversized two-sided brochure) about respite and disseminated it to all members of the SC Legislature.

**Recommendation 5:** Create a lifespan respite toolkit.

**Status:** Future Priority

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

**Status:** In-process and on-going

**Summary:** Every year since releasing the original Lifespan Respite State Plan, the SC Respite Coalition has hosted a Respite Awareness Day at the SC Statehouse and has obtained a proclamation signed by the Governor recognizing the day as Lifespan Respite Awareness Day in South Carolina.

**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.

**Status:** In-process and on-going

**Summary:** Several activities have increased the SC Respite Coalition's visibility and position as the lead advocacy group for respite. Extensive email distribution lists have been developed for use in targeted dissemination of quarterly newsletters, regular informational e-blasts and other respite information. Being a part of the network providing Lifespan and State Respite Voucher funds has increased its visibility significantly with family caregivers and providers; and development of Regional Councils across the state and training for DDSN respite providers has strengthened its position as the lead advocacy group for respite.

**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.

**Status:** Future Priority

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

**Status:** Future Priority

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

**Status:** In-process and on-going

**Summary:** As part of the most recent Lifespan Respite grants, the SC Respite Coalition will revive the annual Respite and the Faith Community Conference and other outreach to faith-based programs. Working with Regional Councils, the conference and other events will be conducted in varying parts of the state.

### **For Implementation in 3-5 years:**

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

**Status:** Future Priority

**Recommendation 12:** Create a dedicated website for respite.

**Status:** In process and on-going

**Summary:** Work is well underway to redesign the SC Respite Coalition's website to be a user-friendly resource dedicated to providing comprehensive respite information and resources.

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

**Status:** Future Priority

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

**Status:** On-going

**Summary:** Several events were coordinated with facilities that could accommodate large parties so that parents could take a break and children with special needs participated in a respite outing tailored according to their needs. Parents had the option to enjoy the outing or spend some time away from the event in other pursuits.

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

**Status:** Future Priority

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

**Status:** On-going

**Summary:** Progress has been made in increasing access to respite services through state funds. In 2014, the SC Legislature allocated one time state funds to the LGOA to provide respite for family caregivers for people 60 years of age and older. Since then, state funds for respite have continued to be allocated as recurring dollars with flexibility to serve family caregivers for people across the lifespan (i.e., of any age, disability or special need) increasing access to respite for a broader population. State funds for lifespan respite have increased in FY2018 to \$2.4 million as a recurring line item for respite and \$900,000 for respite for families caring for someone with Alzheimer's disease or a related disorder. Coordination of respite services has improved through coordinated distribution of respite funds by the Aging Network and SC Respite Coalition to ensure access to families across the lifespan.

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

**Status:** In process

**Summary:** Research of model programs and curricula around the country is being conducted. Initial contact has been made within the technical college system as well as presentation to select student groups.

**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.

**Status:** Future Priority

**For Implementation in 6-10 years:**

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

**Status:** Future Priority

The following section most truly captures the importance of lifespan respite and why we look to the future to ensure respite is a way of life for all family caregivers. The Faces of Respite shares the stories of family caregivers who have benefited from taking a much needed break from the responsibilities of caring for a loved one.



# Faces of Respite

Caregivers are the backbone of the long-term care system for people who are aging and for children and adults with disabilities or special health needs. Here are six brief stories of families who are caring for loved ones across the lifespan and received a voucher for respite so they could “take a much needed break.” In their own words, they tell the story of what respite means to them so we can see the true “faces of respite” that are representative of the hundreds of thousands of family caregivers across South Carolina.



*Our son Thomas is 16 and has severe autism. He’s non-verbal and relies on us for all his needs. It had been 6 years since my wife and I were able to take our other children (ages 11 and 9) on a vacation, but it’s not possible to take Tommy. He is very unhappy when removed from his routines. Had it not been for the respite voucher we received to help offset the cost of Tommy’s care while we were gone, it simply would not have been possible. We had an amazing time! Honestly, we had forgotten what it was like to relax. We were able to connect with our daughters and just have fun.*

— Marc



*Respite has been a true blessing for us. My husband and I have been able to get away and spend time together. We have taken care of my mother for the last 14 years and the last 2 have been a real challenge as her dementia has gotten worse. It was so nice just to be able to do things together again by ourselves.*

— Amy



*Our son Abel is 2 ½ years old and was diagnosed with Down Syndrome at birth. He has had many hospitalizations including 2 open heart surgeries. The endless therapies and doctor's appointments can become very tiring. We do not have any family close and respite funding has allowed us to have much needed breaks. Respite has opened an outlet for us that we would not have had otherwise.*  
— Ashley

*It is difficult finding the right people and training them to take care of kids like my daughter and that hinders us from taking needed time off to, at least, catch a breather at times. Respite funding was heaven sent, because it helped us to offset some of the expenses to take care of our child and provided us with a much needed break. My wife and I enjoyed our trip to the beach. We needed it. We felt a little guilty, but we knew our daughter was in good hands.*

— Antoine





*Respite funding let me pay for someone to sit with my wife so I could fish and hunt. I never thought at 54 years old I would be taking care my wife full-time, but she is worth it. After her stroke, they said she would never talk or walk. She is a miracle to me. We have been through a lot but we are still together and love each other. We used to fish together and she always caught more than me. We will fish together again soon.*

— Donald

*I have a beautiful girl named Hannah with Down Syndrome. I love my daughter and taking care of her. But a life with a child with special needs presents constant challenges and stress. Respite funds have allowed me to have breaks so that I can go grocery shopping, research Hannah's condition and educate myself on ways I can help her, and rest so I can stay strong for Hannah and the baby we are currently expecting.*

— Maria



# Where Are We Going?

South Carolina's population in 2018 is estimated at 5,088,916, up from 4,774,839 in Census 2013. Estimates for 2016 indicate that 850,000 will be age 65 and over. The SC Office of Research and Statistics (2010) reports over 443,000 children and youth with one or more special needs "requiring extraordinary care above a typically developing child." Census estimates (2010) show that 15%, or 814,266, South Carolinians age 5 and over, have a disability of some form. According to estimates from the National Alliance for Caregiving, during the past year, 65.7 million Americans (or 29 percent of the U.S. adult population involving 31 percent of all U.S. households) served as family caregivers for a relative who was ill or had disabilities. AARP (2011) estimates the number of South Carolinians serving as family caregivers at any given time to be 770,000. The 2010 Census also estimates an additional 200,000 South Carolina residents are caregivers for other populations not enumerated in the AARP report. In South Carolina, as across the nation, the number of people with disabilities and special needs in all age brackets continues to grow.

While we have made great strides in increasing the availability and quality of respite services, there is still a long way to go to address the respite needs for all family caregivers across the lifespan. Providing a coordinated lifespan respite system of care is a long and evolving process that will need to continually be reviewed, monitored and adapted to meet the ongoing and emerging needs. As the next phase in that evolutionary process, we present the newest recommendations that have been added to the existing plan of action to guide us into the future.

The SC Respite Coalition will again 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 State Committee on Respite, and the agencies or entities named have not provided a formal review or approval of the recommendations.

## **Recommendation 1:**

Utilize a brief inventory for family caregivers to be able to determine the impact of caregiving and the need for respite as a result of being a caregiver; and develop a parallel inventory for use by health care workers in clinical settings.

## **Rationale:**

1. Caregivers frequently do not self-identify as caregivers and therefore, do not seek information or assistance in caring for themselves or their loved ones.
2. Caregivers disproportionately suffer from poor health, depression and isolation when they are unaware of the toll of caregiving.
3. Physicians, discharge planners and other health care workers need a simple way to assess a family caregiver in clinical settings and refer them to respite resources.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Review needs inventory tools published by other organizations (e.g., American Medical Association, AARP) and adopt an inventory appropriate to caregivers and an inventory appropriate to health care workers.
2. Organize a campaign to distribute needs inventory to health care workers and family caregivers, along with educational materials on what is respite and how to find it.
3. Collaborate with Medicare and Medicaid to make the caregiver needs inventory part of the caregiver component for medical billing.

**Responsible Parties:**

SC Respite Coalition; SC Department of Health and Human Services; SC Department of Disabilities and Special Needs

**Recommendation 2:**

Increase awareness of respite and the needs of families across the lifespan, through targeted outreach to the medical, educational, business, faith and civic communities.

**Rationale:**

1. For systemic change to occur, awareness of the essential role respite plays in sustaining the health of family caregivers is vital. Health care providers, educators, faith leaders, businesses and employers interact with families every day and hold the key to not only identifying caregivers in need, but helping caregivers to understand and accept respite. This also affords the opportunity to offer education and support to family caregivers.
2. Professionals may not be aware of the toll caregiving takes on a family caregiver and how it impacts the health, the ability to work and/or engage in other important activities for the caregiver.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Recruit members from the medical, educational, business, faith and civic communities to actively participate in the State and Regional Lifespan Respite Committees/Coalitions.

2. Build on current efforts to partner with businesses to survey members and educate employers to further develop strategies to address family caregivers in the workplace.
3. Conduct targeted outreach to above cited groups through meetings, conferences and provision of educational materials.

**Responsible Parties:**

SC Respite Coalition; LGOA; SCOR members; stakeholders

**Recommendation 3:**

Initiate a public awareness campaign (PSA) clearly defining respite, highlighting the number and needs of family caregivers, and promoting creative respite options.

**Rationale:**

1. Many family caregivers need help, but are reluctant to ask due to perceived stigma or guilt over leaving a loved one. An awareness campaign is a first step in normalizing caregiving and respite.
2. Many friends and neighbors may be willing and able to help in caregiving situations, but it is not a part of our everyday conversations. Information on respite provides the foundation to build creative respite options.
3. Respite affordability will always be an issue for families in South Carolina; there will never be enough subsidized programs to help everyone in need. Therefore, creative informal respite options need to be publicized and encouraged.

**Implementation Schedule:**

Level 1: This recommendation should be implemented within the next 1-2 years.

Level 2: This recommendation should be implemented within the next 3-5 years.

Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Contact the SC Broadcasters Association's Public Education Program.
2. Conduct fundraising to cover production costs.
3. Disseminate through media outlets, provider and family conferences.

**Responsible Parties:**

SC Respite Coalition; stakeholders

**Recommendation 4:**

Create a series of infographics depicting various informational topics tied to respite care.

**Rationale:**

1. While not an exhaustive resource list, infographics offer key educational information and encourage family caregivers to contact helping agencies.

2. Infographics provide a readily available communication source for case managers, social workers and health care workers.
3. Hard copies could be made available in places frequented by family caregivers and the general public.
4. Infographics are more user friendly than traditional brochures.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.  
 Level 2: This recommendation should be implemented within the next 3-5 years.  
 Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Email to agencies so they may share with their populations.
2. Ask agencies to post on their Facebook pages and other social media.
3. Distribute topic specific infographics to relevant locations for dissemination (e.g. respite for parents in pediatricians’ offices).
4. Make hard copies available at conferences and other events.

**Responsible Parties:**

SC Respite Coalition; LGOA; SCOR members; stakeholders

**Recommendation 5:**

Create a series of short, progressive videos that explain respite and the purpose and use of the Family Caregiver Respite Voucher.

**Rationale:**

1. Many professionals as well as caregivers lack a clear understanding of respite and the voucher program.
2. Greater understanding of respite and respite vouchers will promote appropriate usage among family caregivers.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.  
 Level 2: This recommendation should be implemented within the next 3-5 years.  
 Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Responsible parties will ensure designation of a spokesperson, videographer, messaging and distribution.
2. Videos will be posted on appropriate partner websites and stakeholders will be encouraged to participate in posting as well.
3. Encourage use and download by providers; e.g., doctors’ offices, aging network, faith communities, parish nurses, support groups, advocacy organizations, etc.

**Responsible Parties:**

SC Respite Coalition to take lead with other SCOR members and stakeholders

**Recommendation 6:**

Promote both formal and informal respite arrangements through caregiver and disability specific support groups across the state.

**Rationale:**

1. Support groups are a collective of people facing similar challenges.
2. Support groups foster the building of relationships and trust between members.
3. Support groups are a natural and logical place to establish mutually beneficial relationships through which a caregiver can both receive and provide respite.
4. Members of disability-specific support groups are well versed in the physical and emotional needs of caregivers and care receivers confronting similar issues.

**Implementation Schedule:**

Level 1: This recommendation should be implemented within the next 1-2 years.

Level 2: This recommendation should be implemented within the next 3-5 years.

Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Stakeholders representing organizations with active support groups will commit to ensuring that the development of informal respite arrangements is a part of the planning process of each particular network.
2. The SC Respite Coalition will develop a comprehensive statewide list of caregiver support groups, including contact information.
3. SC Respite Coalition staff will be available as a resource for caregiver support groups statewide, whether as speaker, group facilitator, source for information, etc.

**Responsible Parties:**

SC Respite Coalition; stakeholders; Area Agencies on Aging

**Recommendation 7:**

Increase awareness of respite and the needs of families across the lifespan through educational materials disseminated to leaders of caregiver and disability specific support groups across the state.

**Rationale:**

1. Families need regular discussion and encouragement to utilize respite as a tool to maintain caregiver health.
2. Support groups provide an opportunity to reach multiple targeted populations with consistent information on respite, to include types of respite and the benefits of respite to caregivers.
3. Provides an easy mechanism to share standardized information on a regular basis.



**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Identify listing of support groups through the State Committee on Respite and regional councils.
2. Disseminate information through the AAAs/ADRCs and their affiliated support groups.
3. Make materials available electronically for ease of access and download.

**Responsible Parties:**

LGOA, SC Respite Coalition, Family Connection of South Carolina

**Recommendation 8:**

Develop a Respite Provider Registry.

**Rationale:**

1. Reduce the burden for family caregivers when trying to locate a respite provider.
2. Many families have limited personal support mechanisms and need a way to find potential respite providers.
3. Provides a standardized location for respite workers to promote their qualifications for respite services.
4. Promotes a vital connection between family caregivers in need of respite and trained respite providers.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Research best practices through other state coalitions to identify models of successful respite registries.
2. Coordinate and align efforts with the IMPH LTC workgroup's efforts to develop a Direct Care Registry.
3. Identify where to house a Respite Provider Registry.

**Responsible Parties:**

SC Respite Coalition; LGOA; SC Institute of Medicine and Public Health

**Recommendation 9:**

Develop a standardized respite training course for formal providers.

**Rationale:**

1. Currently there is no formal standardized training for respite providers.
2. Major gaps exist in the types of respite available and the number of providers who can provide respite. Training is a critical component of being able to provide safe and appropriate quality respite care.
3. Significant gaps exist for those needing condition-specific respite care, as well as key age groups.

**Implementation Schedule:**

Level 1: This recommendation should be implemented within the next 1-2 years.

Level 2: This recommendation should be implemented within the next 3-5 years.

Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Research best practices through other state coalitions to develop criteria for training.
2. Work with technical colleges to pilot a respite provider certificate program.
3. Develop a set of online modules covering major topics needed by all respite providers.
4. Customize training for population-specific needs and regional variations as appropriate.

**Responsible Parties:**

SC Respite Coalition; SC Technical College System

**Recommendation 10:**

Reinstitute the annual Respite Solutions in Faith Communities Conference.

**Rationale:**

1. This conference, last held in 2012, provides critical information to faith communities serving not only the spiritual needs but the social needs of their congregants.
2. Faith communities have resources such as facilities and active, compassionate members rooted in the area who are willing to serve as volunteers in various capacities both within and outside of the congregation, to include one-on-one respite provision and respite events through their places of worship.
3. Faith communities need more awareness of the needs of family caregivers, the benefits of respite, and training on the various successful models of respite provision in congregations and how to go about implementation.
4. Faith communities are a source of trusted relationships and a conduit for support across many aspects of social needs.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Organize a Faith Conference Planning Committee, including the SC Respite Coalition, stakeholders, and faith community representatives.
2. The conference will move to a different geographical part of the state each year to reach as many faith communities as possible.
3. The Lifespan Respite Upstate Council, Lowcountry Council, and Pee Dee Council will be part of the planning committee for their respective areas of the state.
4. Seek corporate sponsors to underwrite conference expenses, making it affordable for all who wish to attend.

**Responsible Parties:**

SC Respite Coalition; stakeholders

**Recommendation 11:**

Continue to advocate for funding for both lifespan family caregiver vouchers and vouchers specific to family caregivers of persons with Alzheimer’s disease or a related disorder.

**Rational:**

1. As little as four hours of respite a week can mitigate the physical and emotional impact of caregiving.
2. Caregivers of persons with Alzheimer’s disease or a related disorder experience greater levels of caregiver stress over extended periods of time.
3. Lifespan respite enables caregivers of persons of any age with any disability to receive assistance in order to take a break from caregiving responsibilities.

**Implementation Schedule:**

- Level 1: This recommendation should be implemented within the next 1-2 years.
- Level 2: This recommendation should be implemented within the next 3-5 years.
- Level 3: This recommendation should be implemented within the next 6-10 years.

**Strategies For Implementation:**

1. Continue stakeholder involvement through the Lifespan Respite State Committee on Respite.
2. Provide education and advocacy on caregiver issues and the need for respite vouchers through SC Respite Awareness Day, Alzheimer’s Awareness Day, and other appropriate venues.
3. Utilize PSAs, videos and social media to educate about and promote the use of respite vouchers.

**Responsible Parties:**

SC Respite Coalition; Alzheimer's Association – SC Chapter; State Committee on Respite; stakeholders

**Appendix A**  
**Text of the Lifespan Respite Care Act**

Public Law 109–442 109th  
Congress

**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. Dec. 21, 2006

[H.R. 3248]

*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”.

Lifespan Respite  
Care Act of 2006.  
42 USC 201 note.

**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 <sup>42 USC 300ii.</sup> 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 cir-

cumstances; 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).

Inter-governmental relations.  
42 USC 300ii-1.

“(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.

**“SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.**

“(a) ESTABLISHMENT.—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the ‘center’).

“(b) PURPOSES OF THE CENTER.—The center shall—

“(1) maintain a national database on lifespan respite care; “(2) provide <sup>42 USC 300ii-2.</sup> training and technical assistance to State, community, and nonprofit respite care programs; and

“(3) provide information, referral, and educational programs to the public on lifespan respite care.

**“SEC. 2904. REPORT.**

“Not later than January 1, 2009, the Secretary shall report to the Congress on the activities undertaken under this title. Such report shall evaluate—

42 USC 300ii-3.

- “(1) the number of States that have lifespan respite care programs;
- “(2) the demographics of the caregivers receiving respite care services through grants or cooperative agreements under this title; and
- “(3) the effectiveness of entities receiving grants or cooperative agreements under this title.

**“SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.**

42 USC 300ii-4.

- “There are authorized to be appropriated to carry out this title—
- “(1) \$30,000,000 for fiscal year 2007;
  - “(2) \$40,000,000 for fiscal year 2008;
  - “(3) \$53,330,000 for fiscal year 2009;
  - “(4) \$71,110,000 for fiscal year 2010; and “(5) \$94,810,000 for fiscal year 2011.”.

**SEC. 3. GAO REPORT ON LIFESPAN RESPITE CARE PROGRAMS.**

Evaluation.

Not later than January 1, 2011, the Comptroller General of the United States shall conduct an evaluation and submit a report to the Congress on the effectiveness of lifespan respite programs, including an analysis of cost benefits and improved efficiency in service delivery.

Approved December 21, 2006.

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LEGISLATIVE HISTORY—H.R. 3248:

HOUSE REPORTS: No. 109-716 (Comm. on Energy and Commerce). CONGRESSIONAL RECORD, Vol. 152 (2006):

Dec. 6, considered and passed House. Dec. 8, considered and passed Senate.

## **Appendix B**

### **Adjunct Contributors**

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

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