




2020 ANNUAL RESPITE REPORT





When Caregivers become
immersed with the **NEEDS** of **OTHERS**,
they often forget to take into
a c c o u n t t h e i r o w n
EMOTIONAL and PHYSICAL
w e l l - b e i n g .



What is Respite?

Respite is a key component of family support as well as in-home or community-based long-term services and supports. Respite services strengthen family systems while protecting the health and well-being of both caregivers and care recipients. The Lifespan Respite Care Act of 2006 defines respite care as “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.” Respite services may be provided in a variety of settings, including the home, adult day care centers, faith and community centers or residential care facilities.

Respite can strengthen the ability of families and caregivers to continue to provide care in the home while minimizing the risks of neglect and abuse. These occasional breaks have been shown to impact family well-being positively by reducing^(*) stress, fatigue and social isolation, and improving family quality of life and relationships.

The South Carolina Respite Coalition

The SC Respite Coalition is the only entity in the state solely committed to addressing the needs for respite across the lifespan of all persons caring for a child or adult who has special needs. The Respite Coalition was incorporated in the summer of 2001 as a result of the vision, effort, and partnership of several organizations and agencies.

Today the SC Respite Coalition maintains its mission to educate, advocate and serve family caregivers across the state with several programs and projects. We have served thousands of family caregivers through the Lifespan Respite federal grant program in partnership with the SC Department on Aging; in addition to contracts supporting the Family Selected Respite Program with the SC Department of Disabilities and Special Needs by ensuring Respite Care Providers are trained and in compliance with state and Medicaid requirements.

THE SOUTH CAROLINA RESPITE COALITION TEAM

STAFF

Nicholas Julian, Executive Director
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BOARD OF DIRECTORS

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RESPIRE IN SOUTH CAROLINA

Identified Needs for South Carolina Respite

- **Available funding to provide increased respite vouchers to family caregivers.** Thousands of families are placed on benefit waiting lists, many wait for years to receive services. Increased available funding to support organizations would allow these families to receive respite while waiting for other benefits.
- **Family Caregiver Training.** Essential to the success of family members being caregivers is having education and training to equip them with the necessary tools. In addition to the knowledge and resources for building a support system. Availability of in-home private respite care often places a caregiver in a position to be a household employer. To manage this, caregivers often need training to understand complinace, liabilities, and safety, in addition to learning skills such as basic first aid/CPR, and behavioral interventions. These types of trainings will empower caregivers to be succesful in their caregiving role while also encouraging their self wellness.
- **Centralized coordinating system for respite.** There are many forms of respite and available resources that support family caregivers. However, like many social services, no one place serves as a primary network and source. With a coordinated system around respite, organizations and agencies can network, partner, and better support family caregivers. This also provides an opportunity to increasing access through a complimentary system.
- **Increase in standard pay for care providers.** In the previous 10 years^(*), direct care workers' median annual salaries have only increased \$0.20 across SC, averaging \$11.73/hr. Despite the^(*) well-known demand for direct care workers, their pay and benefits remain uncompetitive. Increasing Medicaid reimbursement rates using the "wage pass-through" model^(*) of other states will allow employers to provide a living wage and improve direct care worker recruitment and retention.
- **Workforce development for non-medical care providers.** With a national shortage of healthcare workers and an anticipated drastic increase in the aging population, developing the non-medical caregiver workforce will be imperative over the next several years. Non-medical providers are able to fill gaps for families in providing care when direct medical care is not available or required for respite. A standard training and career development opportunity can be utilized for not only industry recruitment, but also to improve limited advancement opportunities that have been attributed to high turnover rates among healthcare workers.



South Carolina 1 in 4 are a family caregiver

1 in 6 non caregivers expect to become caregivers in the next 2 years

* U.S. DHHS, CDC



SC RESPITE COALITION

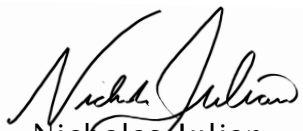
Message from **Nicholas Julian** Executive Director



Family caregiving across the lifespan is a critical public health issue that will impact approximately 1 in 4 South Carolina residents. Although benefits for family caregiving are available, providing continual care can still take an emotional, mental and physical toll. Respite is the most frequently requested support service among family caregivers; however, the vast majority of family caregivers have barriers to receiving respite care and even more indicate not receiving enough. Minimal workforce, benefit wait list or availability, and personal finances have been some of the most indicated obstacles. The Lifespan Respite Care Act of 2006 defines respite as “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.” Access to respite services has been shown to improve caregiver health and well-being; promote family stability; reduce the likelihood of abuse and neglect; and avoid or delay the need for admission to costlier institutional settings, resulting in significant savings for the health care system and taxpayers.

Definitions of respite can vary, and respite care can take many forms. For example, a care provider can provide services in the home so the family caregiver can attend their own medical visits; or respite can occur while the care receiver attends a local day program. Eligibility for many family caregiver services is frequently associated with considerations only to the care receiver rather than the family caregiver. This inadvertently removes the considerations of the family caregiver’s wellness. Respite for family caregivers should be considered an independent outcome, not just a secondary service. This would place the family caregiver’s wellness as the focus, as it should be, when utilizing respite. More importantly, it is under this perception that program and benefit developments can focus on the family caregiver’s needs separate from the care receivers, so they in turn can provide adequate care to their loved one, postpone facility placement and balance their life’s other obligations and relationships.

South Carolina family caregivers often struggle, needing greater support in receiving respite to support their wellness and ability to continue with caregiving. As the general and the aging population grows exponentially over the next 10 years, so does the family caregiver population. Building up the availability of respite in South Carolina through workforce development, increased benefits, and supporting organizational funding, will assist in providing a much needed greater foundational support to residents in the coming years.


Nicholas Julian
Executive Director
SC Respite Coalition

SC RESPITE COALITION

Lifespan Respite Programs 2020-2022



364
Families Served



20,699
Hours of Respite



\$216,061
Savings for Families



6 Respite
Breakrooms
Established

Annual Service to the SC Department of Disabilities and Special Needs Family Selected Respite Program



1,350
Families Served



650+
Respite Providers
Trained



1,400+
Respite Providers
Processed



26
Counties / DSN
Boards Supported

SC Unpaid Caregiver Survey

Conducted by the SC Respite Coalition in partnership with the Univ. of SC College of Social Work.



87%

indicated respite is very important for them

51%

indicated they get LESS THAN 5 hours of respite a week

58%

Indicated they are tired and/or stressed

72%

indicated a reduction of stress after taking respite

Survey was conducted with family caregivers that have engaged with SCRC between 2021 and 2022.



South Carolina Caregivers

AARP estimates the number of South Carolinians serving as family caregivers at any given time to be **730,000**.^{(*)11}



worth of care is provided by SC family caregivers **annually**.^{(*)11}

\$7.6 Billion



610 MILLION HOURS of **unpaid care** are provided annually by South Carolina family caregivers.^{(*)11}



51% of SC seniors will have \$50,000 for retirement, with the yearly average price for a facility being \$3,500 a month.^{(*)4}

44% of SC Caregivers surveyed say that the **lack of availability** of care providers prevents them from using respite.

We're Hiring

44%



74% of SC Caregivers surveyed feel they do not get enough breaks from Caregiving

By 2030, SC is expected to have 1.8 million seniors. However, there is currently only approx. 43,000 facility beds. With an average cost of assisted living at \$3,500 per month and skilled nursing facilities at \$7,604.^{(*)16}



South Carolina's unpaid Family Caregiver's need more access and opportunity to receive respite to ensure their long-term abilities in caring for a family member while also maintaining their own wellness, relationships, and employment.

United States Caregivers

Unless otherwise indicated, statistics have been utilized from reference item #8

In home hospice with unpaid family caregivers has risen every year from 2013 - 2019.

The National Hospice and Palliative Care Organization (NHPCO) reported in their 2021 Facts and Figures, 1.61 million Medicare Beneficiaries for hospice with **98% being paid to in-home care.**^(*12)

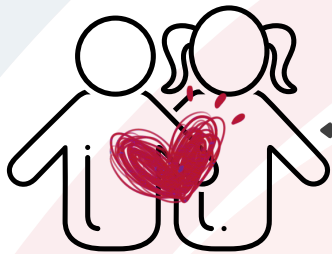
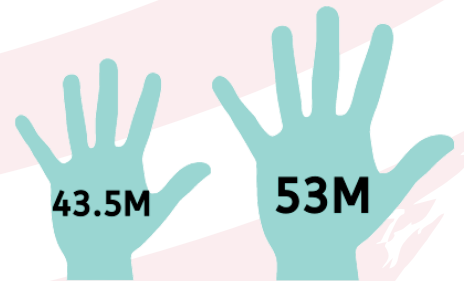


Caregivers need resources to also care for themselves

49% of unpaid Caregivers in the US reported having **feelings of depression**, and **70% feel tired most of the time.**

The aging population continues to grow, increasing the number of family caregivers and the demand for resources

Since 2015, the number of Americans providing care has **increased** from 43.5 million to 53 million in 2020.

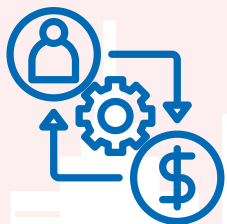
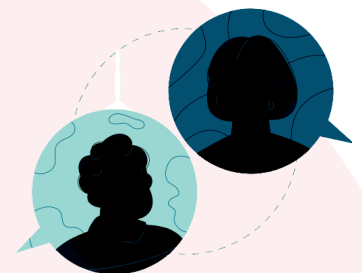


Some minors provide care to adults

1.4 Million caregivers are under the age of 18 years old.

Social isolation is common for family caregivers

50% of Caregivers say being a Caregiver **negatively impacts** their relationship with friends.^(*7)



Most caregivers provide care while maintaining employment

53 million Americans are providing unpaid care to relatives or friends with **61% of those caregivers being employed.**

Advocate to support Family Caregivers through the Lifespan Respite Act H.R. 2035, S. 995
and current funding presented by the Appropriations Committee.

FACES OF RESPITE

Family Caregivers of our Communities

South Carolina
Respite
Coalition

The SC Respite Coalition's mission is to expand quality respite opportunities throughout the lifespan for South Carolina families who have a member with special needs. The following testimonies are provided by family caregivers as a representation of the importance of respite.

www.SCrespite.org

Some testimonies have been edited to conserve space.

FACES OF RESPITE

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SHEVELLE

I always introduce myself as Avery's mom, and then later I go on to say I'm Shevelle. As a mother of Avery, my 18-year-old son with Autism, I believe that I work for Avery's quality of life and inclusion. We know as a caregiver of someone with a disability that this can be an everyday, lifelong undertaking. Often, caregivers forget that we need time for self-care and to rest. The S.C. Respite Coalition has done just that. I had no idea that I could find time to just rest, take a nap, see a movie or have lunch with a friend. Because of the respite voucher I am able to take some time to care for myself so that I am refreshed and renewed. The funds allow me to compensate my trusted person as they spend quality time with Avery. I am appreciative of S.C. Respite, their staff and all the caring individuals that make this possible. Please continue to support our most vulnerable and those that love and care for them.



DIXON

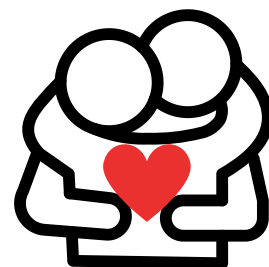
My son is a true gift to my family and me. He brings an abundance of joy to our lives each and every day. As a parent with a child with cerebral palsy and an intellectual disability, I have experienced such joy and love because of River. Having a child with both a physical and cognitive disability can place significant strain on a caregiver's body in addition to limiting the availability of time to self-care. Caregivers can easily find themselves in a state of exhaustion as they continuously place another person's needs above their own. I have truly appreciated the South Carolina Respite Coalition as a caregiver of a child with a disability. The SC Respite voucher has allowed me to compensate a trusted provider to care for my son so that I can have a sliver of time to rejuvenate myself to ensure that I can provide the best care for him. Respite care vouchers improve the overall quality of life for both the cared for and the caregiver.



Since 2020 the SC Respite Coalition has assisted over 1,700 family caregivers.

ANNA

My son was diagnosed with severe autism spectrum disorder about three years ago, and with all therapies and hospital I was drained out, mentally and physically. My family members live in Tennessee, we are not able to visit each other for all these years (because of pandemic). The support that South Carolina Respite Coalition offers us allowed me to visit my family and have my son stay with a great and safe environment with a very good friend of mine, without stressing him out on the trip and give me some time to reset my mind and get relief and rest. That was amazingly, amazingly, helpful! No words can describe my appreciation for all of you at the SC Respite Coalition!!!



FACES OF RESPITE

Family Caregivers of our Communities



JULIE

We know that it is our responsibility as the parents of our son to provide his care and help the restoration for quality of his life. We are thankful for programs like The South Carolina Respite Coalition for helping us get one of the mental, emotional, and physical supports we need. Without programs like these, we would never be as successful as we have been in the care and rehabilitation of our son.



BRENDA

Caring for the caregiver is crucial for the survival of any family raising a child with a rare disease. Trying to balance work, six medical specialists as well as our other child's activities took all our strength. So thankful for respite programs!

GRISELDA

As a Mother of a special needs child with autism it's hard to have some free time for myself. With the help of SC Respite Coalition program it's been less stressful. Thank you for all the hard work that goes into this program. I don't have enough words to thank you for all the help I have received. I really appreciate all the help and support that this program gives to all the families with special needs children.



74% of family caregivers surveyed indicated they do not receive enough respite.

MODORIA

It is hard being a single parent and trying to raise a child and tend to his needs, making sure that he has the best care possible. When you have to make sure that all your "I's are dotted and T's are crossed," it can become overwhelming trying to ensure that you didn't miss anything for your child's care. My mother has been a great support system for me and I'm forever grateful, indebted to her. The additional support of the SC Respite Coalition has been a blessing to me and my family. This "Heaven Sent" organization has allowed me the time to get away to myself for church, outdoor recreational activities, time with my friends, shopping, a weekend getaway, and lunch and dinner with friends. When I receive these breaks they are refreshing and rewarding to me as a parent, and the time to myself allows me the opportunity to regroup. The time to relax is a way to clear my mind so that I'm ready to go with a clear mind, and energy to proceed with my motherly duties providing "quality, supportive, and loving" care to my son. It's hard to find caregivers for someone with challenging or medical needs but "Thank God" for SC Respite Coalition to be in place to be able to assist me financially and emotionally. My family is forever thankful and grateful for you, and I pray that God will continue to bless you all with the love, financial support, and community support needed to keep this wonderful organization up and running in order to keep on making a difference in the lives of families with special needs loved ones.



FACES OF RESPITE

Family Caregivers of our Communities



MARIA

We have two beautiful children. Our smart and beautiful 7 year old girl has down syndrome and a very busy schedule for a girl of her age. Being the primary caregiver of my daughter has been a blessing, but at the same time I have to recognize it is emotionally and physically exhausting. The South Carolina Respite Coalition helped me understand that its very important to have time for myself. Being able to do my hair, take a long shower, sleep, spend time with friends or having a date with my husband definitely helped me to recharge my batteries.

ROCHELLE

Our sons and I can't thank the SC Respite Coalition enough for being a blessing to our family especially me. It gives me an opportunity to take a break away from being the Caretaker and to focus on me at the same time making sure my husband is cared for. My husband, their father had multiple strokes back in 2017 which caused him to go blind. He also has seizures and hip bursitis which requires 24/7 around the clock care. He enjoys listening to sports and old classic TV shows, spending time with family, eating snacks and good food. Since becoming a part of the SC Respites family. It gives me an opportunity to step away for some much needed Me Time. This allows me some time to self-care without the stress of finances or worrying about who and how I am going to pay someone to care for my husband during my time away. As the sole provider in my family, it's hard to break away. However, since SCRC, I can break away without the stress. So, for this reason alone, I am forever grateful to SC Respite Coalition and pray the donations continues to help families in need such as myself. Thanks again to SCRC for thinking of a way to help provide relief to the Caretakers because we too need self-care. Blessings to all.

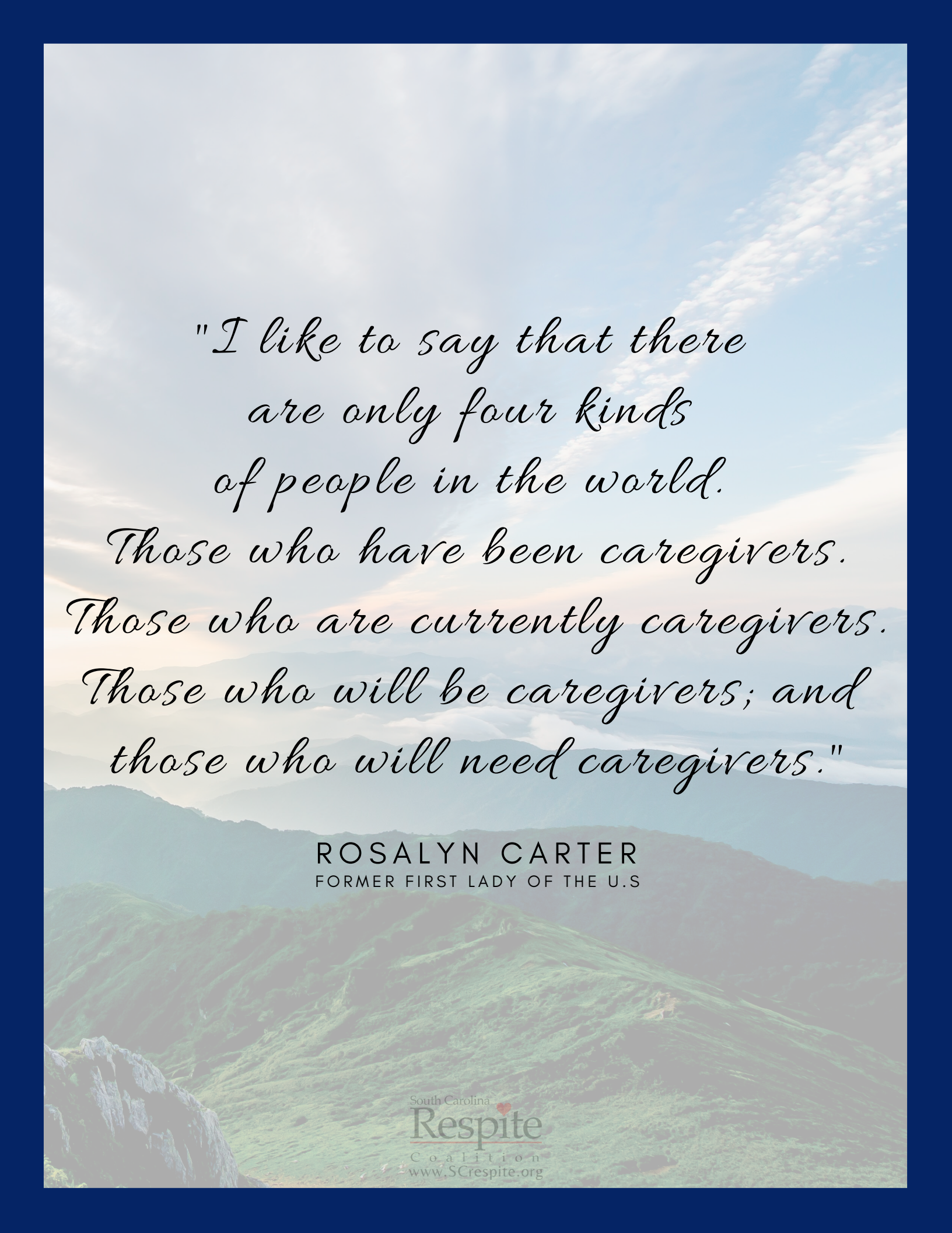


51% of SC Surveyed Family Caregivers said they receive LESS THAN 5 hours of respite a week.



ROBIN

I want to write to say how much I appreciate the support offered by the South Carolina Respite Coalition. my son Chase Miller has extreme anxiety; therefore, it is very challenging to leave him with family members at times. The funds were used for his aunt in Clemson to care for him so that I could take a much-needed weekend break. I read a good book during my vacation, slept, and had dinner with friends.



*"I like to say that there
are only four kinds
of people in the world.
Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers; and
those who will need caregivers."*

ROSALYN CARTER
FORMER FIRST LADY OF THE U.S

RESOURCES

SC Respite Coalition
PO Box 497
Columbia, SC 29201
www.SCrespites.org
(803) 935-5027

Dept. On Aging
1301 Gervais St Suite 350,
Columbia, SC 29201
www.aging.sc.gov
(803) 734-9900

SC Long Term Care Ombudsmen
(800) 868-9095

Dept. of Disabilities and Special Needs
3440 Harden Street Extension
Columbia, SC 29203
www.ddsn.sc.gov
(803) 898-9600

Family Connections
1800 St. Julian Place, Suite 104
Columbia, SC 29203
www.familyconnections.sc.org
(800) 578-8750

AARP - SC Chapter
2101 Main St Suite 1720
Columbia, SC 29201
www.states.aarp.org/south-carolina
(866) 389-5655

Bright Start SC
720 Gracern Road Suite 450
Columbia, SC 29210
www.brightstartsc.com
(803) 929-1112

Easterseals SC
PO box 5715
Columbia, SC 29250
www.easterseals.com/southcarolina/
(803) 466-4089

Leeza's Care Connection
201 St. Andrews Road
Columbia, SC 29210
www.leezascareconnection.org
(803) 888-7525

South Carolina Autism Society
806 12th Street
West Columbia, SC 29169
www.scautism.org
(803) 750-6988

SC Spinal Cord Injury Association
PO Box 292368
Columbia, SC 29229
www.scspsc.org
(803) 252-2198

www.GetCareSC.com

SC Thrive
120 Research Drive
Columbia SC 29203
www.scthrive.org
(800) 726-8774

The Ark of South Carolina
502 West 5th North Street
Summerville, SC 29483
www.thearkofsc.org
(843) 471-1360

U.S. Dept. of Veterans Affairs
6437 Garbers Ferry Road
Columbia, SC 29209
www.va.gov
(800) 827-100

Alzheimer's Assoc. - SC Chapter
140 Stoneridge Dr #640
Columbia, SC 29210
www.alz.org/sc
(803) 791-3430

PASO's
120 Research Drive
Columbia, SC 29203
www.scpasos.org
(864) 407-2586

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