

SOUTH CAROLINA RESPITE COALITION CAREGIVER SURVEY

KEY FINDINGS

In August 2020, the South Carolina Respite Coalition sent a survey to family caregivers and organizations serving family caregivers to get an idea of who South Carolina caregivers are and the impact of caregiving on their lives. We asked for basic information about the caregiver and care recipient, the impact of caregiving, the caregiver's employment situation, use of respite, use of care resources, and the impact of COVID-19 on the caregiver and care recipient.

We received 130 responses. While the survey was not designed to provide a comprehensive portrait of all caregiving in SC, we do believe its results are enlightening.

Here are key findings from the survey. (Note: for questions where multiple responses were allowed, percentages may total more than 100.)

- ♥ In line with other data on caregivers, the vast majority (91%) of responding caregivers were female.
- ♥ The average age of caregivers was 56, with a range of 29 to 85.
- ♥ Most respondents (57%) were caring for a son or daughter. A total of 22% were caring for a spouse/partner and 13% were caring for a parent or in-law.
- ♥ The age range of those being cared for was infant to 98.
- ♥ The disabling condition of the care recipient most often cited was intellectual/developmental disability (54%). Alzheimer's disease or other irreversible dementia was noted by 28% and physical disability by 23%.
- ♥ The overwhelming majority (76%) of respondents have been providing care for their loved one for five or more years.
- ♥ When asked all the ways caregiving has had an effect, the responses listed most often were being tired/worn out a lot of the time and having a decreased social life (both 75%). Positive impacts were also reported. Some 72% of respondents said they had gained empathy about others' situations and 52% said they made new friends with people in similar situations.
- ♥ Caregivers were asked to select from a list of difficulties they may have experienced as a result of caregiving. The most-noted difficulties were those related to the caregiver's wellbeing (e.g. meeting their own personal needs, balancing caregiving and work responsibilities, balancing needs of the rest of the family). Other difficulties most often reported were finding reliable home-care providers, understanding government programs, and having enough money to pay for care.
- ♥ Respondents were asked, "When you are talking with someone about help for your loved one, do you ask about help for yourself as a caregiver?" Over half (55%) said they never ask for help for themselves.
- ♥ A bit less than half (47%) of respondents were employed outside their home. For those with jobs, 53% said caregiving had caused them to decrease work hours and 40% said caregiving had led them to quit a job.
- ♥ Almost three quarters (72%) of respondents said they had taken respite, with 54% having received vouchers to pay for respite.

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- ♥ Of those who have taken a respite break, the ways they have used respite include running errands (83%), spending time with their spouse or other family (76%), having "me time" (70%), getting sleep/rest (60%), and going to healthcare appointments (their or another family member's) (58%).
- ♥ When asked all the ways respite helped them, 82% of respite users said they felt less overwhelmed, 45% said they had less depression or anxiety, 36% said it balanced other responsibilities, 36% said it enhanced relationships with other family members, and 31% said it increased social activities.
- ♥ A total of 47% of those using respite care said they had difficulty in obtaining it before COVID-19 restrictions. The most common reason for difficulty was not being able to find a care provider (63% of those having difficulty).
- ♥ A variety of sources were used for information about where to find resources to help care for loved ones. These included case managers/early interventionists (38% of all respondents), other families in a similar situation (36%), support organizations (32%), social media (29%), and doctors or other healthcare providers (28%).
- ♥ A total of 70% reported they had received services, resources or benefits to help care for their loved one in the past year. The organizations most often used for help were the Department of Disabilities and Special Needs or local disability board, nonprofit organizations, home healthcare agencies, and Social Security.
- ♥ Caregivers were asked all the ways COVID-19 has added to their challenges as a family caregiver. A total of 37% said they were not comfortable having a care provider come into their home. Some 14% said COVID-19 had not added to their challenges as a caregiver.
- ♥ In regard to the impacts of COVID-19 on the person being cared for, 75% said that person has less social interaction, 58% said their loved one was tired of staying at home, 44% said the care recipient does not understand why things have changed, and 35% said the care recipient's difficult behaviors have increased.

For more information, contact the South Carolina Respite Coalition at 803-935-5027 or info@screspitcoalition.org. Visit us at www.screspitcoalition.org.

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