



Extension

UNIVERSITY OF WISCONSIN-MADISON

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RESEARCH BRIEF – JUNE 2022

FAMILIES UNDER STRESS

ASSESSING PARENTS' ADAPTATION, COPING AND RESILIENCE THROUGH THE COVID-19 PANDEMIC

The COVID-19 pandemic brought many changes to the daily lives of families around the world. Significant emerging research documents the negative impact of COVID-19 and surrounding circumstances on families' mental health well-being. School and childcare closures have placed parents in dual positions of teacher and caregiver as they balance working remotely, economic insecurity, and their own stress. Meanwhile, parents of children with special healthcare needs (CSHCN) have taken on increasing responsibility for care tasks due to social distancing and quarantine guidelines. Changes in routine, stress, and social isolation are impacting families of all types across the state and globally. In order to best support families both during and after the pandemic, it is critical to understand how COVID-19 has affected Wisconsin families.

METHODS AND APPROACH

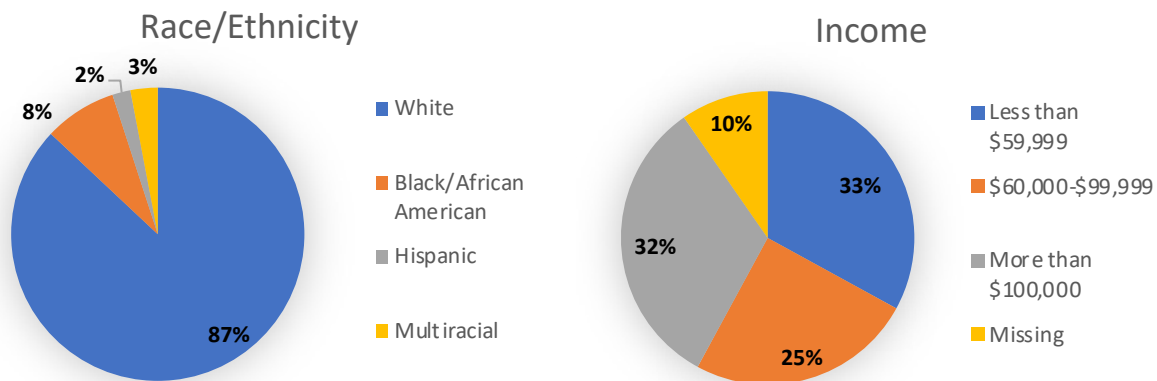
Data were from the COVID-19 Community Impact Survey collected by the Survey of the Health of Wisconsin (SHOW). The SHOW is a population-based health examination survey designed to collect information from representative sample of Wisconsin residents. In May of 2020, SHOW launched a statewide online/phone survey of early impacts of COVID-19 on health and well-being across diverse families. The second wave was collected in December 2020 to examine the ongoing impact of COVID-19, and the third wave was collected in June 2021.

A total of 1,403 adult participated at Wave 1, of which 342 (24%) were parents of at least one child under 17 years of age. Wave 2 included 1,889 adults, of which 425 (23%) were parents. Wave 3 included 1,615 adults, of which 424 (26%) were parents. Participants reported on 1) COVID-19 perceptions, beliefs, behaviors; 2) economic well-being; 3) food security, diet, and housing; 4) personal, social, and community context; 5) health and healthcare access; 6) mental and emotional health; 7) information sources and literacy; 8) lifestyle behaviors; and 9) caregiving.

We aggregated the data to understand how parents with and without children with special healthcare needs (CSHCN) perceived and adapted to the pandemic on average, as well as which characteristics were associated with better well-being over time¹.

■ SUMMARY OF SAMPLE DEMOGRAPHICS ■

Most of the parents (71%) were mothers. On average, parents were 41 years of age (SD = 11.5 years). The majority of the parents identified as non-Hispanic white (77%) and had at least some college education (82%). The average annual family income was \$84,582 (SD = \$52,620), with a mean household size of 3.9 people (SD = 1.3). Most parents had at least one medical condition (73%) and had health insurance (96%).



■ CAREGIVING FOR A CHILD ■

DEMOGRAPHIC CHARACTERISTICS AND SITUATIONAL CHANGES DUE TO COVID-19

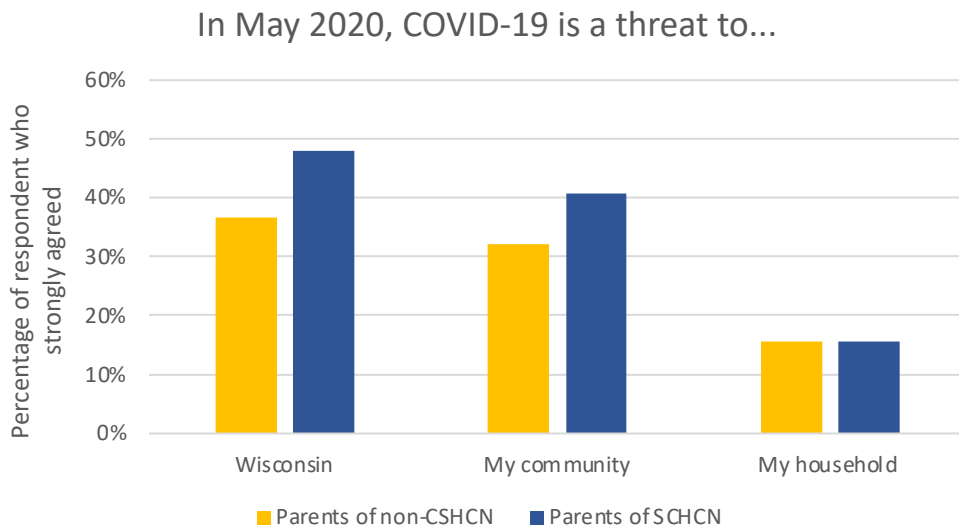
At Wave 1 (May 2020), 28% of the parents (n = 96) reported caring for a child with one or more special health care needs or physical health conditions (CSHCN). At Wave 2 (December 2020), 32% of the parents (n = 137) reported caring for CSHCN and at Wave 3 (June 2021), 25% of the parents (n=69) reported caring for CSHCN (note that the items asking about care for CSHCN were modified in Wave 3).

The average age of parents of CSHCN and parents of non-CSHCN at Wave 1 was 41.3 years (SD = 11.8) and 41.5 years (SD = 10.8), respectively. About 70% of parents of CSHCN and 80% of parents of non-CSHCN identified as non-Hispanic white. Parents of CSHCN and parents of non-CSHCN were similar in employment status with about 70% employed within both groups in the beginning of COVID-19, and about 66% experiencing some change in employment status due the pandemic. However, parents of CSHCN reported lower income with 40% reporting an annual income of less than \$59,999 compared to 33% of parents of non-CSHCN. Parents of CSHCN also reported having more medical conditions that were not related to COVID-19 at Wave 1 (2.6 compared to 1.9 conditions) and were more likely to report not having any health insurance (7% compared with 3%) than parents of non-CSHCN. They were also more likely to have been using benefits prior to the pandemic (40% compared with 24%) and to have reported using benefits because of changes due to COVID-19 (47% compared to 34%).

¹Chi-square and t-tests were performed to determine if there were significant differences between parents of CSHCN and parents of non-CSHCN using an alpha level of 0.10.

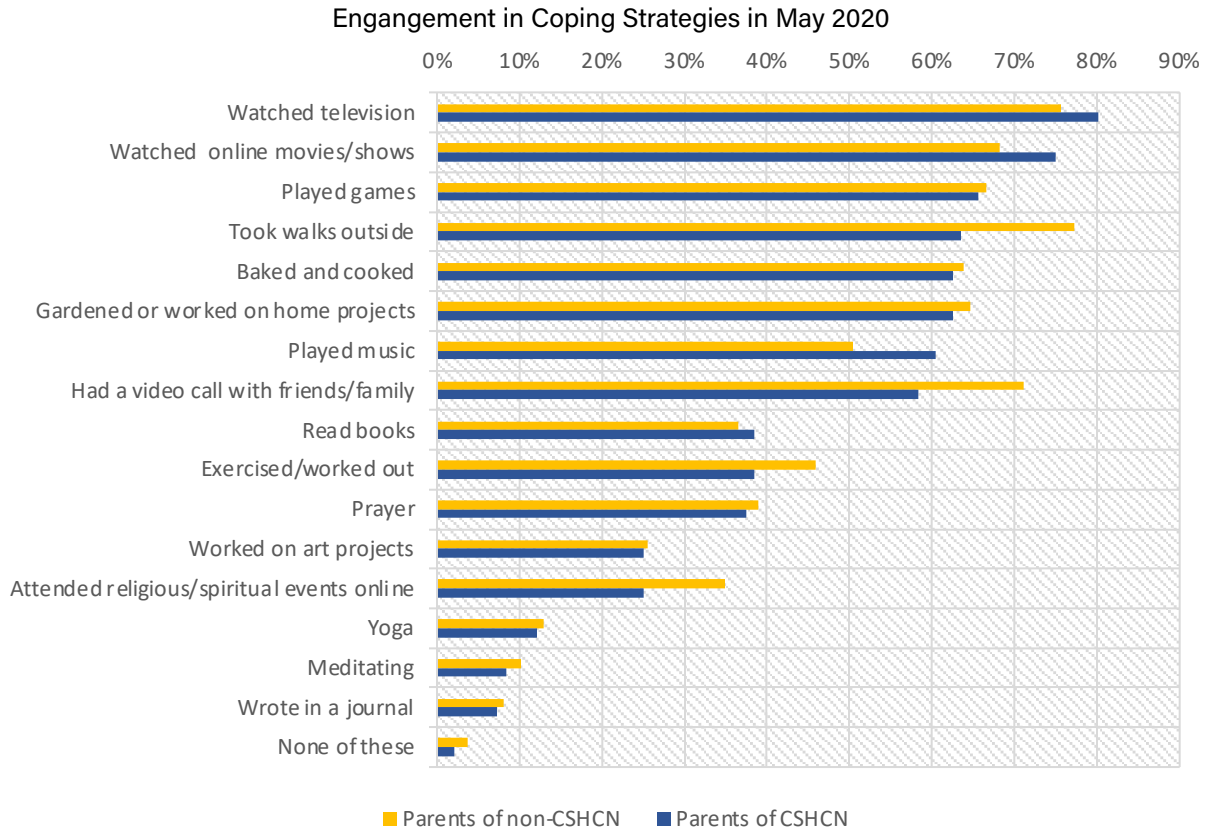
COVID-19 PERCEPTIONS, BELIEFS, AND BEHAVIORS

During the early months of the pandemic (May 2020), parents of CSHCN were more likely to say that they strongly agreed that COVID-19 was a threat to Wisconsin (48% compared to 37%) than parents of non-CSHCN. However, they did not differ in COVID-19 threat perception to the community and household. Parents of CSHCN were similar to parents of non-CSHCN in their perceived exposure to COVID-19 and participation in practicing precautionary behaviors. For both subgroups at Wave 1, 30% of parents reported recent perceived exposure to COVID-19 and parents reported using an average of six COVID precautions (out of nine listed examples such as staying at home, practicing social distancing, washing hands and canceling social gatherings).



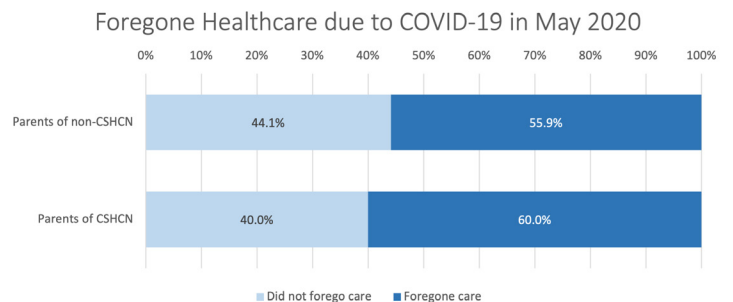
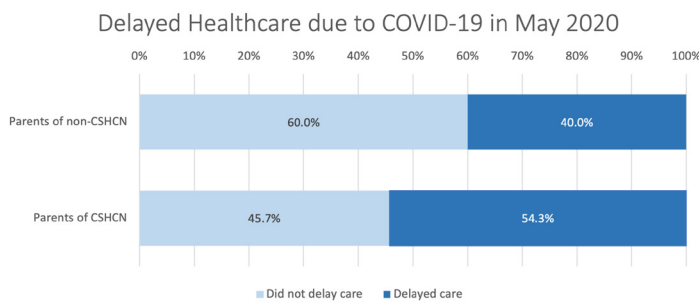
■ COPING STRATEGIES DURING COVID-19 ■

Survey respondents were asked to identify whether they had done any of 16 activities to cope with change, stress, and anxiety during COVID-19. Both groups of parents (CSHCN and non-CSHCN) reported practicing about seven coping behaviors in May 2020. However, parents of CSHCN were less likely than parents of non-CSHCN to report taking walks outside (64% compared to 77%), having video calls with friends and family (58% compared to 71%), and attending religious or spiritual events online (25% compared to 35%).



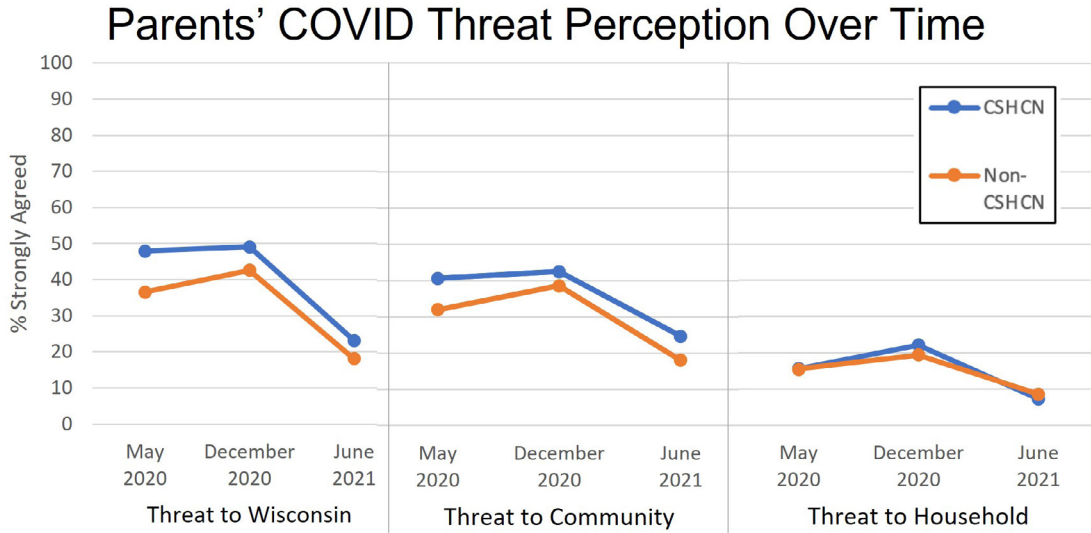
■ HEALTH AND HEALTHCARE ■

Parents of CSHCN and parents of non-CSHCN also used different approaches in navigating healthcare in the beginning of the pandemic. Parents of CSHCN were more likely than parents of non-CSHCN to report that they delayed getting health care due to COVID-19 (54% compared to 40%). They were also more likely to forego health care during the early months of the pandemic, specifically in getting prescription medication (10% compared to 4%) and mental health care or counseling (12% compared to 4%).



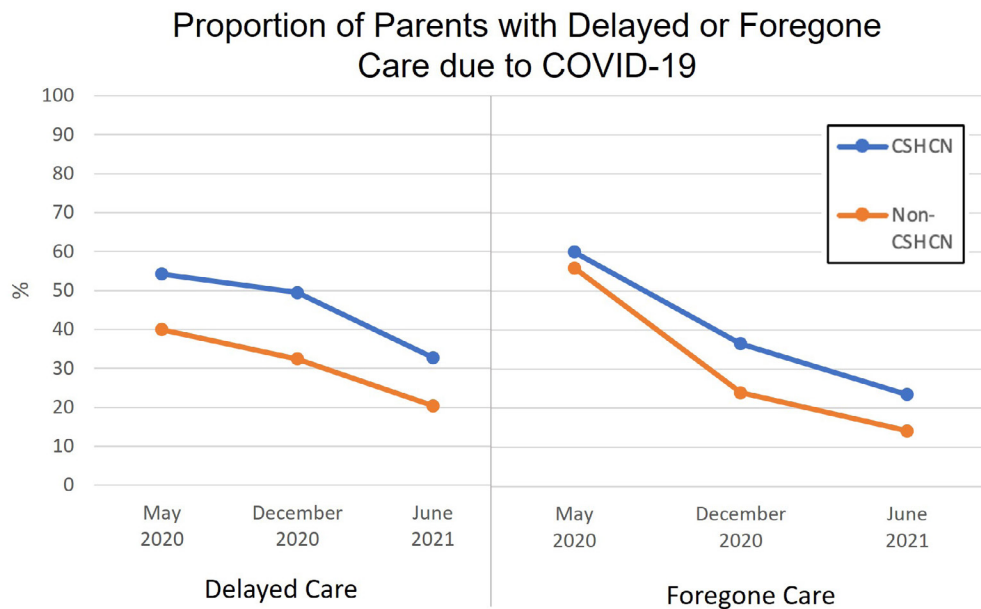
CHANGES OVER TIME

As the pandemic intensified into the winter, perceptions of the risk of COVID increased for both groups of parents, but tended to increase more among parents without CSHCN, decreasing the gap in the proportion of parents who strongly agreed that COVID was a threat. Perceived threat decreased dramatically for both groups by June 2021.



Both parents of CSHCN and parents of non-CSHCN continued to use about 7 coping behaviors on average in December 2020, with a slight decrease (to just over 6 coping behaviors) by June 2021. This pattern mirrors the trends seen in non-parents, as well.

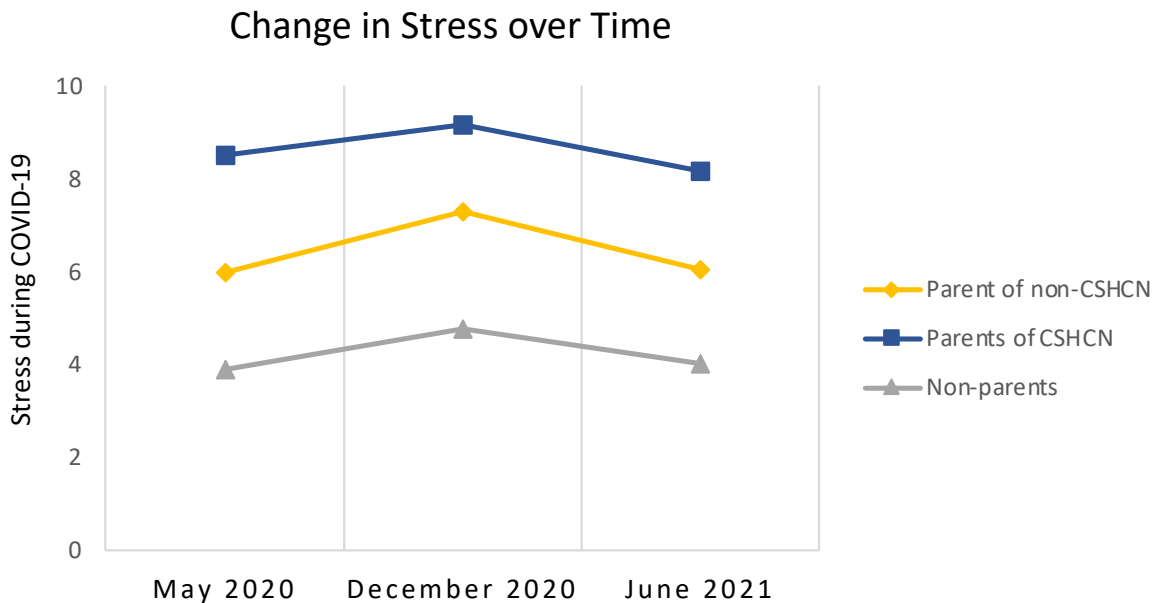
In addition, parents of CSHCN continued to report delayed and foregone healthcare at higher rates than their non-CSHCN counterparts, particularly foregone mental health counseling (11% compared to 3% at Wave 2).



MENTAL AND EMOTIONAL HEALTH

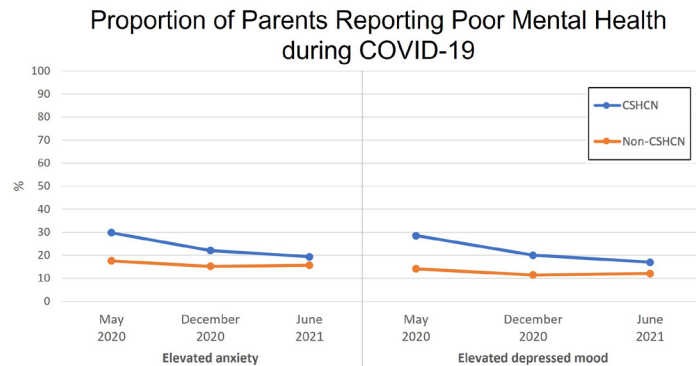
STRESS AND ADAPTATION

Throughout the pandemic, parents reported higher levels of stress than non-parents. Furthermore, parents of CSHCN had greater levels of stress than parents of non-CSHCN. Several months into the pandemic, average stress levels increased for both groups of parents, with stress levels of parents of CSHCN remaining significantly higher. Particularly, parents who took on a caregiving role (those who reporting beginning to care for a child of special health care needs) between May 2020 and December 2020 reported the greatest increase in stress several months later (December 2020). In May 2020, parents of CSHCN reported greater stress in several domains, including stress related to caring for others, medical problems, meeting basic needs, loss of money or finances, racism/discrimination, and in relationships with others. In December 2020, parents of CSHCN continued to report greater stress related to caring for others, meeting basic needs, loss of money or finances, and in relationship with others, but no longer reported significantly greater stress related to medical problems or racism/discrimination. In June 2021, stress levels slightly decreased across all groups to levels similar to those at the beginning of the pandemic.



PSYCHOLOGICAL GROWTH

Many parents experienced elevated levels of anxiety and depressed mood over the course of the pandemic, and parents of CSHCN were more likely to experience elevated anxiety and depressed mood than non-CSHCN.

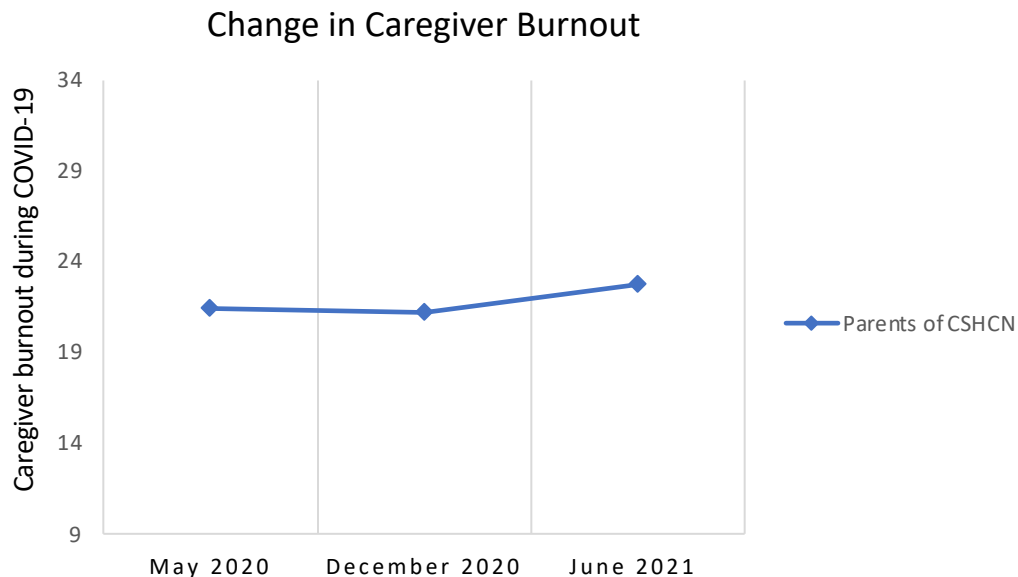


Parents of CSHCN were also more likely to cultivate a positive mindset and report psychological growth than parents of non-CSHCN, particularly in the beginning of the pandemic. In May 2020, parents of CSHCN were more likely to agree that their experience during the pandemic had made them a stronger person (51% versus 42%), helped them to better cope with life's challenges (47% versus 41%), and became a reason to make positive changes in life (49% versus 44%). However, while these perceived positive impacts tended to remain steady or increase over time among parents of non-CSHCN, they tended to decrease among parents of CSHCN over the course of the pandemic (with the exception of coping better, which tended to increase overall by December 2020).



CAREGIVER BURNOUT

Parents of CSHCN also reported on their thoughts and feelings about caregiving during the pandemic. Parents of CSHCN answered questions about their emotional state such as, “I am in survival mode”, “I feel completely run down”, and “I have a sense of purpose”. On a range from 5 to 35, the mean score was 21.4, indicating that parents of CSHCN reported feeling moderately burned out with caregiving responsibilities. Levels of burnout stayed stable from May 2020 to December 2020 and increased slightly from December 2020 to June 2021.



IMPLICATIONS AND TAKE-AWAYS

The COVID-19 pandemic upended daily life, placing parents in unexpected and stressful circumstances, especially parents caring for children with special healthcare needs. During the pandemic, parents of CSHCN were more likely to report that COVID-19 was a threat to their communities and household, take more precautionary behaviors, use fewer coping behaviors, and forego healthcare than parents of non-CSHCN. Parents of CSHCN also had significantly greater levels of stress than parents of non-CSHCN and all parents reported higher levels of stress than non-parents in the sample. Burnout was also a concern for parents of CSHCN over the course of the pandemic.

LIMITATIONS TO CONSIDER

It is possible that some parents and caregivers were too busy, stressed, or overwhelmed to respond to the survey. In addition, the majority of the respondents identified as non-Hispanic white (77%). The COVID-19 pandemic has disproportionately affected underserved and minority populations and communities of color, and may have differentially affected caregiving experiences of caregivers from diverse racial/ethnic backgrounds. The information in this report should be interpreted with caution given the low percentage of caregivers and the lack of racial and ethnic diversity represented in the sample. It may be possible some caregivers might have experienced even greater challenges and/or benefits that we know. Policies and programs should be tailored to reflect the various needs of caregivers and better support them during the stressful times, such as the COVID-19 pandemic.

RESOURCES FOR CAREGIVERS AND FAMILIES

Many resources are available to support parents of CSHCN and families, both during the pandemic and as we begin to recover and return to a new sense of normalcy.

Regional Children and Youth with Special Health Care Needs (CYSHCN) Centers throughout Wisconsin (<https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>) provide a system of information, referral, and follow-up services for all families of children and youth with special health care needs.

Family Voices of Wisconsin (<https://familyvoiceswi.org>) is a statewide network of families who have children with special health care needs and disabilities and those who work on their behalf. The focus of their work is health care access, coverage and supports and services for children with special needs.

Parent to Parent of Wisconsin (<https://p2pwi.org>) helps parents find one-to-one connection with another parent, who knows firsthand about the feelings and realities that come with having a child with special health care needs.

Extension programming can support the well-being of parents of CSHCN and their families. Program examples include Powerful Tools for Caregivers (often taught through an Aging and Disability Resource Center or other local partner) and local programming specifically designed for caregiver needs. Take a look at the Extension calendar of events (<https://extension.wisc.edu/events/>) or your local Extension homepage (<https://counties.extension.wisc.edu/>), or contact your local Extension offices to learn more about programs that might meet your needs.



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