

PARENTS OF CHILDREN & YOUTH WITH SPECIAL HEALTHCARE NEEDS



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FRAMING MATTERS

Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. Care recipients can range from children to older adults and have chronic illnesses or disabling conditions.¹

Caregiving is rewarding and meaningful but also comprised of challenges. Prior to the COVID-19 pandemic, many caregivers already struggled with balancing caregiving with paid work, household responsibilities, and taking care of their own health. Changes in availability of respite care during the height of the pandemic, fear of COVID-19 infection, and increased social isolation had a significant effect on caregivers during the pandemic.

There has been an historic absence of comprehensive data for this population. Due to the large sample size of the survey, CCIS provides a unique source of data on the challenges faced by caregivers in Massachusetts and validates some of the anecdotal data that programs have received.

CAREGIVERS IN MASSACHUSETTS

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

- **Screener question:**

- Are you a parent / guardian of a child or youth with special health care needs? We define children and youth with special health care needs as those who: Have a chronic physical, developmental, behavioral or emotional condition that has lasted or will Have a chronic physical, developmental, behavioral or emotional condition that has lasted or will last 12 months or longer, and Need health and other services beyond what is generally required by children.

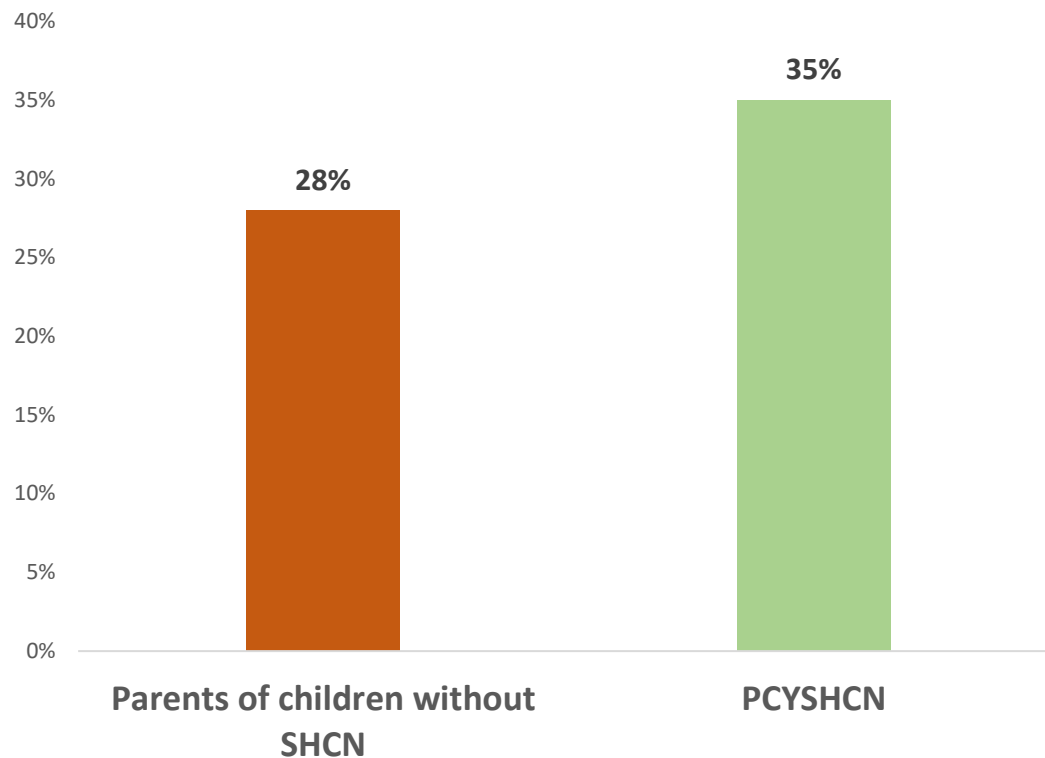
PCYSHCN sample:

- 786 respondents
- Average age of 47 years
- 88% urban
- 84% female
- 80% employed
- 80% white, 17% people of color
- 16% speak a primary language other than English
- 10% of the caregivers have one or more disabilities

CAREGIVERS IN MASSACHUSETTS

PCYSHCN were 25% more likely to be very worried about COVID-19 infection compared to other parents

Percent of Parents Reporting Being "Very Worried" about COVID-19 Infection in MA by Caregiver Status*



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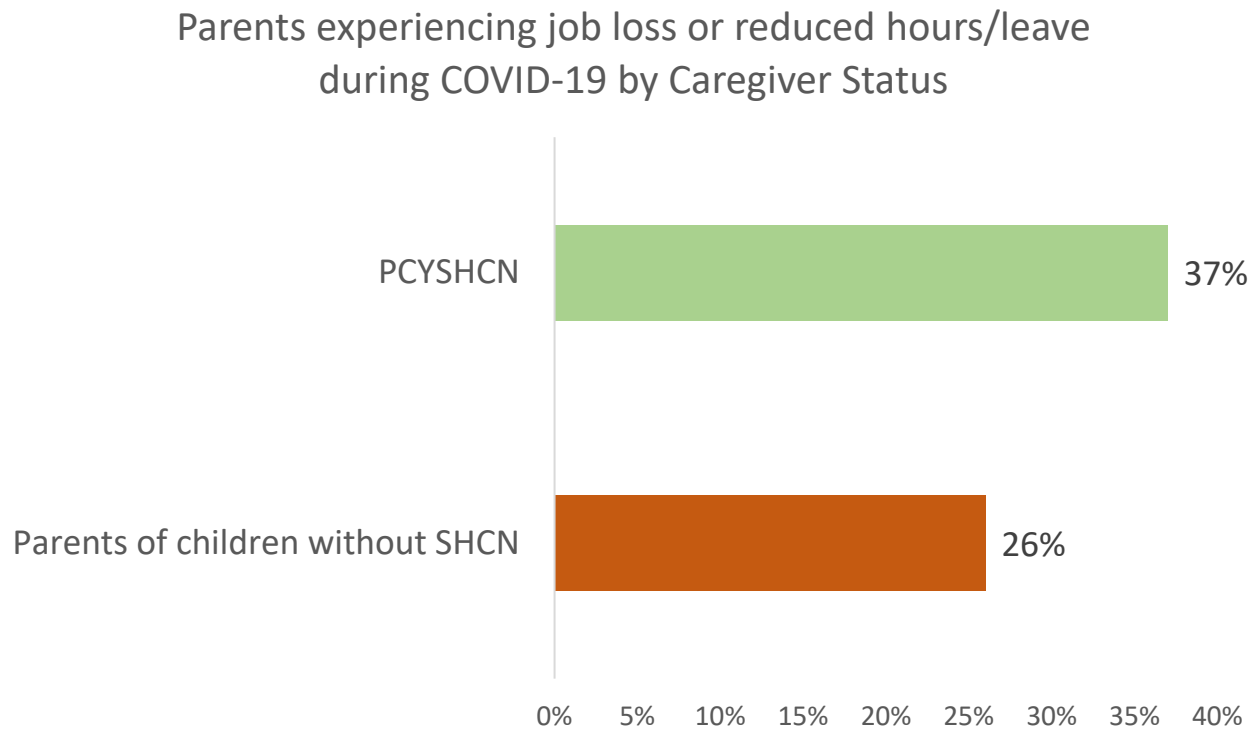
Parents of children & youth with special healthcare needs may be worried about who will care for their children if they become ill. They may also be worried about infecting their children with COVID-19.

More than 40% of PCYSHCN with disabilities and PCYSHN of color were very worried about COVID-19 infection.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,676; Effective sample size = 3,460.

CAREGIVERS IN MASSACHUSETTS

More than 1 in 3 PCYSHCN lost their jobs, reduced their hours, or took leave during the pandemic



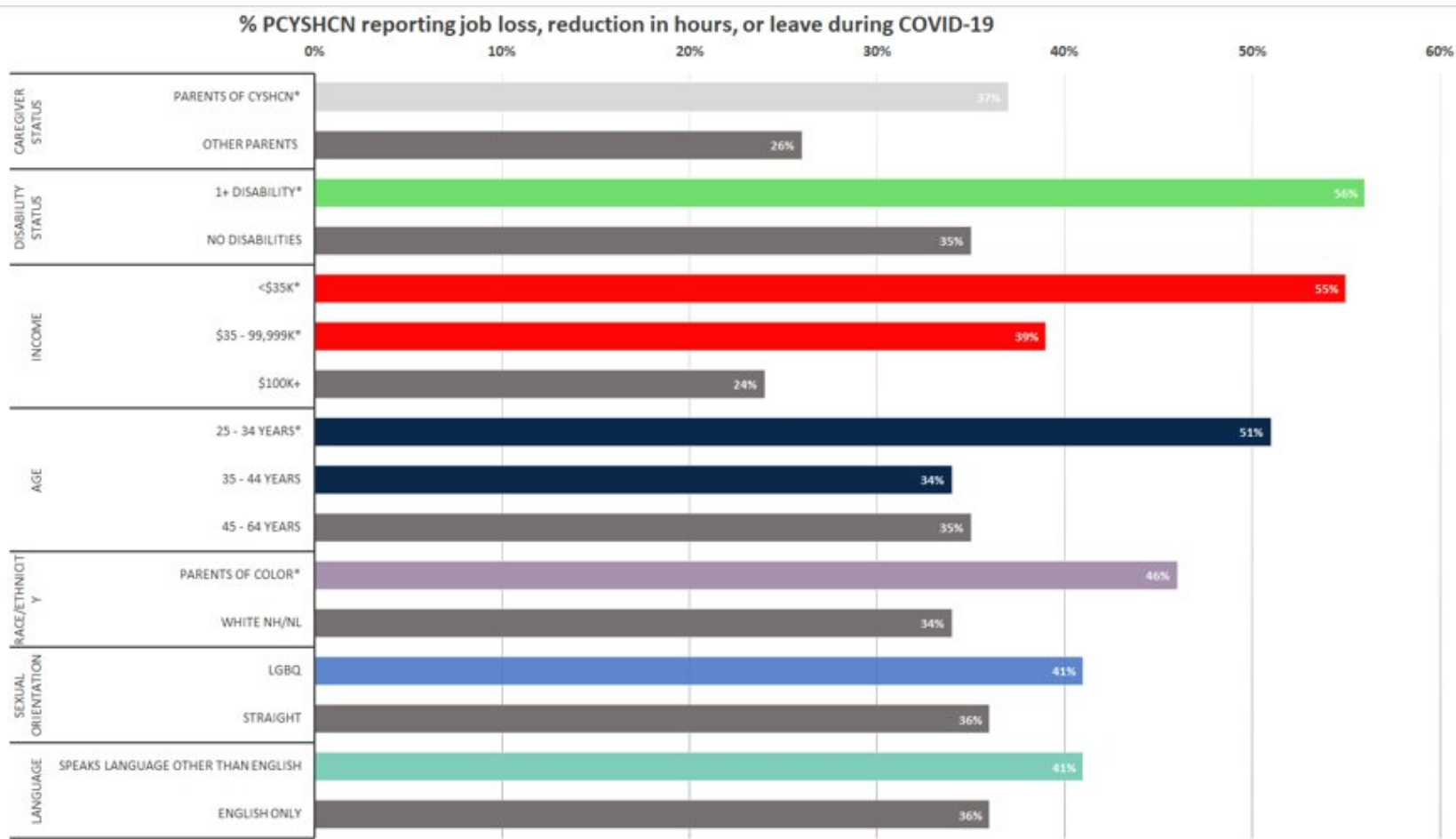
Parents of children & youth with special healthcare needs were 45% more likely to report job loss, reduction of hours, or leave than other parents. Parents overall were 35% more likely to report job loss/reduced hours/leave compared to non-parents.

PCYSHCN were more likely than other parents to say their employment status changed due to needing to take care of a child (32% vs 23%) respectively.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,676; Effective sample size = 3,460.

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

More than half of certain groups of PCYSHCN lost their jobs, reduced their hours, or took leave



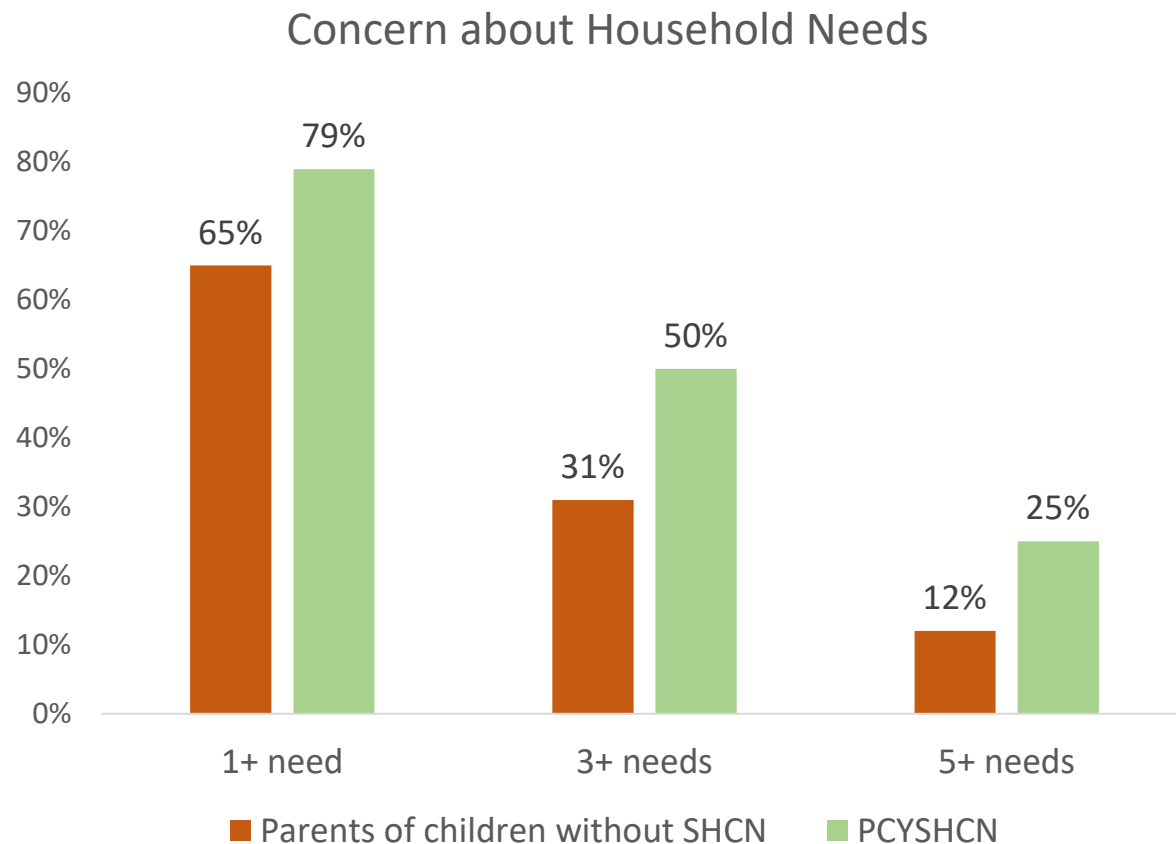
Certain groups of PCYSHCN were more likely to lose their jobs or reduce their hours:

- Parent with disabilities
- Parents with incomes under \$100K
- Parents under age 35
- Parents of color

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) sample size = 476; Effective sample size = 432

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

1 in 4 PCYSHCN were concerned about 5 or more household needs during the first 6-8 months of the pandemic. Nearly 80% were concerned about at least one household need.



Household needs include food or groceries, face masks, cleaning and paper products, hygiene products, and menstrual products.

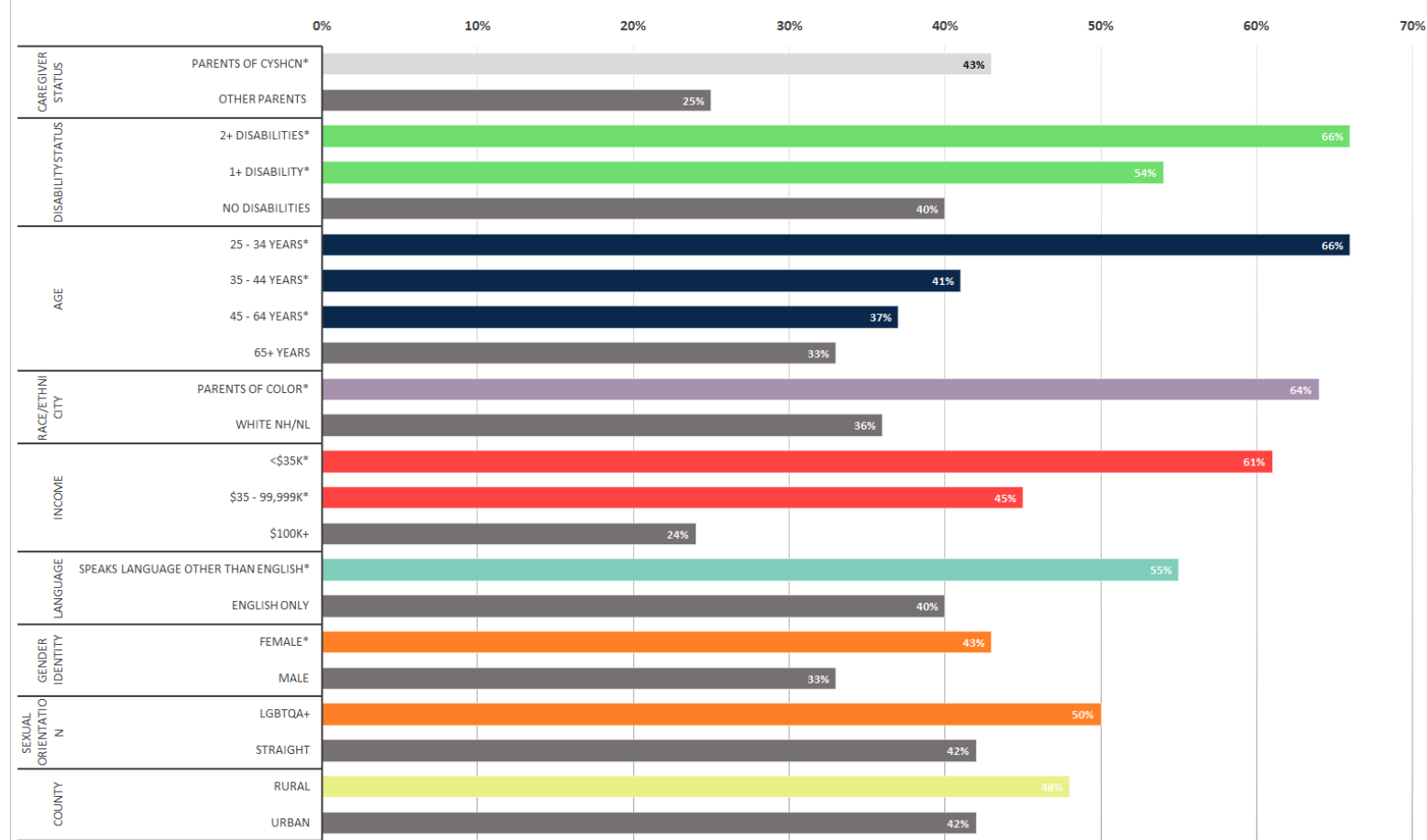
In addition, 1 in 4 parents of children and youth with special healthcare needs reported having an unmet child need, including accessing available and affordable childcare, diapers, or formula.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,464; Effective sample size = 3,236

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

Parents of children and youth with special healthcare needs were nearly 2x more likely to be worried about food or groceries compared to other parents.

% PCYSHCN reporting concerns about food or groceries during COVID-19 pandemic



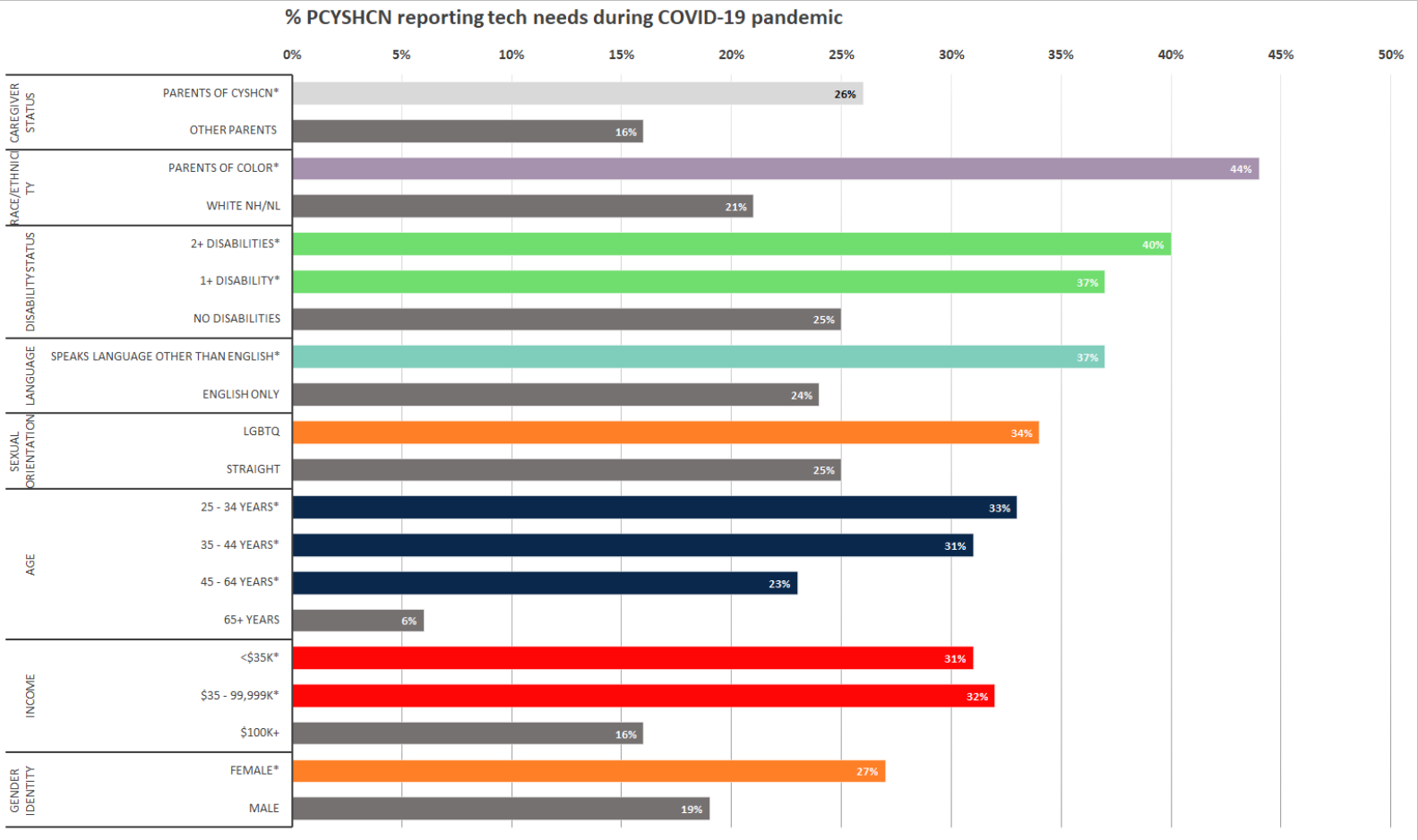
Certain groups of PCYSHCN were more likely to report worrying about buying food or groceries:

- Parent with disabilities
- Parents under the age of 35
- Parents of color
- Parents with incomes under \$35K
- Parents who speak a language other than English

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 742; Effective sample size = 724

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

1 in 4 parents of children and youth with special healthcare needs were also concerned about tech needs, including accessing the internet access and access to a computer, tablet, or cell phone.

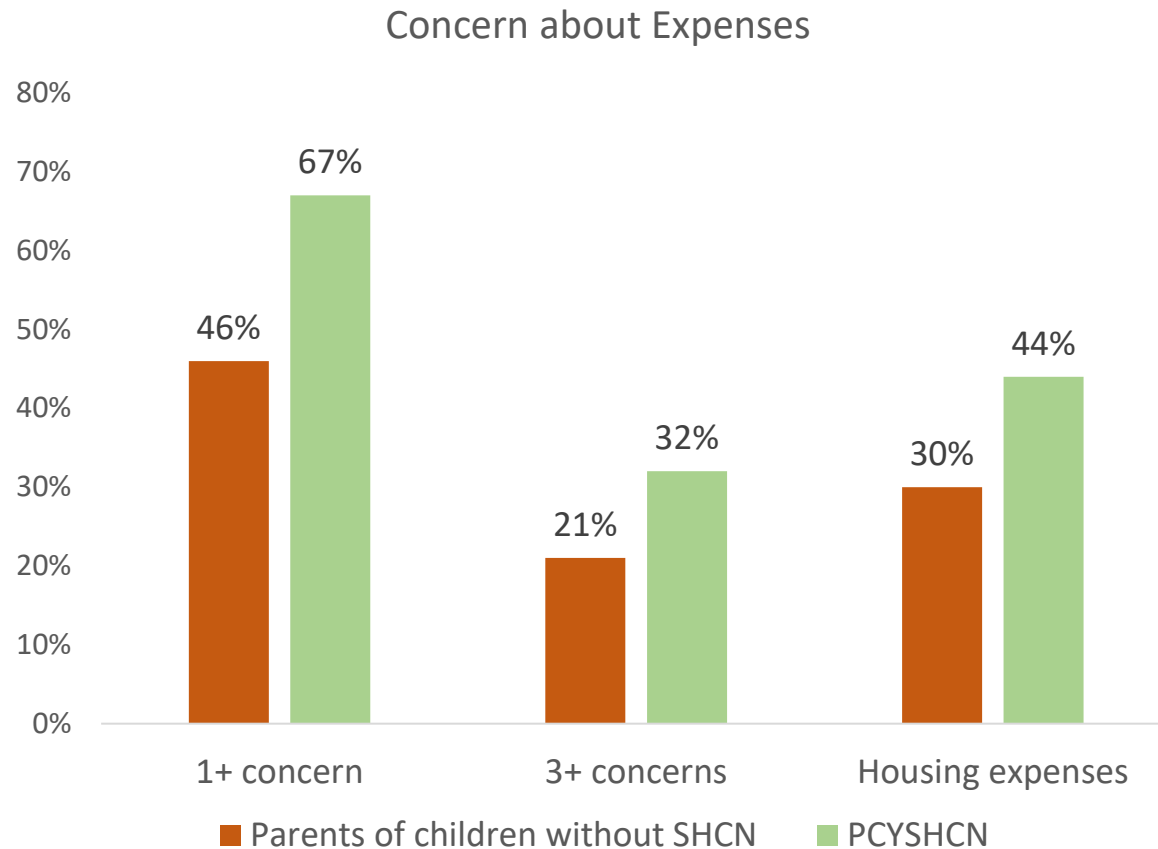


- Certain groups of PCYSHCN were more likely to have unmet tech needs:
- Parents of color
 - Parent with disabilities
 - Parents who speak a language other than English
 - LGBTQA+ parents
 - Parents under the age of 45
 - Parents with incomes under \$100K

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 712; Effective sample size = 687

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

2 in 3 PCYSHCN were concerned about expenses



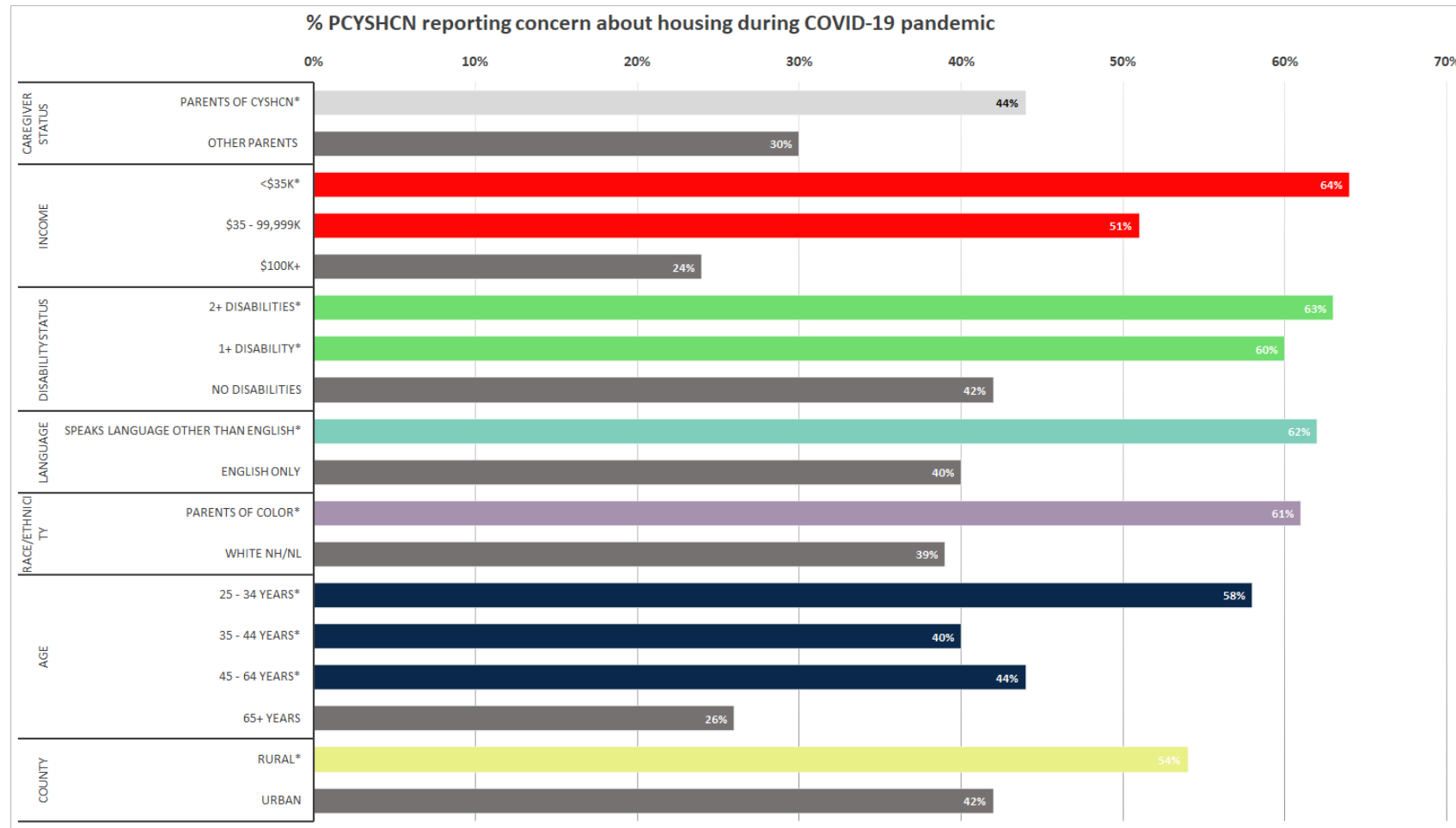
As many as 80% of the following groups of PCYSHCN were worried about expenses:

- Parents with disabilities
- Parents with incomes under \$35K
- Parents under the age of 35
- Parents of color
- Parents who speak a language other than English

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,464; Effective sample size = 3,236

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

Nearly half of PCYSHCN were worried about housing expenses

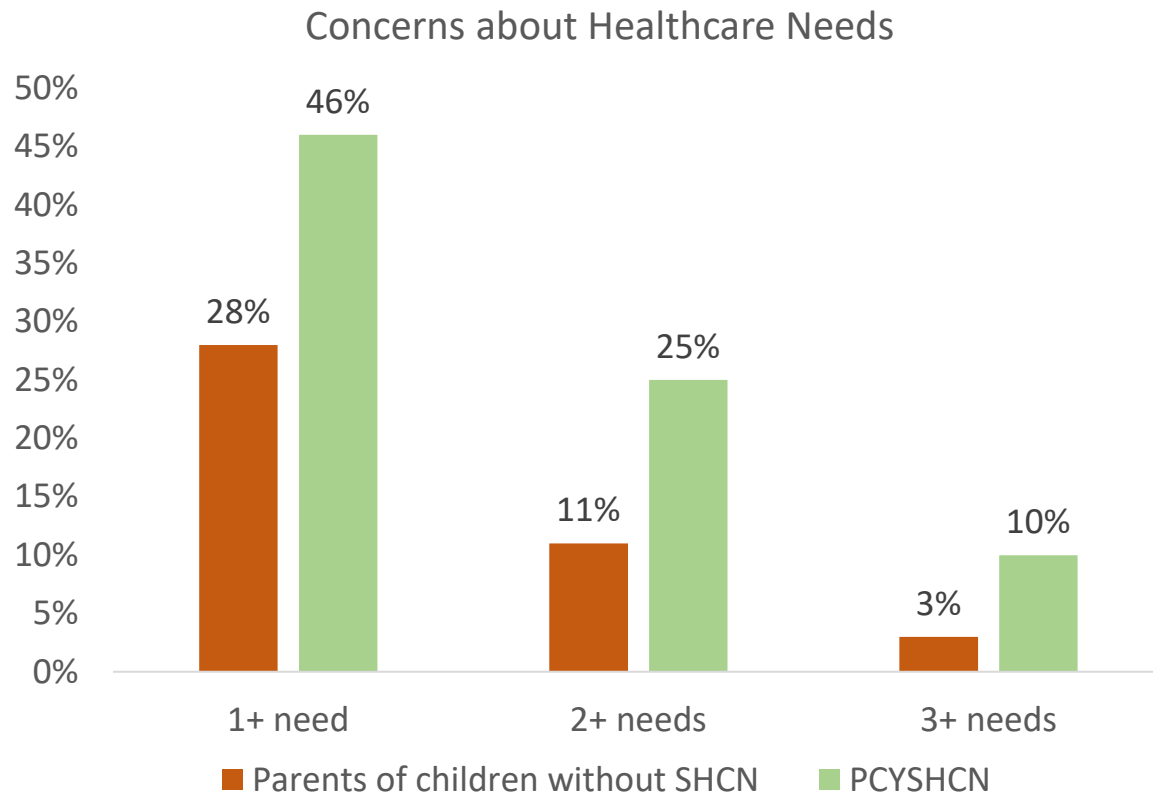


- As many as 60% of certain groups of PCYSHCN reported being worried about housing:
- Parents with incomes under \$35K
 - Parent with disabilities
 - Parents who speak a language other than English
 - Parents of color
 - Parents under the age of 35
 - Parents in rural counties

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 712; Effective sample size = 687

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

Nearly 1 in 2 PCYSHCN were worried about getting healthcare or medications for themselves or their families.



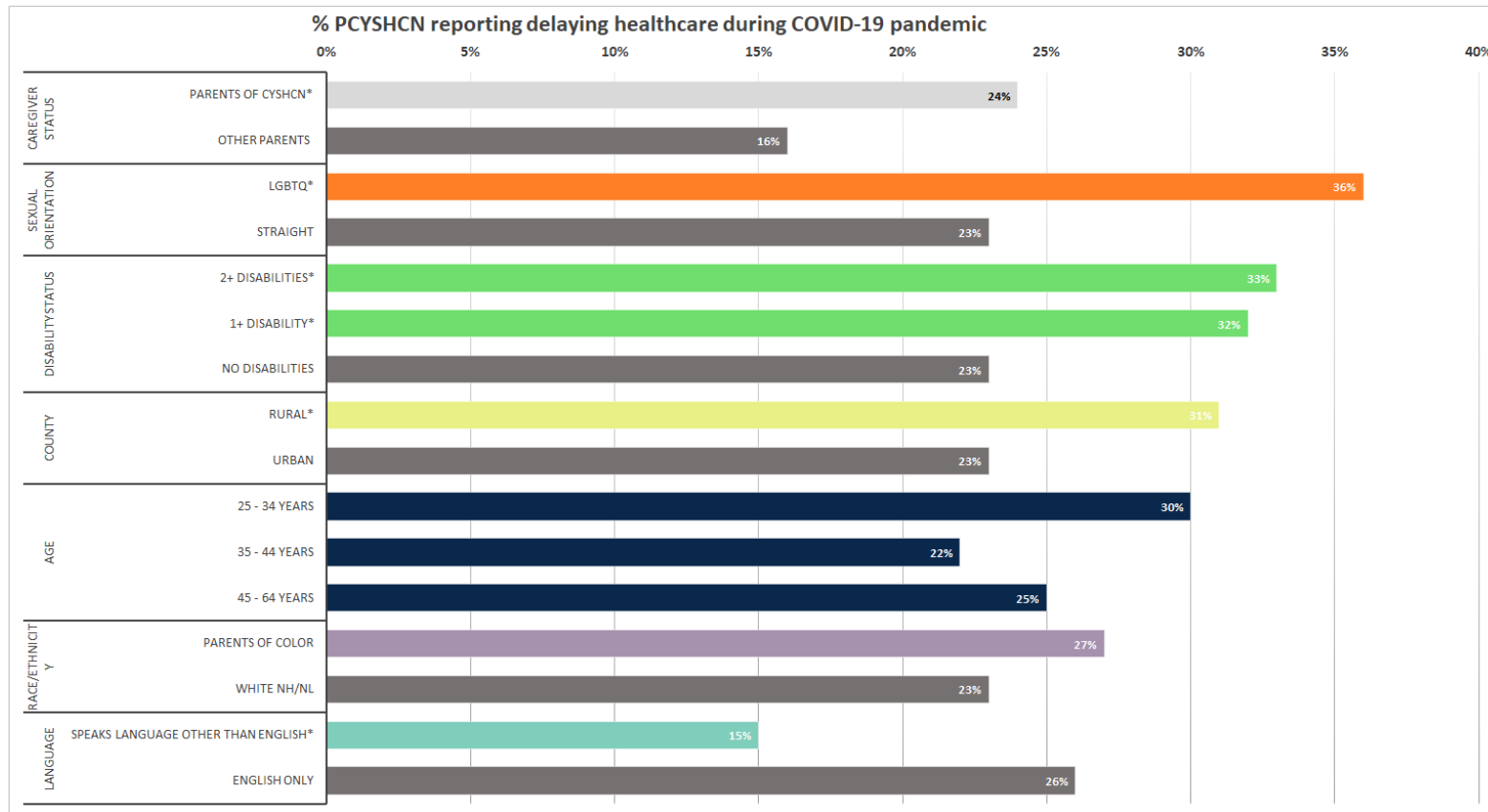
Certain groups of PCYSHCN were more likely to be worried about accessing healthcare or medications:

- Parents with disabilities
- Parents of color
- Parents under the age of 35

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,464; Effective sample size = 3,236

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

Nearly 1 in 4 PCYSHCN delayed healthcare during the first 6-8 months of the COVID-19 pandemic.



PCYSHCN were 50% more likely to delay healthcare for themselves compared to other parents (24% vs. 16%).

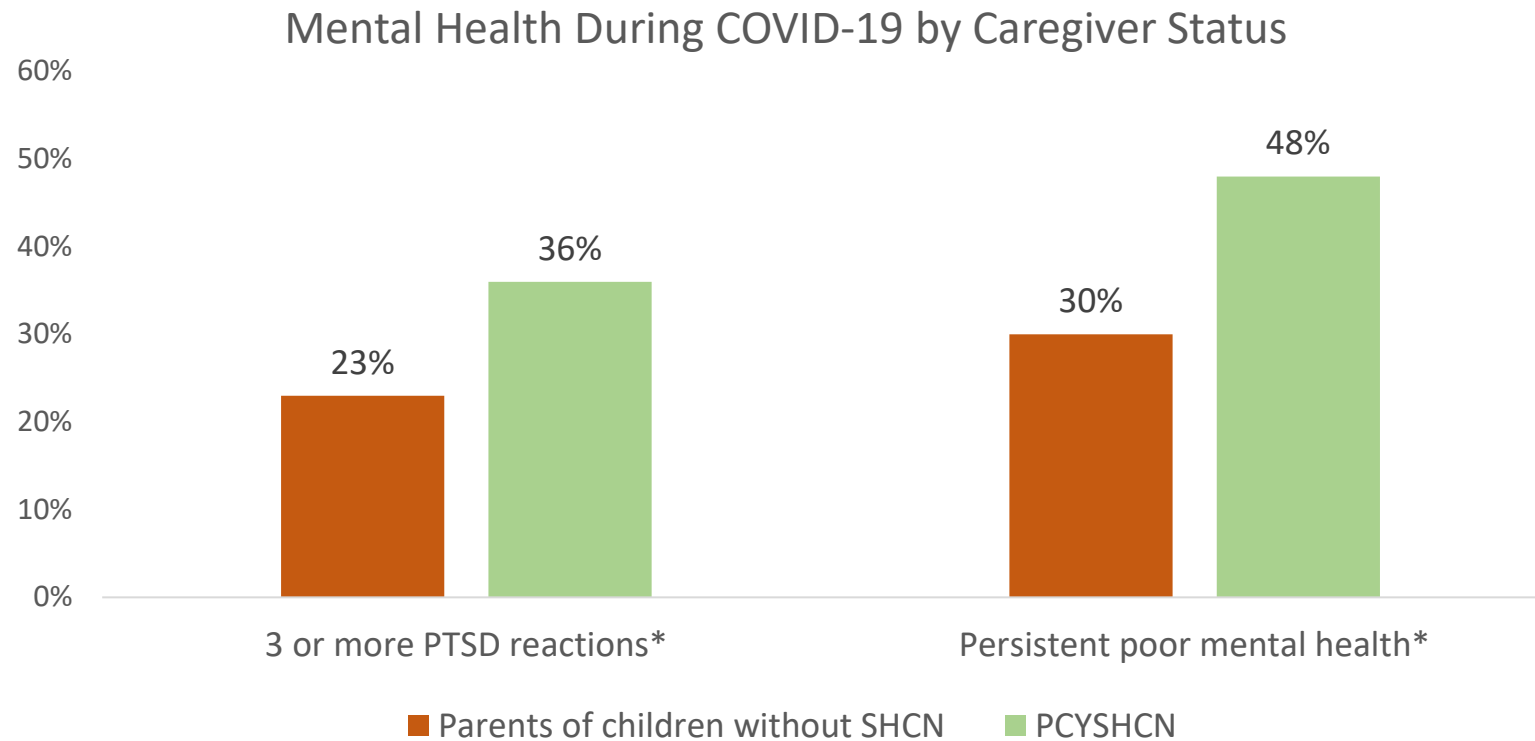
Certain groups of PCYSHCN were more likely to delay care:

- LGBTQA+
- Parents with disabilities
- Parents in rural counties

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 612; Effective sample size = 580

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

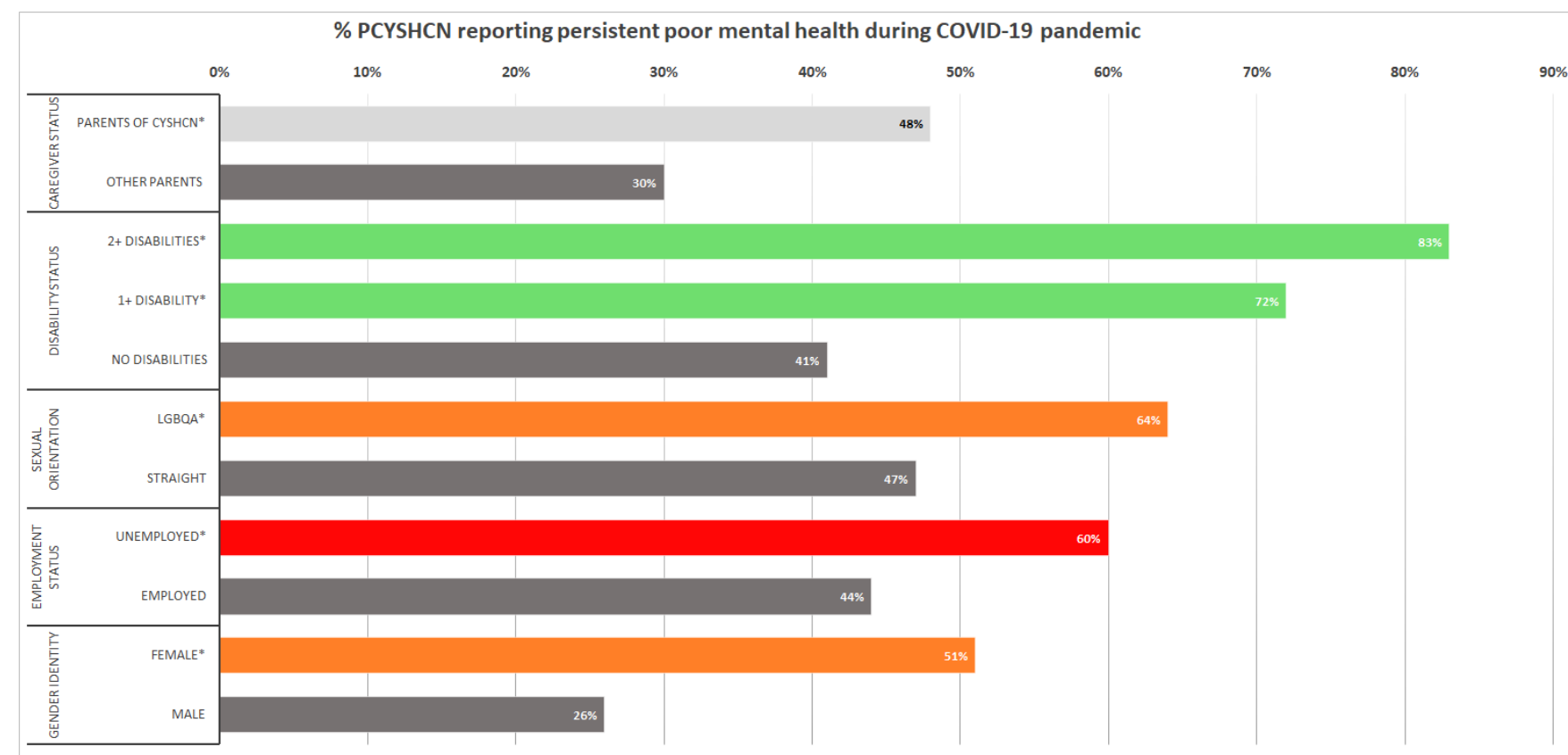
Nearly half of PCYSHCN reported persistent poor mental health during the first 6-8 months of the COVID-19 pandemic.



Data notes: 1)* denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 3,113; Effective sample size = 2,850

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

More than 60% of certain groups of PCYSHCN reported poor mental health



Sixty percent (60%) of certain groups of PCYSHCN reported persistent poor mental:

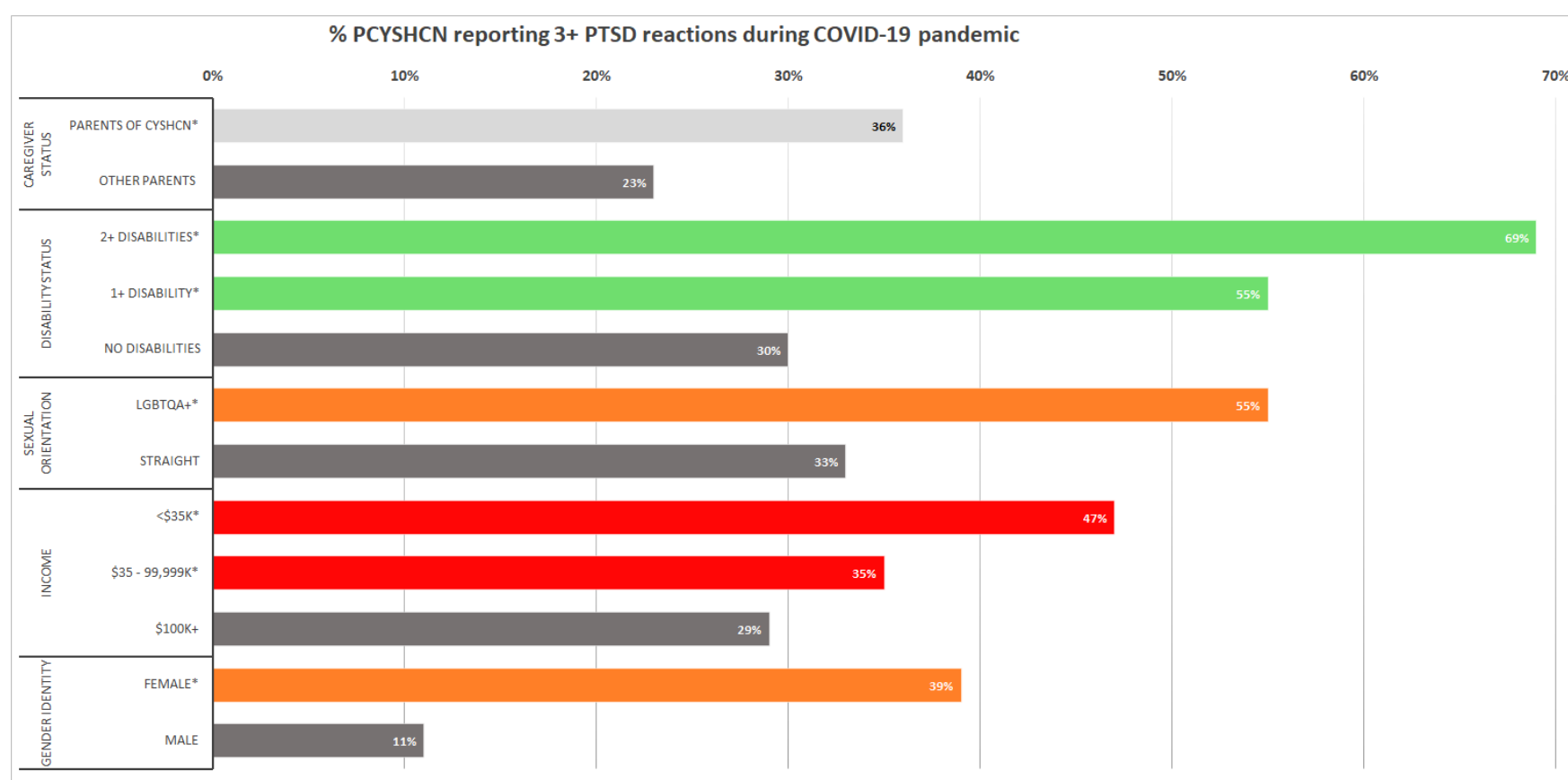
- Parents with disabilities
- LGBTQA+ parents
- Unemployed parents

Female parents of children and youth with special healthcare needs were more likely to report poor mental health compared to male parents.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 651 Effective sample size = 620

Parents of Children and Youth with Special Healthcare Needs (PCYSHCN)

More than 1 in 2 PCYSHCN with disabilities and LGBTQA PCYSHCN reported 3 or more PTSD symptoms during the pandemic



Certain groups of PCYSHCN were more likely to report 3+ PTSD reactions:

- Parents with disabilities
- LGBTQA+ parents
- Unemployed parents
- Parents with incomes under \$35K

Female parents of children and youth with special healthcare needs were more likely to report 3+ PTSD reactions compared to male parents.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 652; Effective sample size = 611

KEY TAKEAWAYS: ECONOMIC SECURITY

- **Economic security is a major concern for caregivers**
 - Multiple household members may be supported by a caregiver's salary, since family members they are caring for are not able to work. Economic needs may therefore be greater for caregiving households.
 - Lack of support for caregiving affects employment. The employer community across public, private and non-profit sectors should consider ways to support family caregivers in their workforce, such as providing increased flexibility, investing in benefits, and creating a culture that acknowledges caregiving.
 - The Paid Family & Medical Leave policies that recently went into effect in Massachusetts may provide some relief to caregivers.
 - In June 2020, emergency support funding totaling \$63,700 was provided to 157 families with children and youth with special health needs across Massachusetts directly affected by COVID through loss of income or illness through the Care Coordination Program. 72% (n=113) of these families experienced financial hardship directly related to job loss or other form of income loss. Between March – June 2021, another round of funding totaling \$77,136 was provided to 204 families through the Care Coordination Program, the Family TIES Program, the Community Support Line and the Catastrophic Illness in Children Relief Fund.

KEY TAKEAWAYS: TECHNOLOGY NEEDS

- Caregivers were significantly more likely to have an unmet technology need (including WiFi, tablets, computers, and cell phones)
 - Accessing broadband – both during the height of the pandemic and currently – is critical for accessing telehealth, accessing education, and working from home. Given caregivers' increased concern about COVID-19 infection, working from home may allow continued employment for certain caregivers.
 - The distribution of devices to families via school systems narrowed the gap in unmet technology needs, but there are still many families without access.
 - The Title V MCH Program, the Early Intervention Provider PCCD and the City of Lawrence developed a project to bridge the “digital divide” in Lawrence by providing access to a telehealth kiosk. The kiosk has been installed in the Lawrence Public Library and is a pilot to study this solution.

KEY TAKEAWAYS: MENTAL & PHYSICAL HEALTH

- Family caregivers are experiencing increased mental and behavioral health needs and may face significant barriers accessing healthcare
 - Caregivers may put their mental and physical health secondary to their caregiving responsibilities.
 - Programs and policymakers should consider how to make urgent care more accessible for caregivers more accessible for caregivers, including transportation options, respite care, and assistance with telehealth access.
 - Economic insecurity can contribute to poor mental and physical health
 - Caregiving is associated with poor mental health, compromised immune function, and lower life expectancy¹
 - As a result of these CCIS findings, mental health in particular is one priority that DPH is revisiting within our HRSA-MCHB Block Grant.
 - The CCIS findings highlight the strong correlation with social determinants of health such as income and housing impacting caregivers' mental health. The other finding about caregivers not seeking therapeutic support also confirms family reports that fixing the system of care will lead to better mental health and that layering on therapies without a root cause solution will perpetuate the situation.

KEY TAKEAWAYS: RESPITE CARE

- Respite for caregivers is crucial so that caregivers can maintain employment, access healthcare, get groceries, and simply take a break from caregiving responsibilities.
 - Even if a caregiver wants to attend a support group or access mental health resources, caregivers need respite care.
 - The Division for Children and Youth with Special Health Needs (CYSHN) at DPH contributed to the planning of an upcoming Caregiver Respite Line hosted by MassOptions and [training video](#) for case managers and others who may refer caregivers to the line.
 - There is a crisis for caregivers of CYSHN in need of respite care in the current environment and in general. There is no systems level solution to fully cover families for these needs and few fully qualified services to provide respite.
 - In 2020, the CYSHN reached out to and actively worked with the Office of the Child Advocate, MassHealth, and the Pappas Rehabilitation Center to explore alternative care options for families of children with medical complexity (CMC) whose primary caregiver becomes ill and incapacitated due to COVID. They explored options such as locating a dedicated pediatric skilled nursing facility (SNF) for children needed skilled care or having public health workforce volunteers stay in the home to assist. No options were viable.
 - Following the first wave of the pandemic, the Division for Children & Youth with Special Health Needs at DPH received an influx of requests to find respite care from desperate, overextended families of children and youth with special health needs (CYSHN) and children with medical complexity (CMC), There were no beds in the two SNFs available.

KEY TAKEAWAYS: INTERSECTIONALITY

- Certain groups of caregivers were more likely to be affected by job loss, economic insecurity, and to experience delays in healthcare
 - Caregivers with lower incomes, caregivers of color, caregivers under the age of 45, caregivers with disabilities, LGBTQA+ caregivers, and caregivers who speak a language other than English had varying greater socio-economic and health needs
 - Programs and policies serving caregivers should examine structural barriers to engaging in those programs and ensure equitable access

RESOURCES

For caregiving resources visit <https://www.mass.gov/topics/caregiving>

MassOptions - <https://www.massoptions.org/massoptions/> - and phone is 800-243-4636. MassOptions is trained to do a warm hand-off of the caller to an Aging Services Access Point or Independent Living Center (ILC – to reach DDS/MRC-type services).

Resources for employers who want to support caregivers can be found at the [Mass. Employers Toolkit](#).