

Massachusetts Department of Public Health

COVID-19

Community Impact Survey (CCIS)

Preliminary Analysis Results as of
January 12, 2022

Presented by Justine Egan

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CCIS COMMUNITY PARTNERS

Many groups that were critical in the success of this effort and gave important input on the development and deployment of the survey:

- Academic Public Health Volunteer Corps and their work with local boards of health and on social media
- Mass in Motion programs, including Springfield, Malden, and Chelsea
- Cambodian Mutual Assistance
- The Mashpee Wampanoag Tribe
- The Immigrants' Assistance Center, Inc
- Families for Justice as Healing
- City of Lawrence Mayor's Health Task Force
- The 84 Coalitions, including the Lawrence/Methuen Coalition
- Boys and Girls Clubs, including those in Fitchburg and Leominster and the Metro South area
- Chinatown Neighborhood Association
- Father Bill's
- UTEC
- MassCOSH
- Stavros Center for Independent Living
- Greater Springfield Senior Services
- Center for Living and Working
- DEAF, Inc.
- Massachusetts Commission for the Deaf and Hard of Hearing
- Viability, Inc.

OVERVIEW

1. Purpose and Approach of the Covid-19 Community Impact Survey (CCIS)
2. Preliminary Findings
 - Spotlight on Caregivers: caregivers of adults with special needs and parents of children & youth with special healthcare needs
3. Appendix

RESULTS TOPICS TO DATE



MITIGATING INDIVIDUAL RISK OF INFECTION



ACCESS TO TESTING



ACCESS TO HEALTHCARE



SOCIAL DETERMINANTS OF HEALTH



MENTAL HEALTH



EMPLOYMENT



SUBSTANCE USE



DISCRIMINATION: & RACE SPOTLIGHTS



PARENTS & FAMILIES



YOUTH SPOTLIGHT



SOGI POPULATION SPOTLIGHTS



INTIMATE PARTNER VIOLENCE



HOUSING STABILITY



RURAL COMMUNITIES SPOTLIGHT



PERSONS WITH DISABILITIES SPOTLIGHT



NEW: CAREGIVERS SPOTLIGHT

CAREGIVER SPOTLIGHT



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CAREGIVERS IN MASSACHUSETTS

Caregiver Respondents: Terms Used

Parents of Children & Youth with Special Healthcare Needs (PCYSHCN) (N=786)

- 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 last 12 months or longer and need health and other services beyond what is generally required by children.

Caregivers of Adults with Special Needs (N=344)

- Are you a caretaker of an adult(s) with special needs in your household?
- The survey did not ask if caregivers were paid for their caregiving duties. The screener question may have been interpreted to indicate unpaid and/or paid caregiving, depending on the individual responding to the survey.

Caregivers - Used in this presentation to broadly refer to caregivers of adults with special needs and PCYSHCN

Other parents – Parents who did not indicate they were caring for a child with special healthcare needs

Non-caregivers of adults – Respondents who did not indicate they were caring for an adult with special needs

FRAMING MATTERS

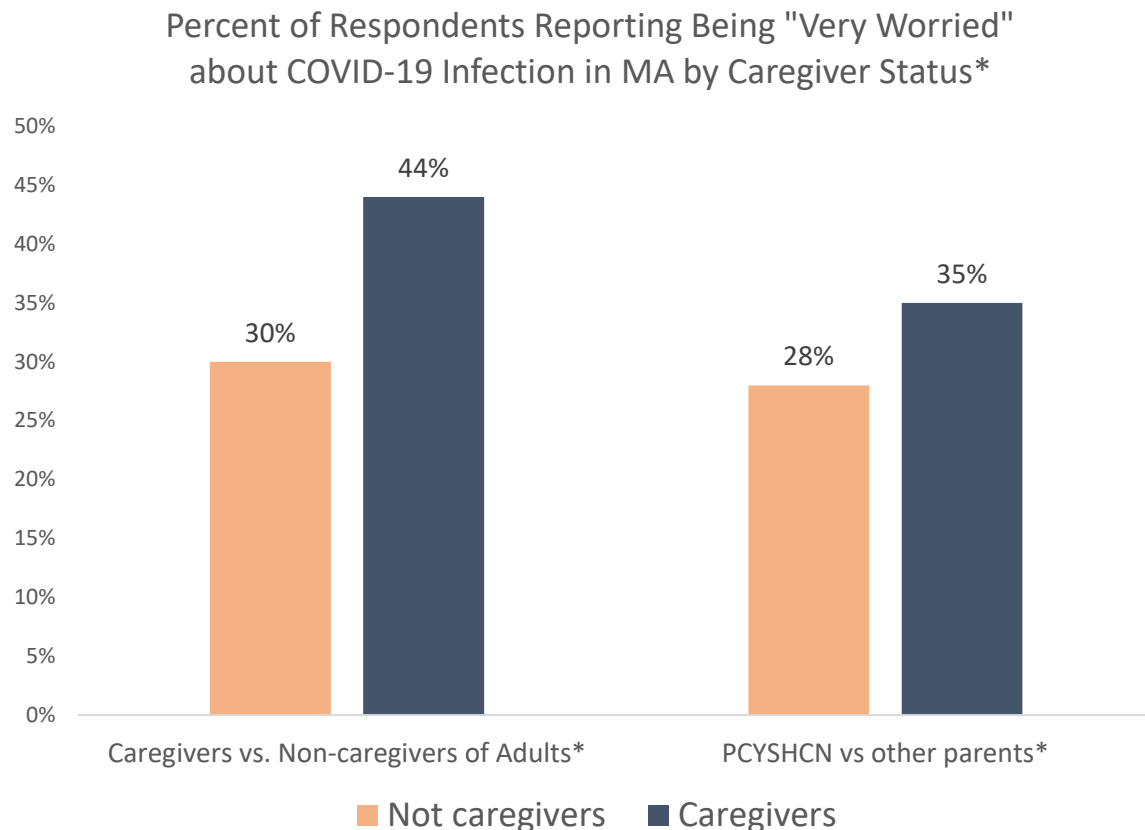
Caregivers provide care to people who need some degree of ongoing assistance with everyday tasks on a regular or daily basis. Care recipients can range from children to older adults and have chronic illnesses or disabling conditions.¹

Caregiving is rewarding and meaningful but also comprised of challenges. 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.

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

Caregivers were significantly more likely to be very worried about COVID-19 infection compared to non-caregivers

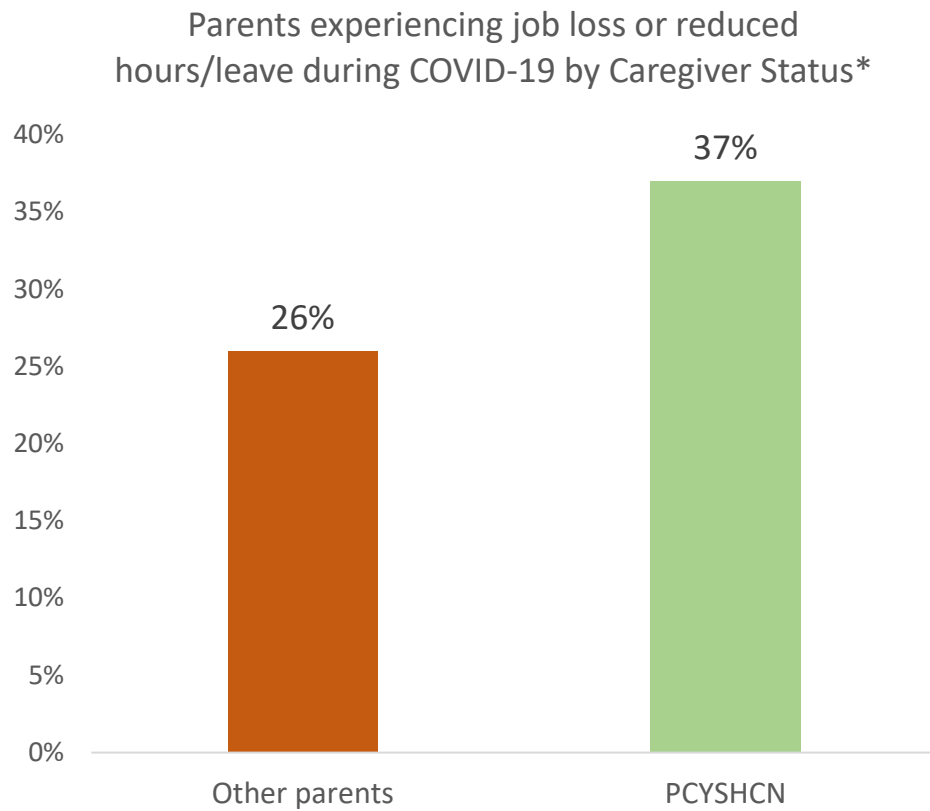


- Caregivers may be concerned about not being able to fulfill their caregiving responsibilities if they become ill. They may also be worried about infecting those they care for with COVID-19.
- 51% of caregivers of adults with incomes under \$35,000 reported being very worried about COVID-19 infection
- Caregivers with disabilities were more likely to report being very worried about COVID-19 infection

Data notes: 1) * denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 6,479; Effective sample size (caregivers of adults) = 6,521. Sample size (parents) = 3,676; Effective sample size (parents) = 3,460.

CAREGIVERS IN MASSACHUSETTS

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

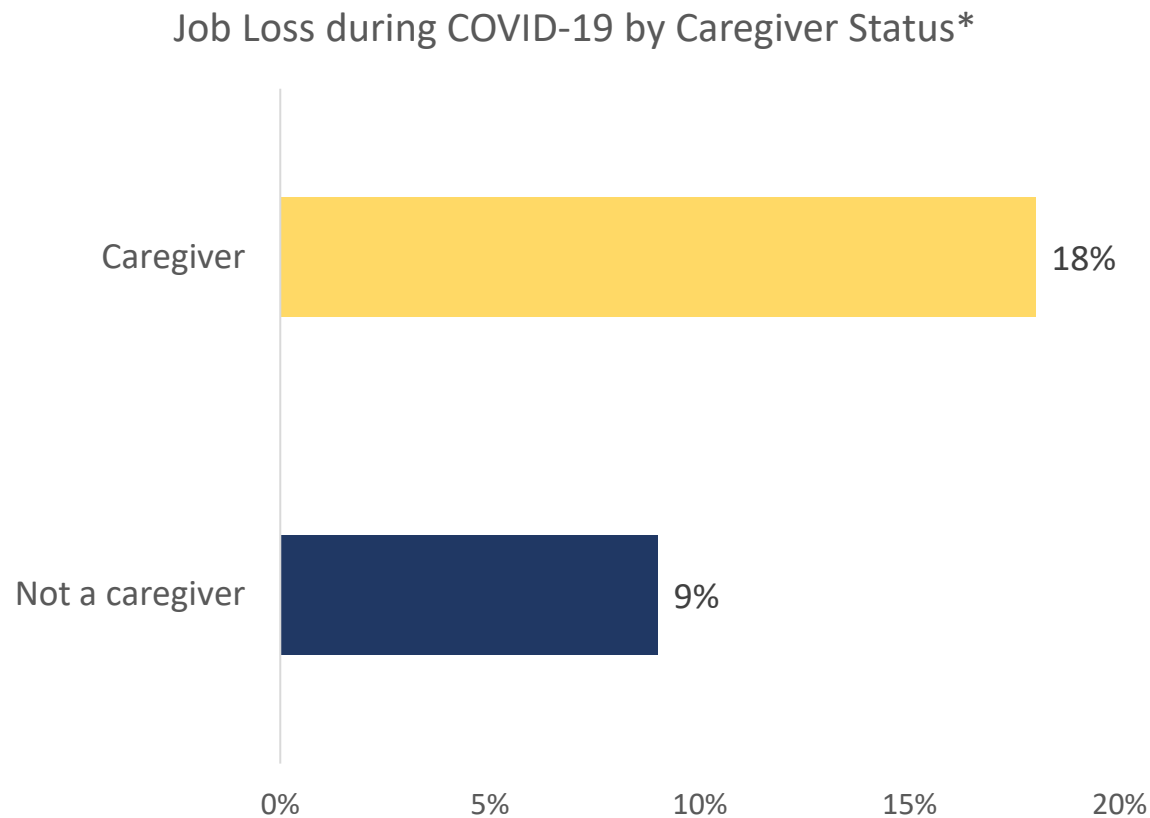


- PCYSHCN were 45% more likely to report job loss, reduction of hours, or leave than other parents. Parents overall were 35% more likely to report job loss/reduced hours/leave compared to non-parents.
- PCYSHCN were more likely than other parents to say their employment status changed due to needing to take care of a child (32% vs 23%) respectively.
- PCYSHCN with disabilities, with incomes under \$100K, under age 35, and PCYSHCN of color were more likely to report changes in job status

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

Caregivers of adults were twice as likely to lose their jobs compared to non-caregivers. Nearly 1 in 5 caregivers of adults lost their jobs during the pandemic.



- Caregivers of adults were more likely to say their employment status changed due to needing to take care of a child (36%) or sick family member (8%) compared to non-caregivers of adults (26% and 2%).
- Caregivers of adults were also more likely to say their job status changed due to fear of getting COVID-19 at work (23% vs. 17%).
- **Caregivers of adults who themselves have disabilities and caregivers with incomes of less than \$35K were 3 times more likely to report job loss than those without disabilities and those making over \$35k, respectively.**

Data notes: 1) * denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 4,208; Effective sample size = 3,827.

CAREGIVERS IN MASSACHUSETTS

Caregivers were more likely to be concerned about expenses and housing

- Caregivers were **40% more likely to be worried about expenses** during the pandemic
- **60%** of caregivers of adults and **67%** of PCYSHCN were worried about expenses
- **85%** of PCYSHCN aged 25-34 and **84%** of PCYSHCN of color were worried about expenses
- **82%** of LBGTA+ caregivers of adults were worried about expenses



- Caregivers were **nearly twice as likely to be worried about housing** costs compared to non-caregivers
- Nearly **1 in 2 caregivers** were worried about housing
- **63%** of younger caregivers of adults (aged 25-44) were worried about housing
- **58%** of PCYSHCN of color were concerned about housing

Data notes: 1) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 6,159; Effective sample size (caregivers of adults) = 6,168. Sample size (parents) = 3,464; Effective sample size (parents) = 3,236

CAREGIVERS IN MASSACHUSETTS

Caregivers were more likely to be concerned about basic needs



- Nearly **80%** of caregivers were worried about at least one household need during the first 6-8 months of the pandemic compared to 65% of non-caregivers/other parents

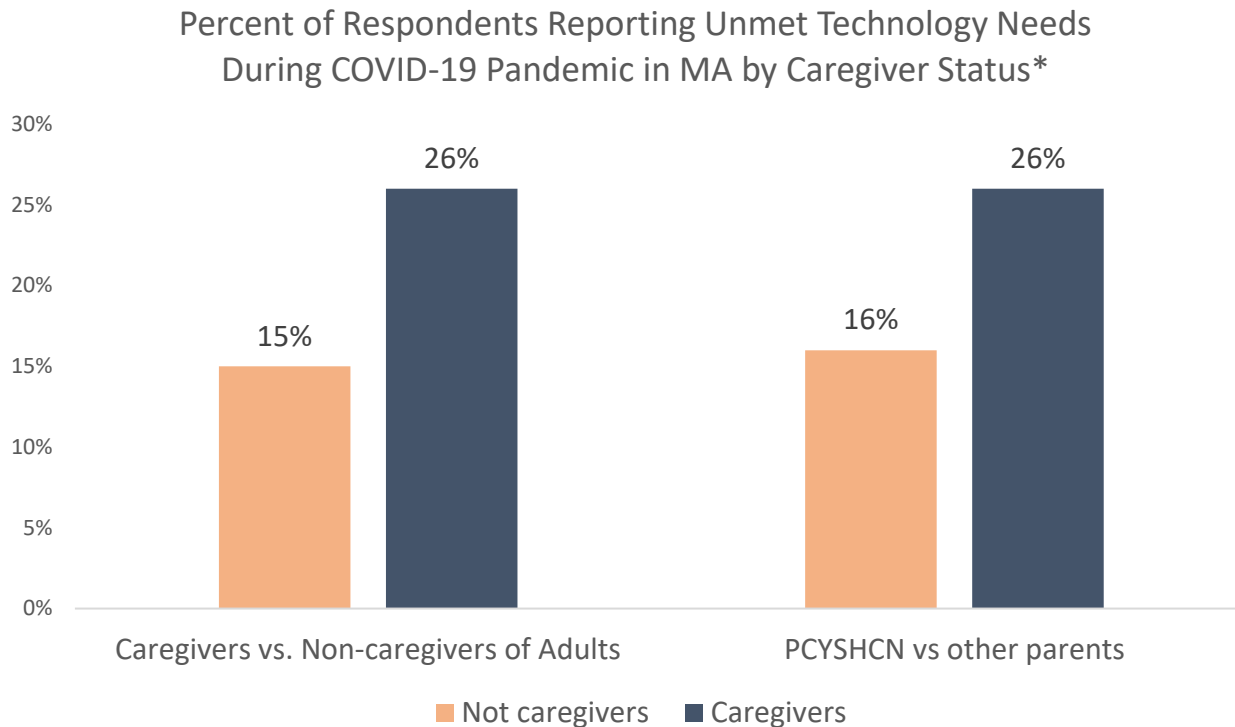


- Caregivers were **nearly twice as likely to be concerned about food and groceries** than non-caregivers
 - **47% of caregivers of adults** were worried about food and groceries compared to 27% of non-caregiver of adults and **43% of PCYSHCN** were worried about food and groceries compared to 23% of non-caregiver other parents
 - **68% of caregivers of adults who speak a language other than English** were concerned about food or groceries
 - **66% of PCYSHCN aged 25-34** and **64% of PCYSHCN of color** were worried about groceries

Data notes: 1) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 6,159; Effective sample size (caregivers of adults) = 6,168. Sample size (parents) = 3,464; Effective sample size (parents) = 3,236

CAREGIVERS IN MASSACHUSETTS

Caregivers were more likely to have unmet technology needs compared to non-caregivers



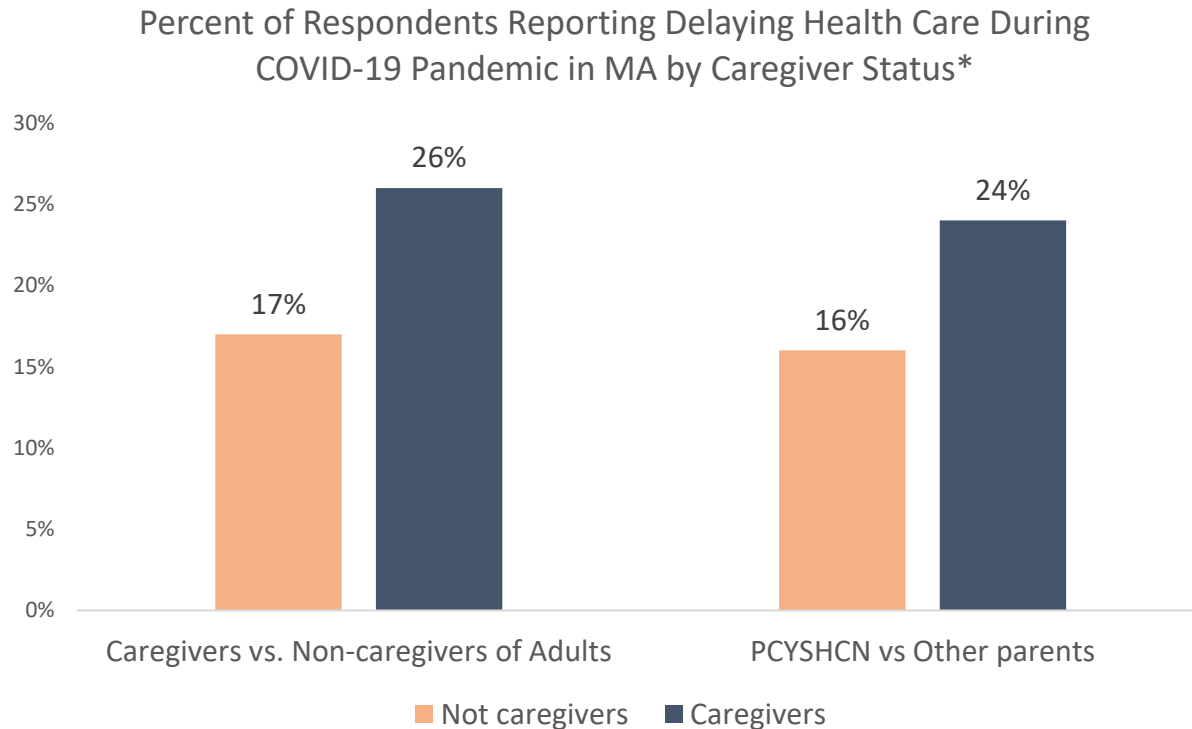
Certain groups of caregivers were more likely to have unmet technology needs:

- LGBTQA+ caregivers of adults (48%)
- PCYSHCN of color (44%)
- Caregivers of adults with incomes under \$35K (41%)
- Caregivers of adults who speak a language other than English (40%)
- PCYSHCN who speak a language other than English (37%)

Data notes: 1)* denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 6,159; Effective sample size (caregivers of adults) = 6,168. Sample size (parents) = 3,464; Effective sample size (parents) = 3,236

CAREGIVERS IN MASSACHUSETTS

Caregivers were 50% more likely to experience delays in care compared to non-caregivers. 1 in 4 caregivers experienced delays in healthcare during the first 6-8 months of the pandemic.



Certain groups of caregivers were more likely to experience delays in care:

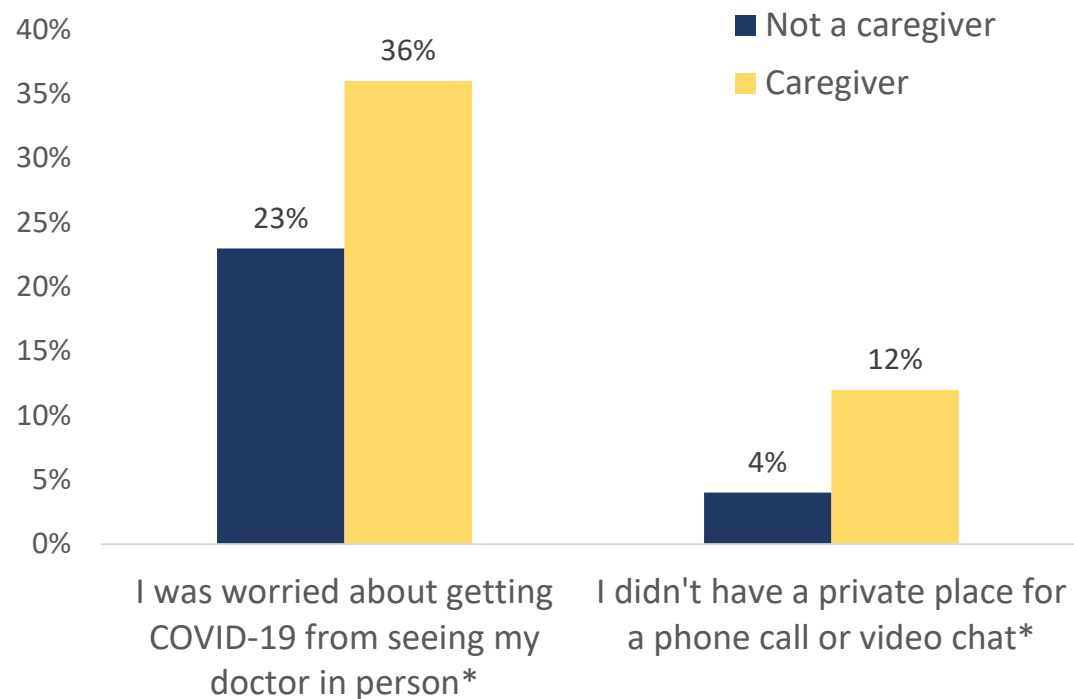
- 1 in 2 caregivers of adults who identified as LGBTQA+ and 36% of LGBTQA+ PCYSHN
- 45% of younger caregivers (aged 25-44) of adults delayed care
- 44% of caregivers of adults with incomes less than \$35K
- 42% of caregivers of adults and 31% of PCYSHN in rural counties

Data notes: 1)* denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 6,159; Effective sample size (caregivers of adults) = 6,168. Sample size (parents) = 3,464; Effective sample size (parents) = 3,236

CAREGIVERS IN MASSACHUSETTS

Caregivers of adults were more likely to be worried about getting COVID-19 from seeing a doctor and were less likely to have a private place for a phone call or video chat.

Reasons for Delaying Care by Caregiver Status



If a caregiver becomes ill or is hospitalized, there may not be anyone to care for their family member in their absence. Caregivers may also be concerned about infecting those they care for with COVID-19.

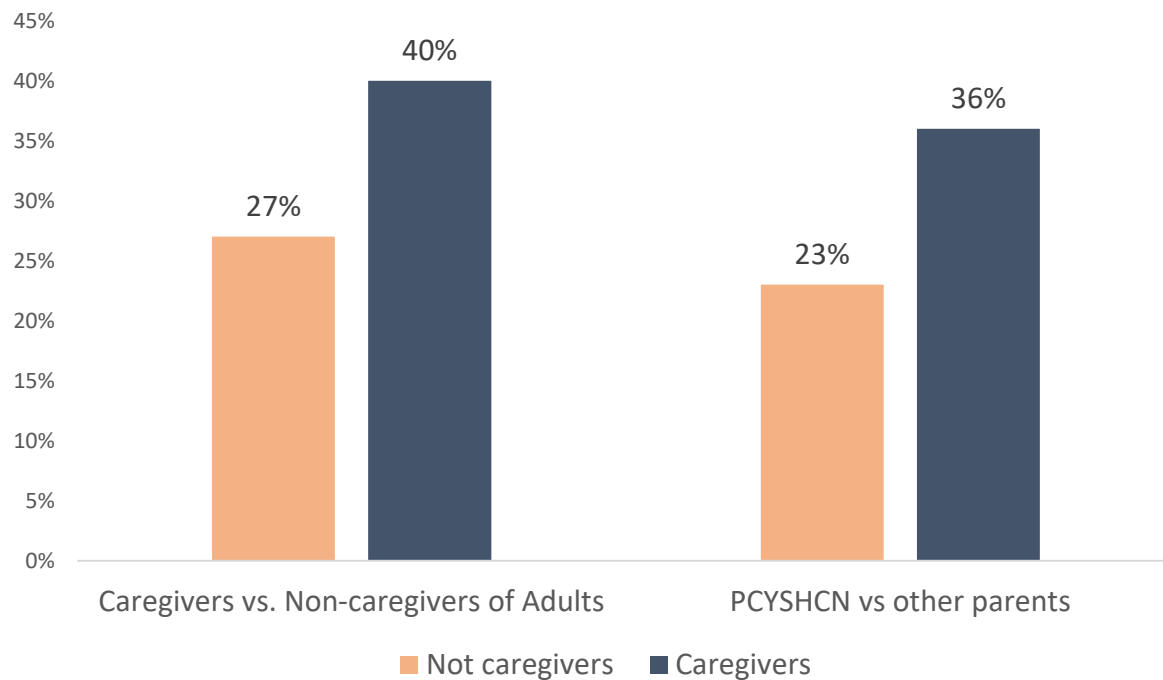
Caregivers may also lack private spaces in their homes due to living with family members they are caring for.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 894; Effective sample size = 892

CAREGIVERS IN MASSACHUSETTS

Caregivers were more likely to report 3+ PTSD reactions during the first 6-8 months of the COVID-19 pandemic.

Percent of Respondents Reporting 3+ PTSD reactions During COVID-19 Pandemic in MA by Caregiver Status*



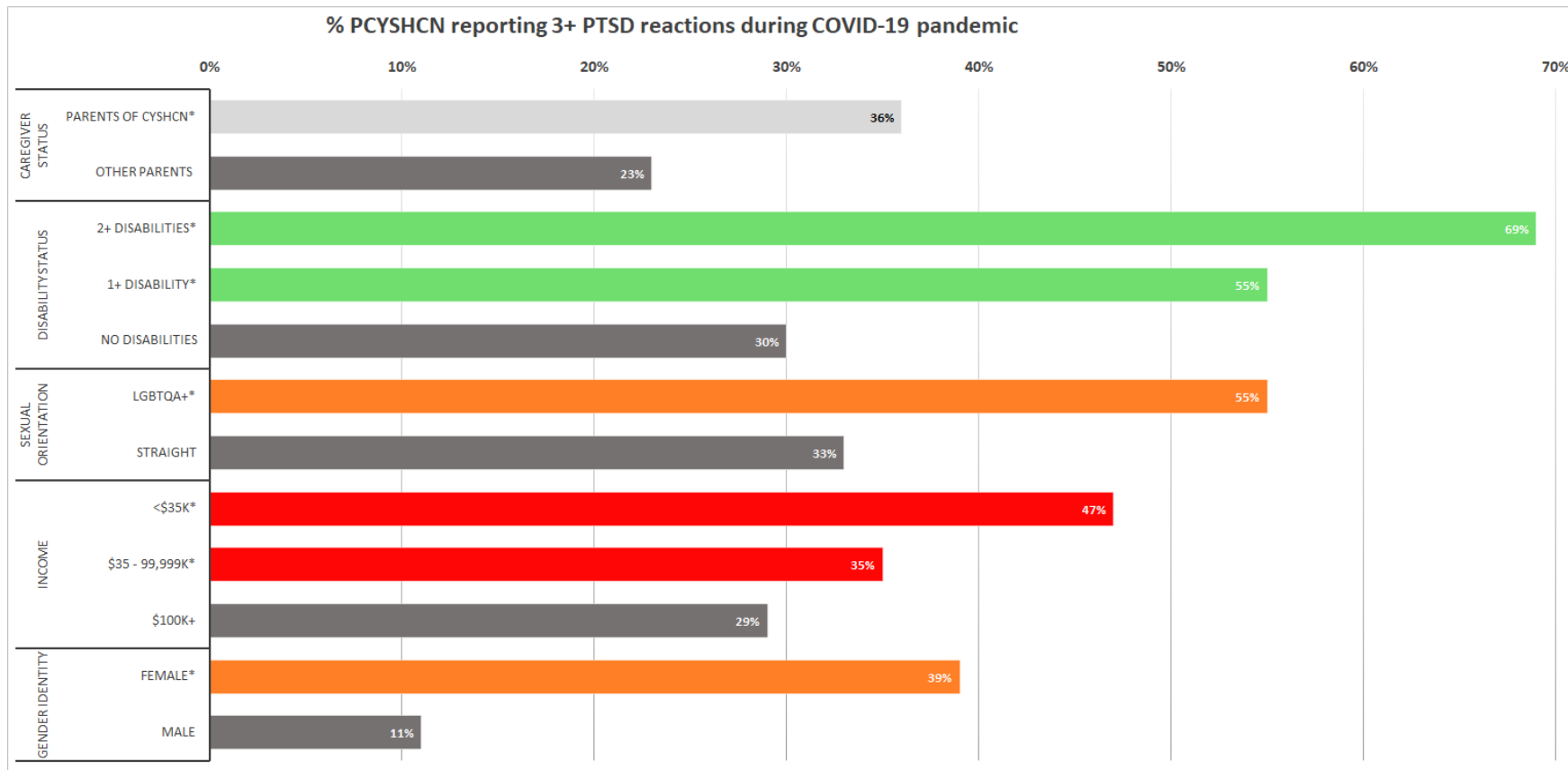
Respondents were asked how many times they had any of the following reactions to the COVID-19 outbreak in the past month:

- Having nightmares or thinking about it when you didn't want to
- Going out of your way to avoid situations
- Constantly being on guard, watchful, or easily startled
- Feeling numb or detached
- Feeling guilty or unable to stop blaming yourself

Data notes: 1) * denotes rate is significantly different ($p < 0.05$); 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size (caregivers of adults) = 5,670; Effective sample size (caregivers of adults) = 5,455. Sample size (parents) = 3,113; Effective sample size (parents) = 2,850.

CAREGIVERS IN MASSACHUSETTS

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



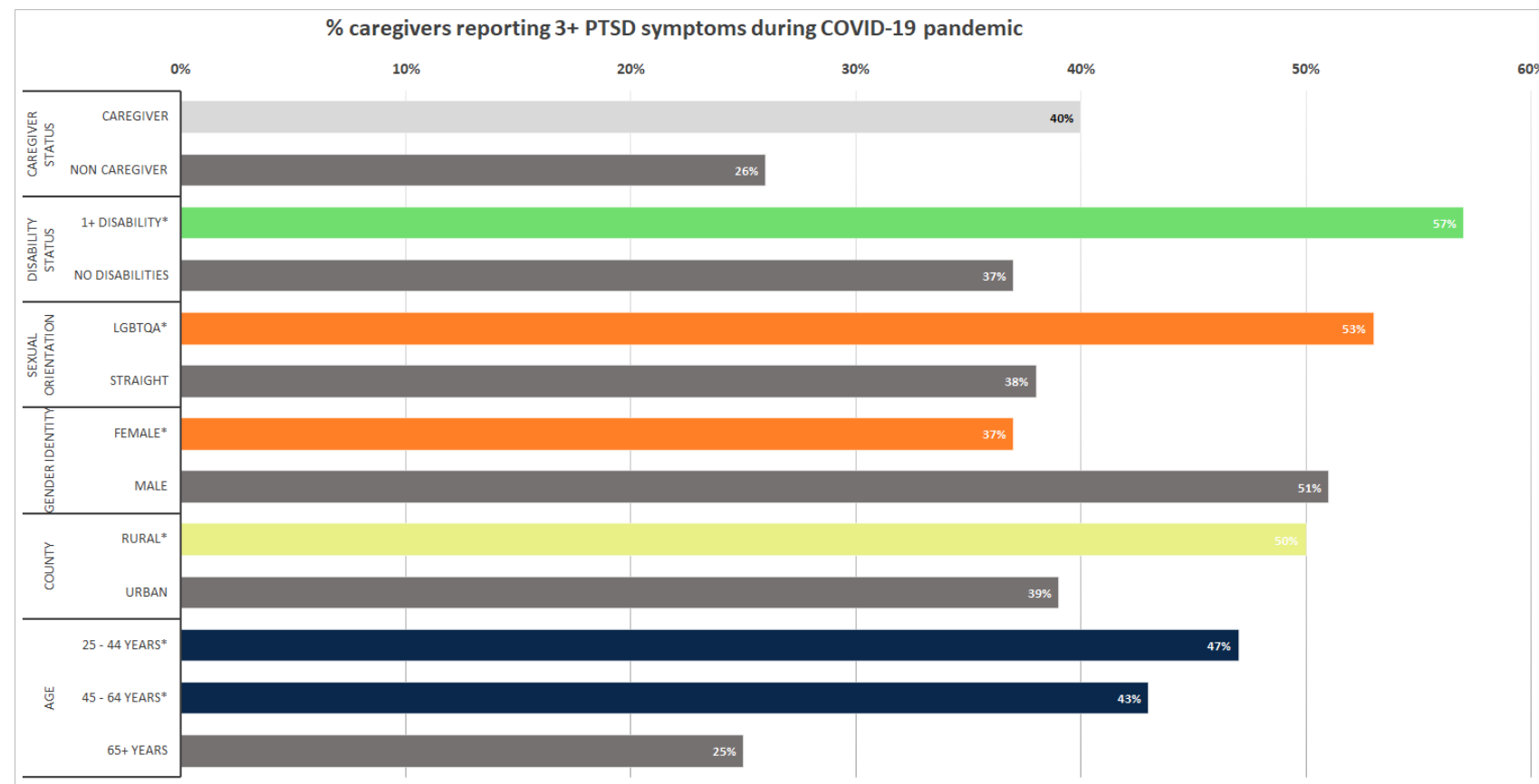
Certain groups of PCYSHCN were more likely to report 3+ PTSD reactions:

- PCYSHCN with disabilities
- LGBTQA+ PCYSHCN
- PCYSHCN with incomes under \$35K

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

CAREGIVERS IN MASSACHUSETTS

1 in 2 caregivers of adults in certain groups reported 3 or more PTSD reactions during the first 6-8 months of the pandemic.



Half of certain groups of caregivers of adults were more likely to report 3 or more PTSD reactions:

- Caregivers with disabilities
- LGBTQA+ caregivers
- Male caregivers
- Caregivers in rural areas

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 = 278; Effective sample size = 319

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.
- **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.

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.
 - Economic insecurity can contribute to poor mental and physical health
 - Caregiving is associated with poor mental health, compromised immune function, and lower life expectancy¹
- 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.
 - 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.

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

DATA TO ACTION

Economic security

- The Paid Family & Medical Leave policies that recently went into effect in Massachusetts may provide some relief to caregivers.
- Emergency support funding was provided to 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.
- 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.

Physical & Mental Health

- As a result of these CCIS findings, mental health is one priority that DPH is revisiting within our HRSA-MCHB Block Grant.
- 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](#).