

CAREGIVERS OF ADULTS WITH SPECIAL NEEDS



Elizabeth Beatriz, PhD

Justine Egan, MPH

Amy Flynn, MS

Allison Guarino, MPH

Beatriz Pazos Vautin, MPH

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

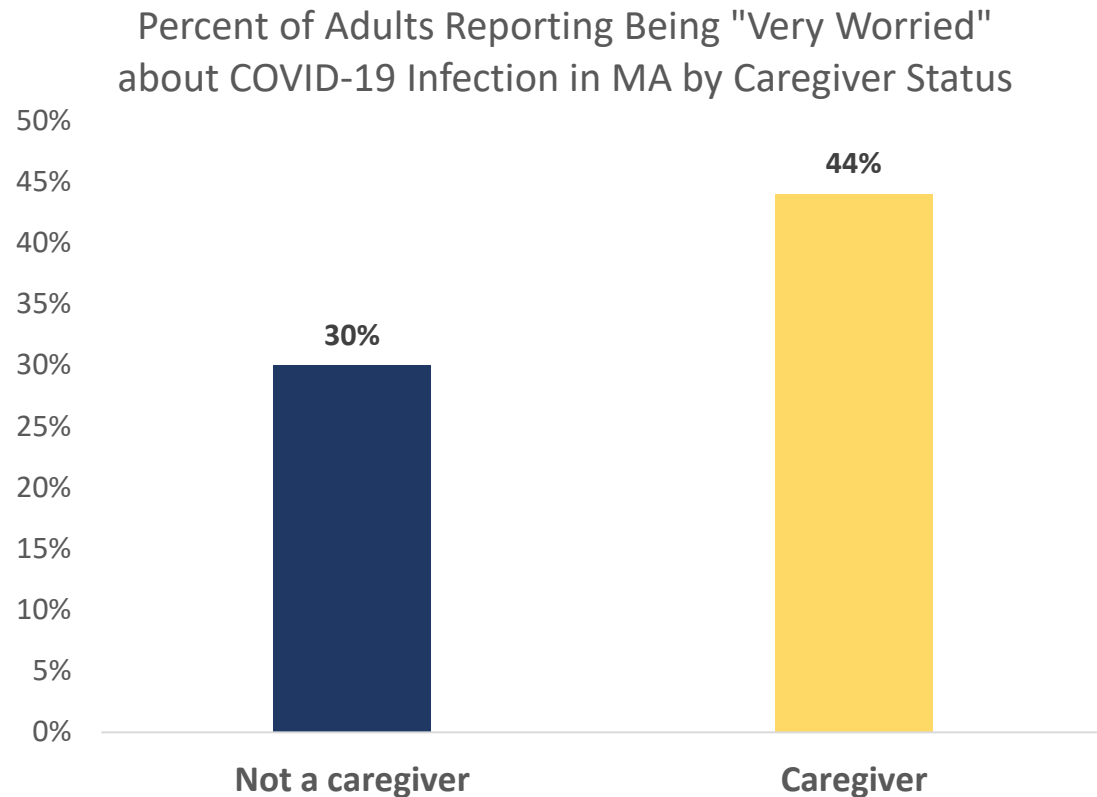
Caregivers of Adults with Special Needs

- Screener question:
 - Are you a caretaker of an adult(s) with special needs in your household?¹
- 344 respondents
- Average age of 52 years
- 85% urban
- 82% female
- 74% employed
- 66% white, 31% people of color
- 27% speak a primary language other than English
- 19% of caregivers have one or more disabilities

1) 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 IN MASSACHUSETTS

Caregivers of adults with special needs were significantly more likely to be very worried about COVID-19 infection compared to non-caregivers



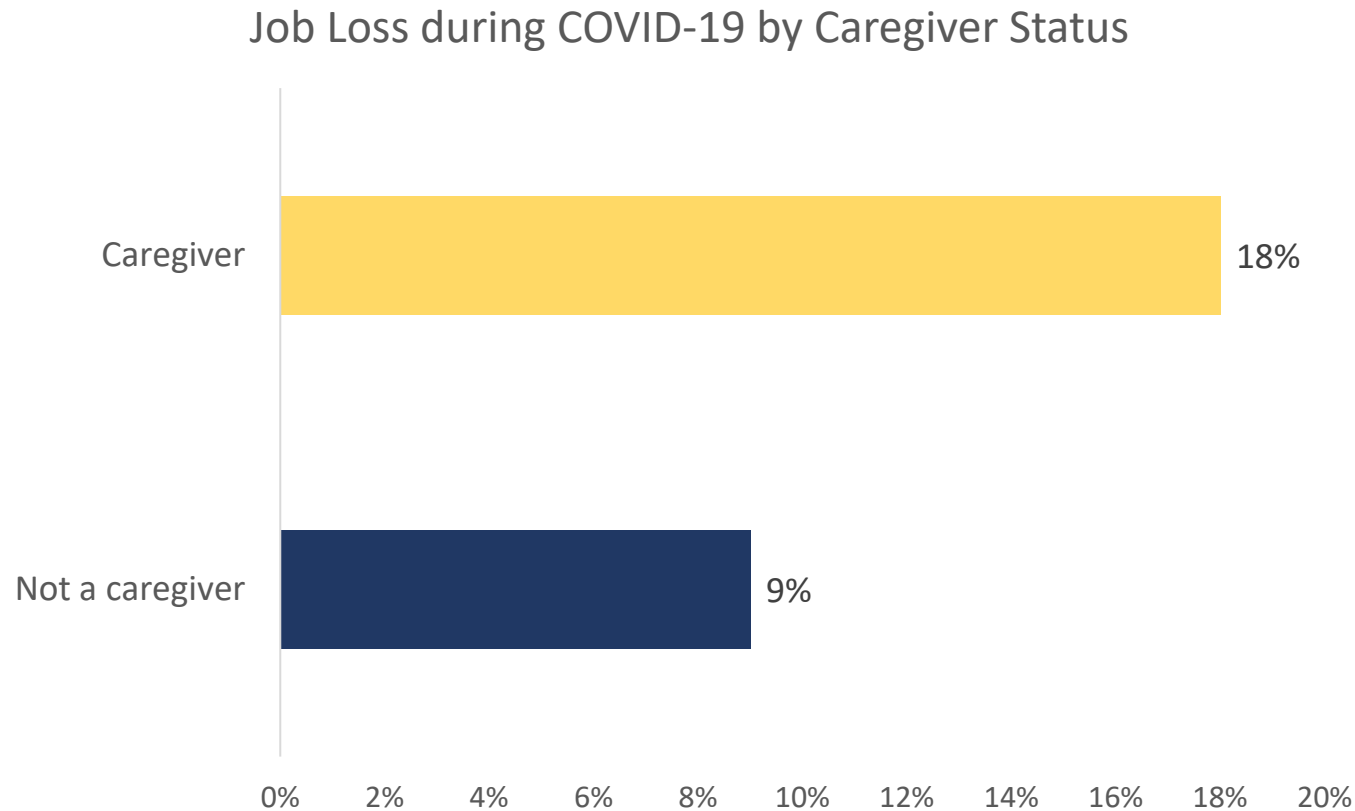
Caregivers may be concerned about not being able to fulfill their caregiving responsibilities if they become ill. They may also be worried about infecting those they care for with COVID-19.

More than half of caregivers with disabilities and with incomes under \$35,000 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 = 6,479; Effective sample size = 6,521.

CAREGIVERS IN MASSACHUSETTS

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



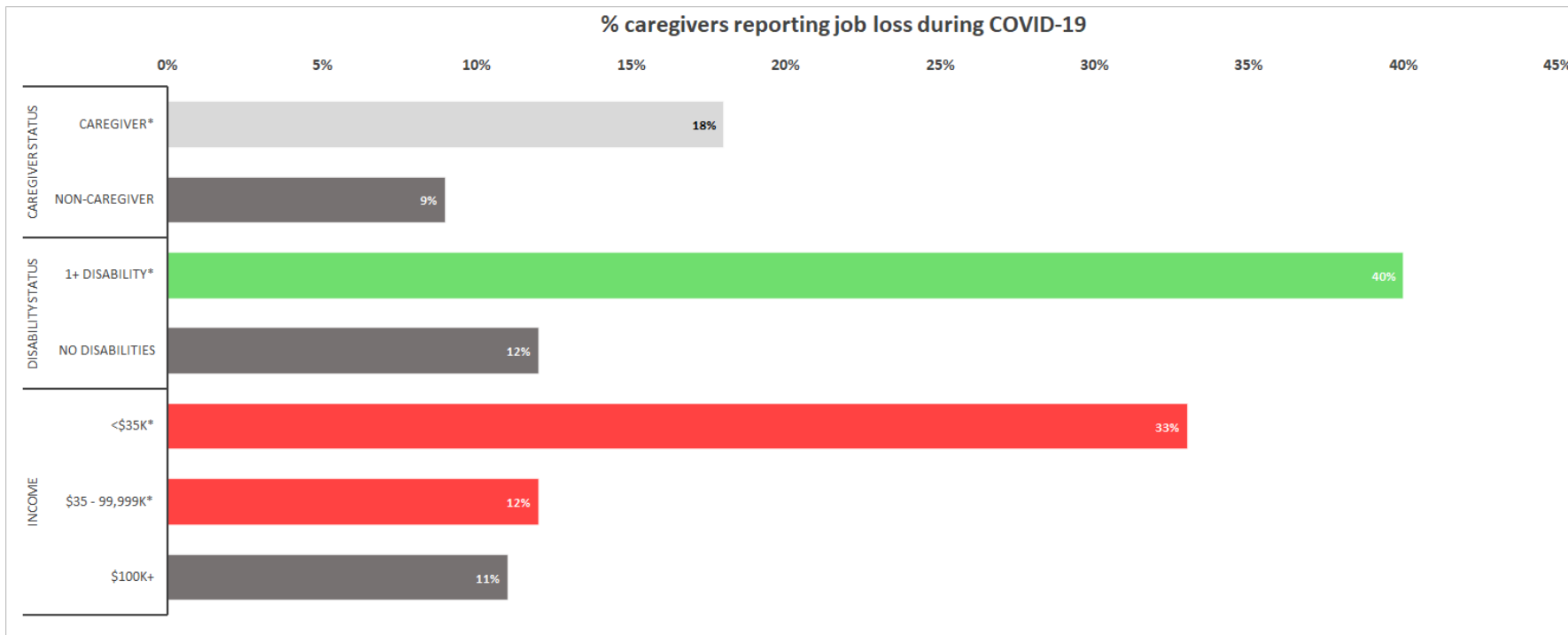
Caregivers were more likely to say their employment status changed due to needing to take care of a child (36%) or sick family member (8%) compared to non-caregivers (26% and 2%).

Caregivers were also more likely to say their job status changed due to fear of getting COVID-19 at work (23% vs. 17%).

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 = 4,208; Effective sample size = 3,827.

CAREGIVERS IN MASSACHUSETTS

More than 1 in 3 caregivers with disabilities and with incomes less than \$35K reported job loss

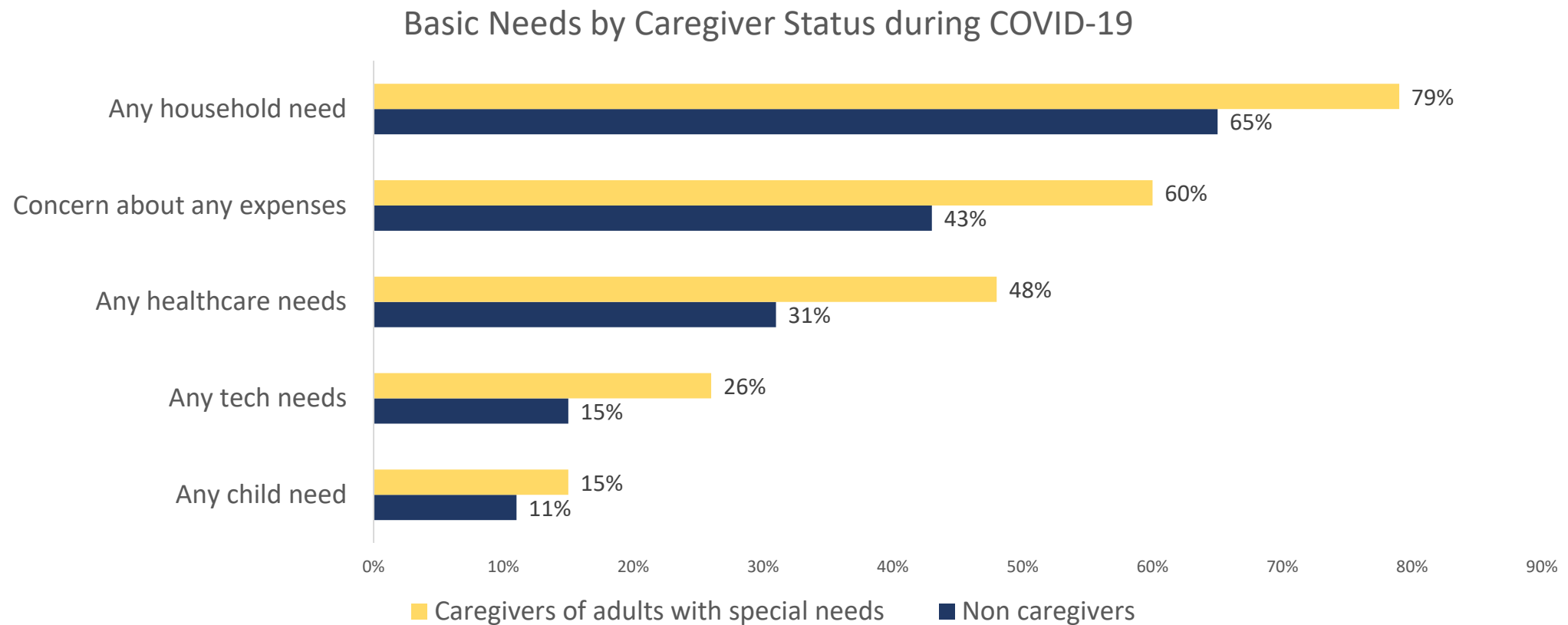


Caregivers with disabilities and caretakers with incomes of less than \$35K were 3 times more likely to report job loss than those without disabilities and those making over \$35k, respectively.

Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 185; Effective sample size = 208
11.10.2021 release

CAREGIVERS IN MASSACHUSETTS

Caregivers are more likely to be concerned about basic needs compared to non-caregivers.

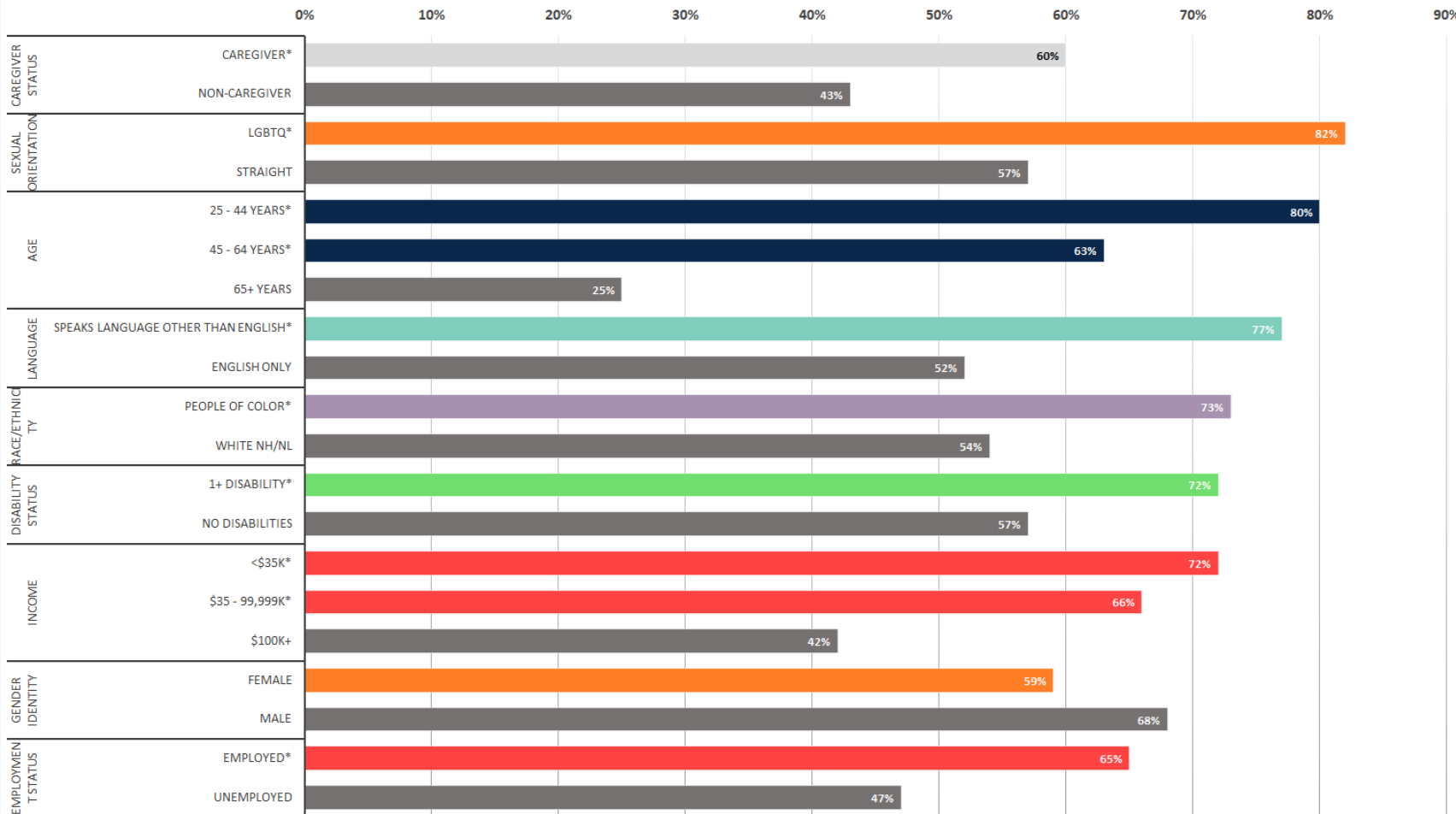


Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 6,159; Effective sample size = 6,168

CAREGIVERS IN MASSACHUSETTS

Caregivers were 40% more likely to be worried about expenses compared to non-caregivers

% caregivers reporting concerns about any expenses during COVID-19 pandemic



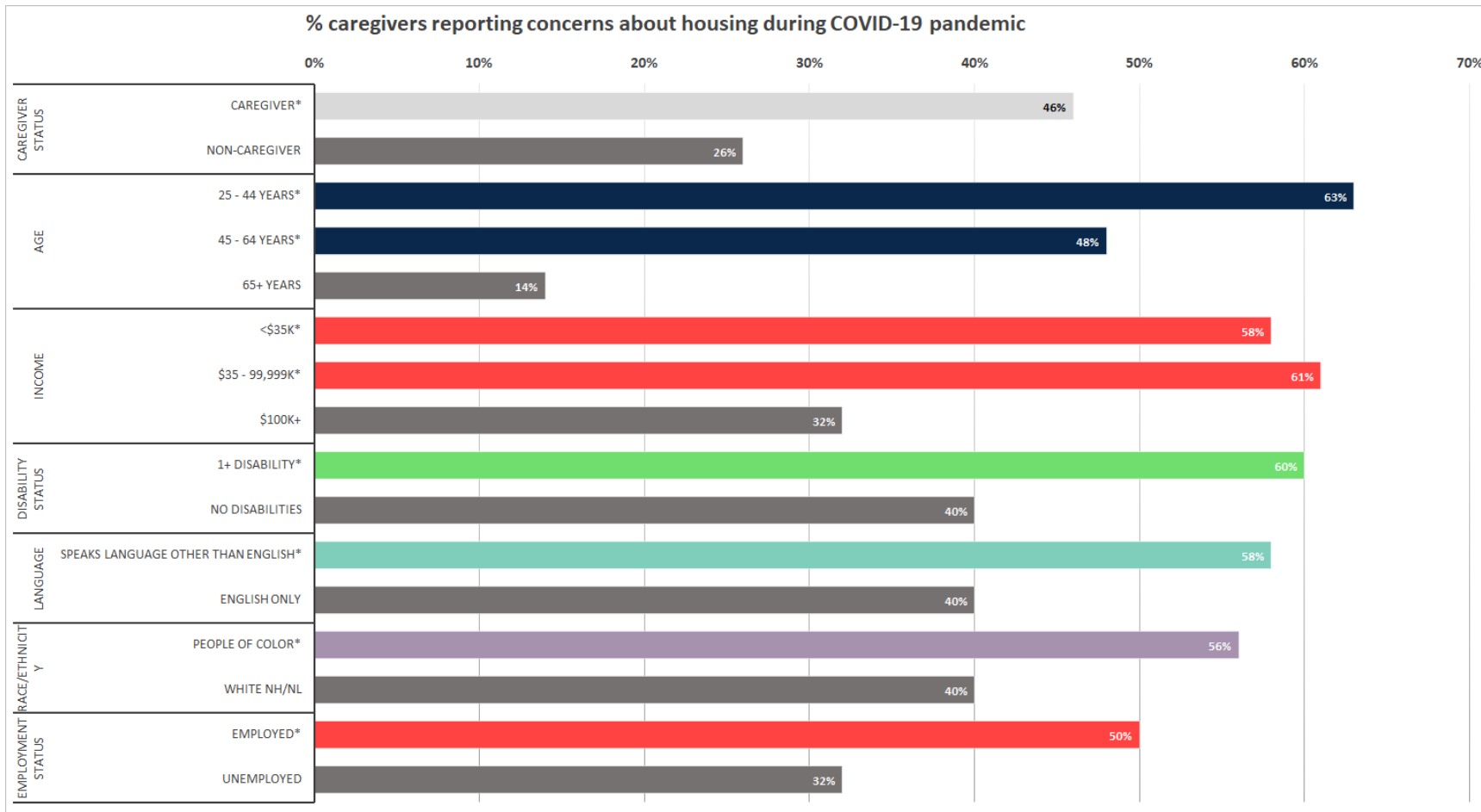
More than 70% of certain groups of caregivers were more likely to be very worried about expenses:

- Caregivers under the age of 45
- LGBTQA+ caregivers
- Caregivers who speak a language other than English
- Caregivers with disabilities
- Caregivers of color
- Caregivers with incomes under \$35K

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 = 309; Effective sample size = 357

CAREGIVERS IN MASSACHUSETTS

Nearly 1 in 2 caregivers were worried about housing



Caregivers more likely to be worried about housing were:

- Caregivers under the age of 45
- Caregivers with disabilities
- Caregivers with incomes under \$100K
- Caregivers who speak a language other than English
- Caregivers of color

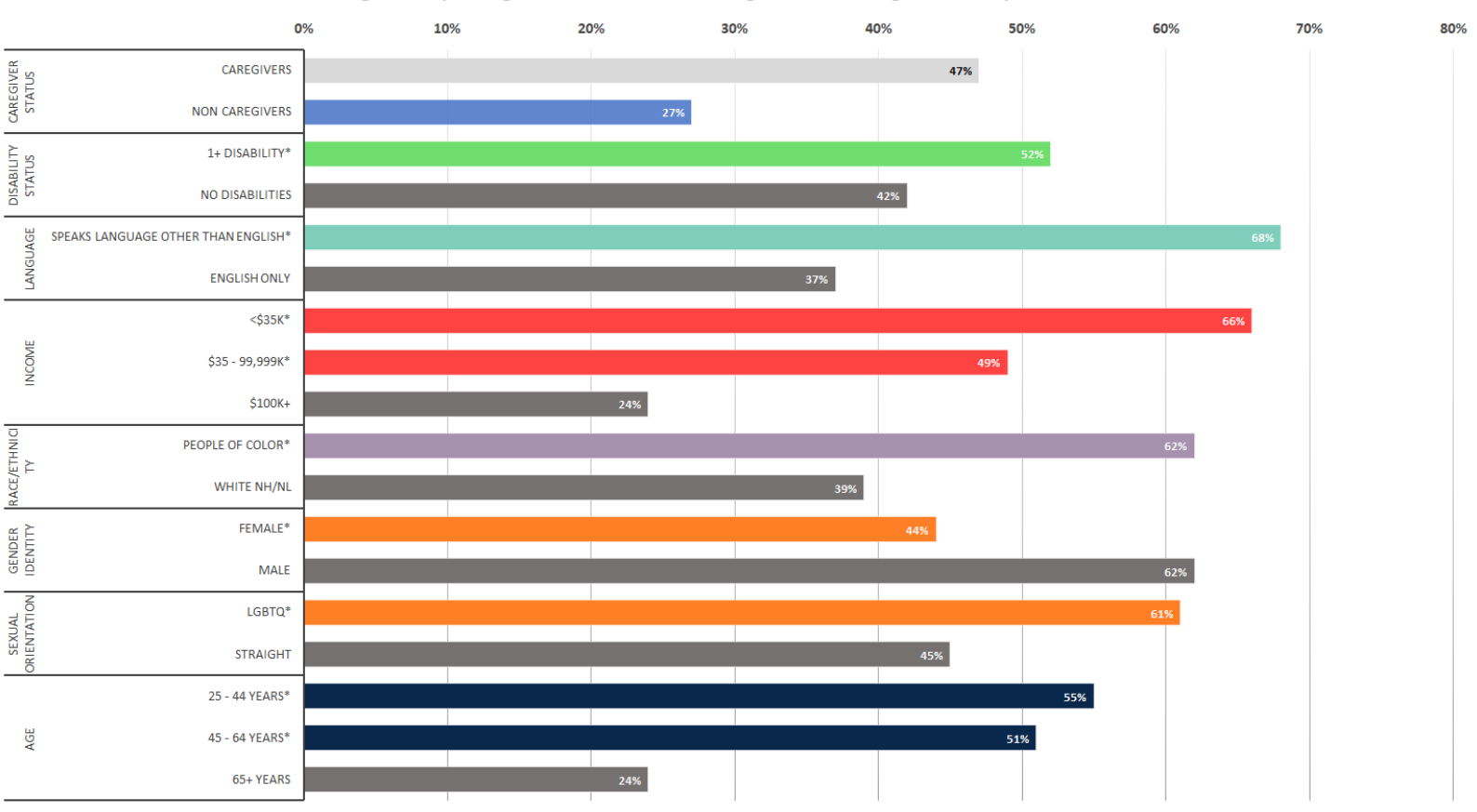
Employed caregivers were more likely to be worried about housing than unemployed caregivers.

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 = 309; Effective sample size = 357 9

CAREGIVERS IN MASSACHUSETTS

Nearly half of caregivers were worried about affording food or groceries

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



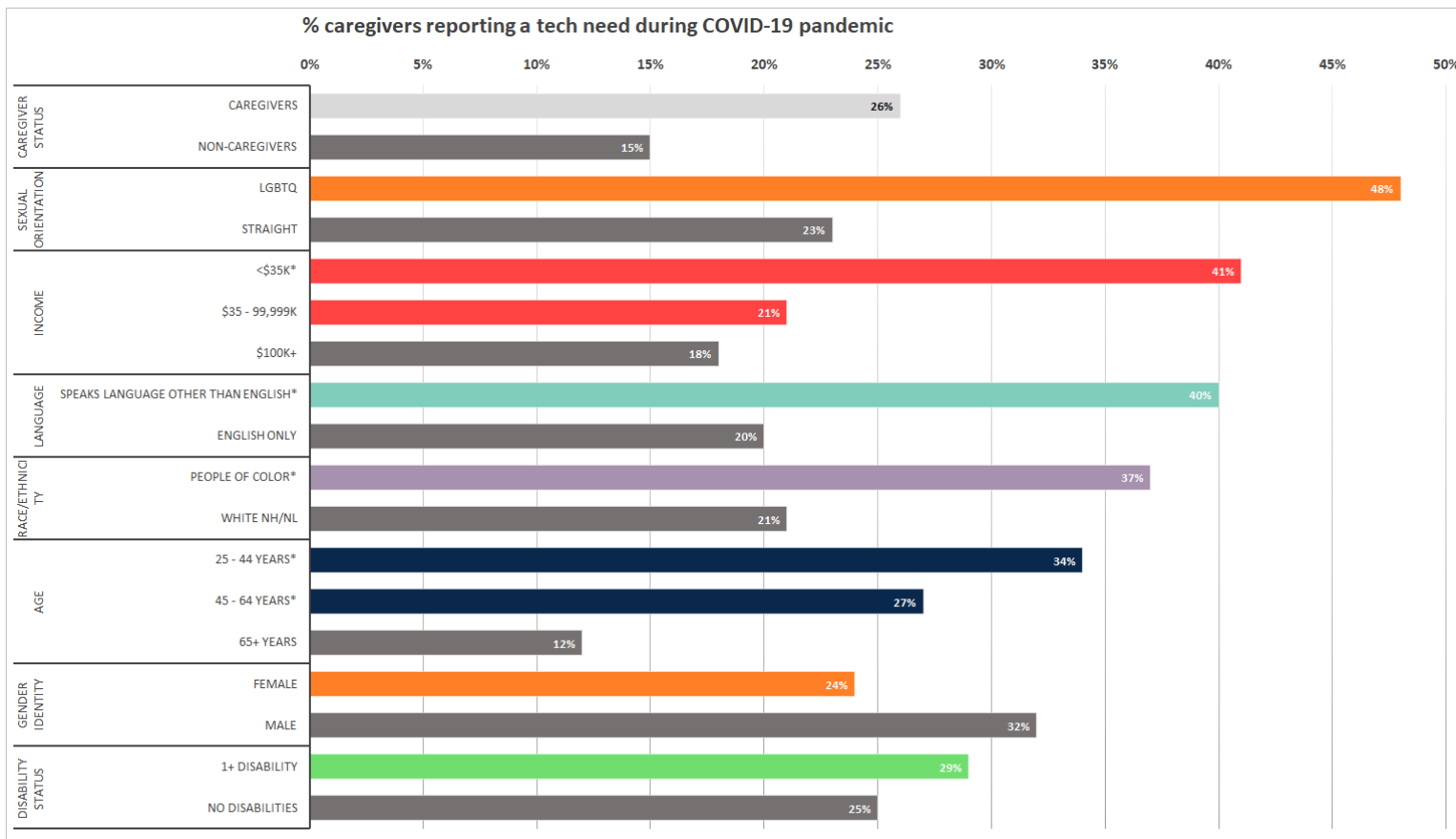
Over 60% of certain groups of caregivers were more likely to be very worried about food or groceries:

- Caregivers with disabilities
- Caregivers who speak a language other than English
- Caregivers with incomes under \$35K
- Caregivers of color
- Male caregivers
- LGBTQA+ caregivers
- Caregivers under the age of 45

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 = 309; Effective sample size = 357

CAREGIVERS IN MASSACHUSETTS

1 in 4 caregivers had unmet technology needs during the first 6-8 months of the pandemic. Some groups of caregivers were 3x as likely to report technology needs compared to non-caregivers.



26% of caregivers reported tech needs compared to 15% of non-caregivers.

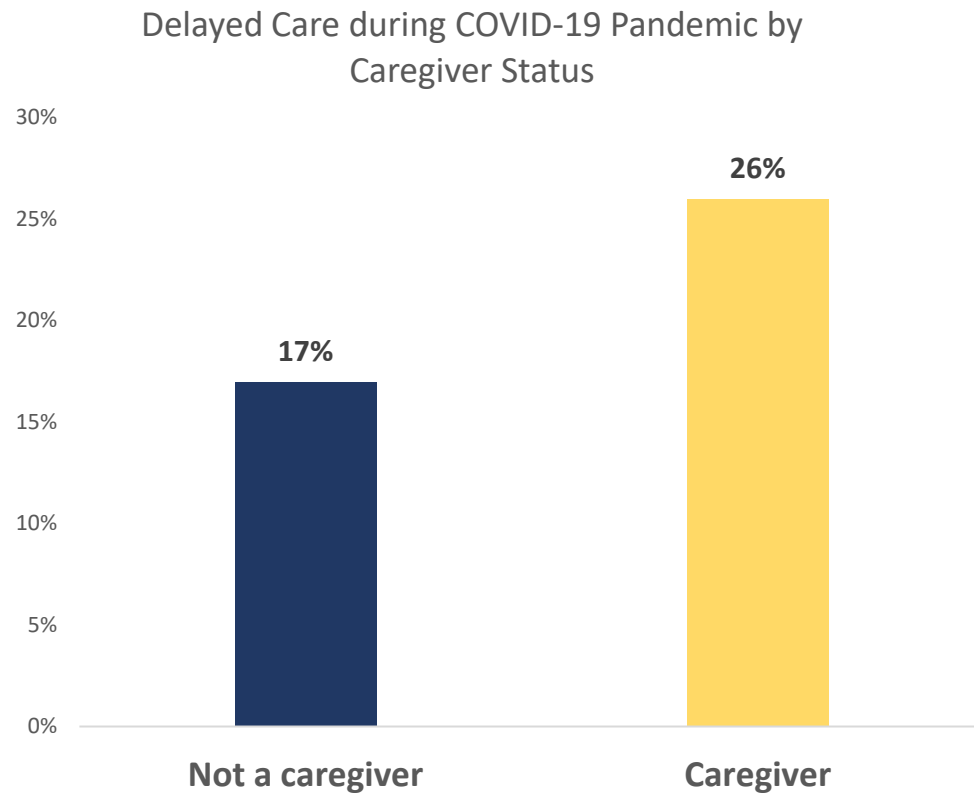
Certain groups of caregivers were more likely to have technology needs:

- LGBTQA+ caregivers
- Caregivers with incomes under \$35K
- Caregivers who speak a language other than English
- Caregivers of color
- Caregivers under the age of 45

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 = 309; Effective sample size = 357

CAREGIVERS IN MASSACHUSETTS

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



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

- 1 in 2 caregivers who identified as LGBTQ+ delayed care.
- 45% of those aged 25-44 delayed care.
- More than 40% of caregivers with 2+ disabilities, those with incomes less than \$35K and those in rural counties reported delaying care.

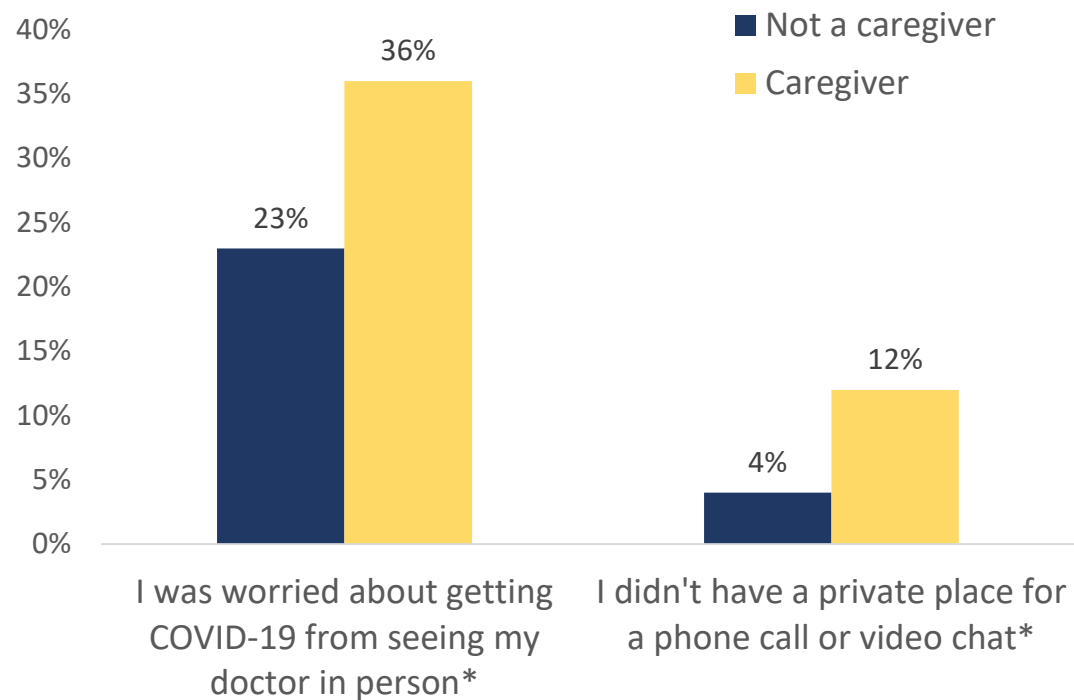
Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 5,009; Effective sample size = 4,985

11.10.2021 release

CAREGIVERS IN MASSACHUSETTS

Caregivers 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.

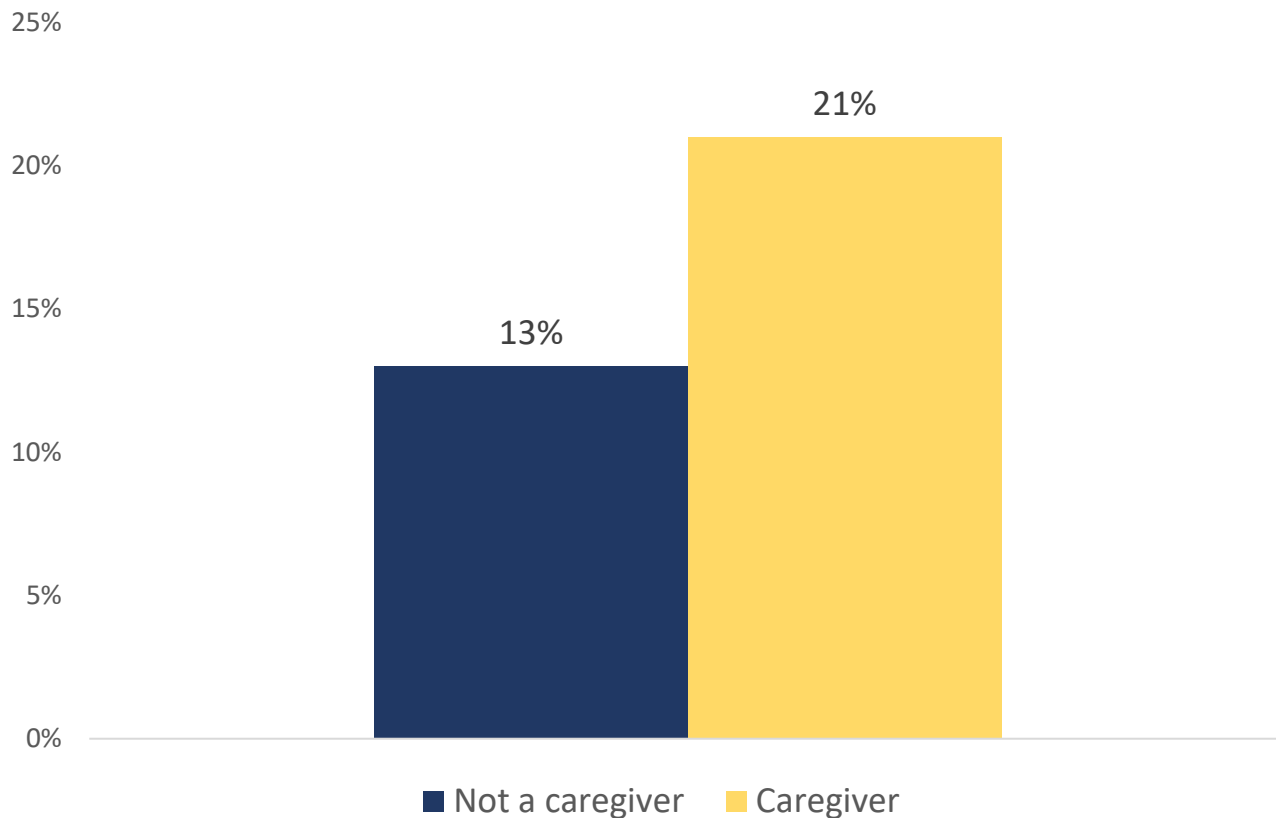
Data notes: 1) * denotes rate is significantly different ($p < 0.05$) between parents and non-parents; 2) All percentages are weighted to the statewide age and educational distribution of those ≥ 25 years.; 3) Sample size = 894; Effective sample size = 892

11.10.2021 release

CAREGIVERS IN MASSACHUSETTS

1 in 5 caregivers experienced delays in urgent care for themselves during the pandemic

Delayed Urgent Care by Caregiver Status



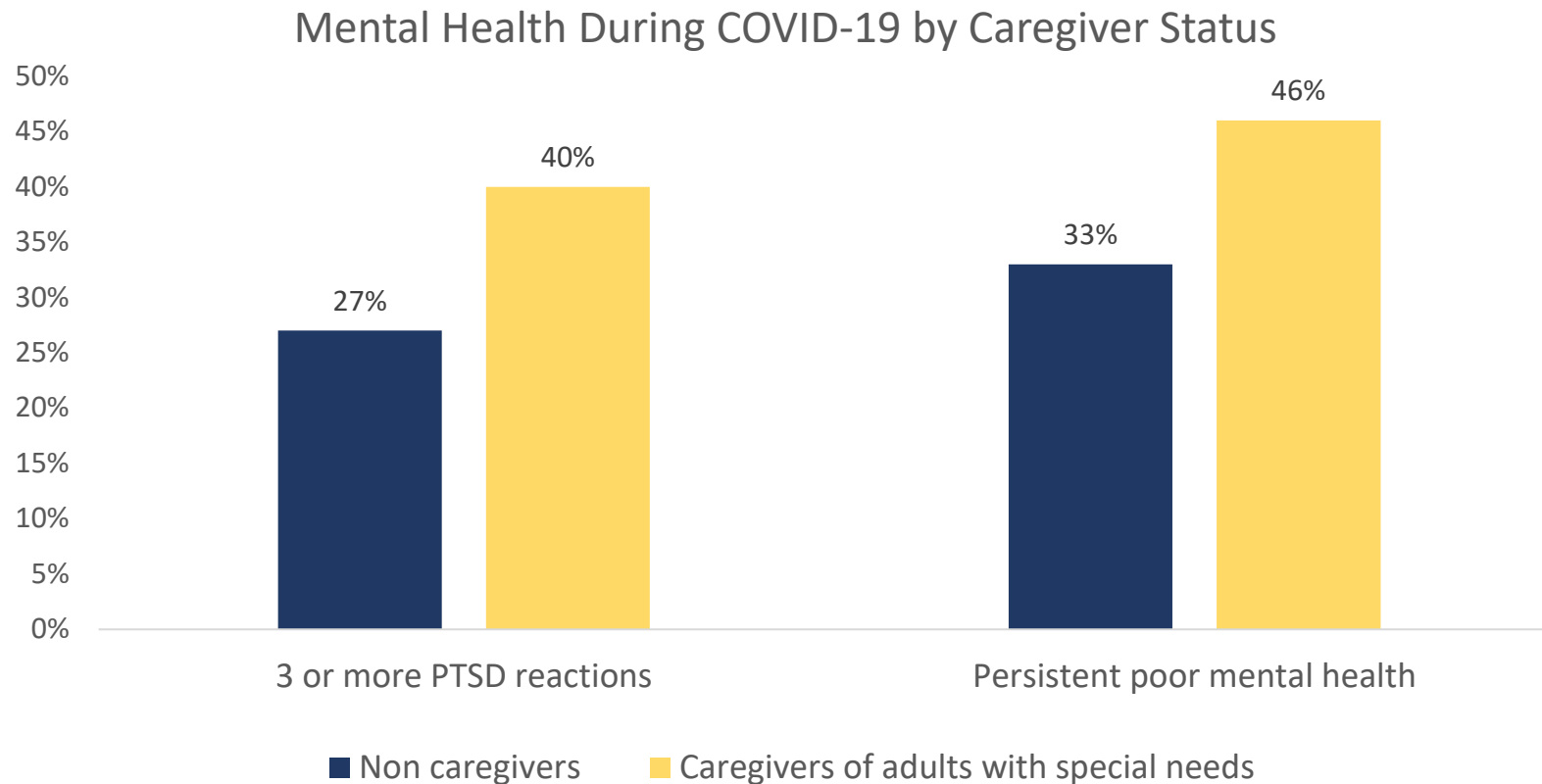
Caregivers were more likely to experience delays in urgent care compared to non-caregivers.

While routine care can be postponed for a short time without ill health effects, delaying urgent can have more serious consequences.

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 = 894; Effective sample size =

CAREGIVERS IN MASSACHUSETTS

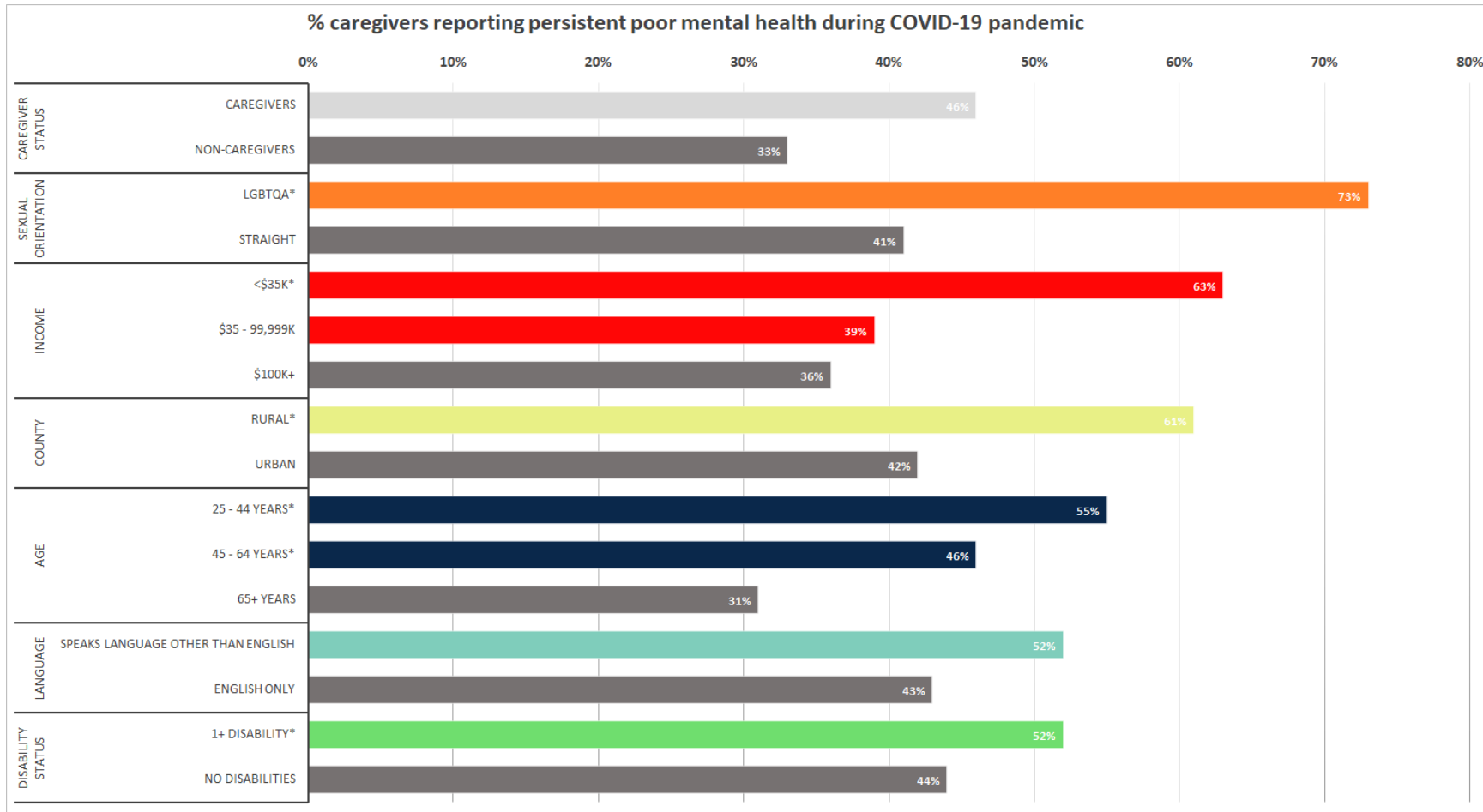
Caregivers were more likely to report 3+ PTSD reactions and more likely to report persistent poor mental health during the first 6-8 months of the COVID-19 pandemic.



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 = 5,670; Effective sample size = 5,455

CAREGIVERS IN MASSACHUSETTS

Certain groups of caregivers were much more likely to report poor mental health.



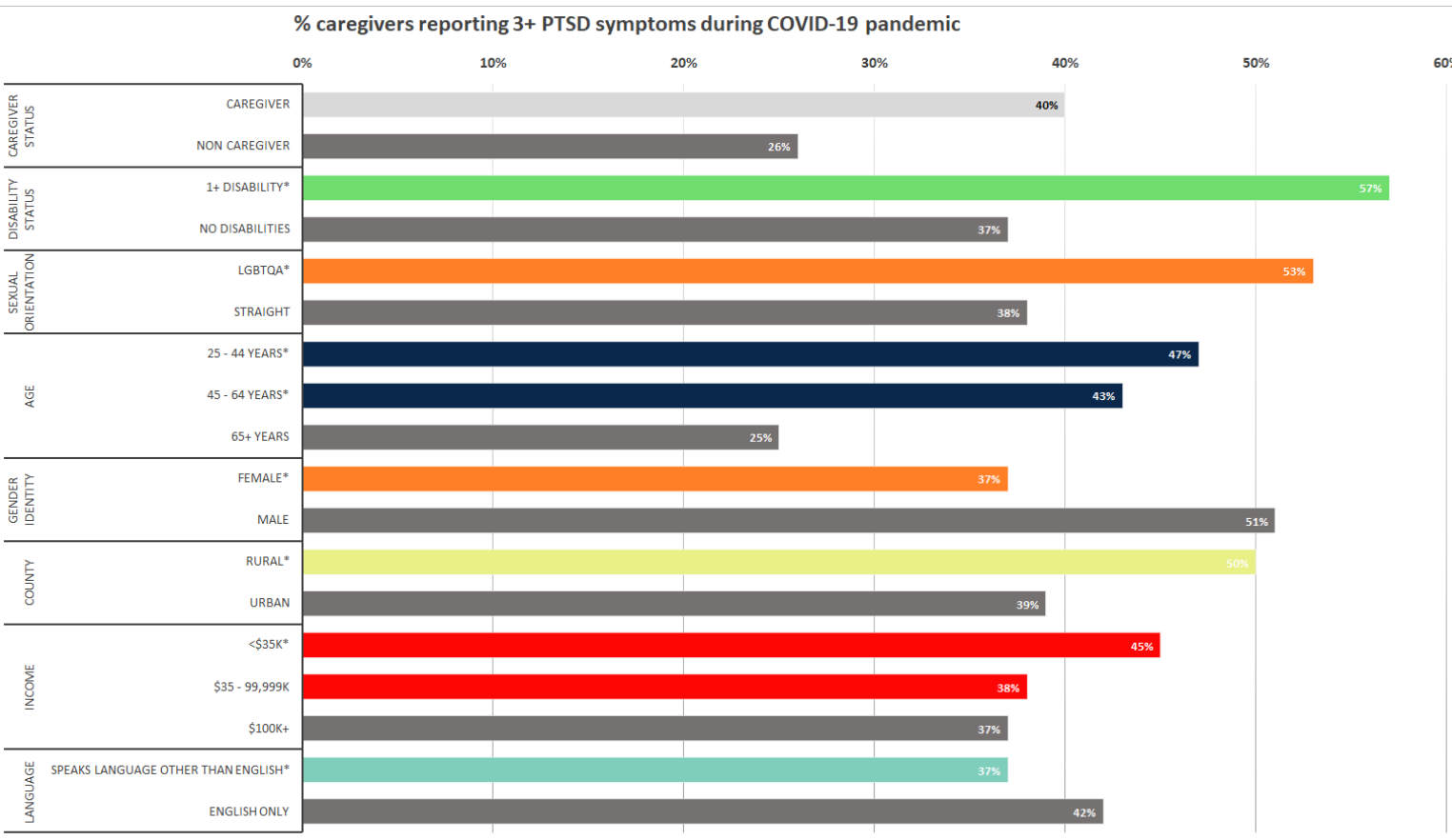
Certain groups of caregivers were more likely to report persistent poor mental:

- LGBTQA+ caregivers
- Caregivers with incomes under \$35K
- Caregivers in rural areas
- Caregivers under the age of 45
- Caregivers with disabilities

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 = 273; Effective sample size = 307

CAREGIVERS IN MASSACHUSETTS

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



More than half of certain groups of caregivers 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.
 - 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 medically 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](#).