Massachusetts Department of Public Health

COVID-19 Community Impact Survey(CCIS)

Preliminary Analysis Results as of December 8, 2021

Presented by Nassira Nicola

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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
   - Persons with Disability Spotlight
3. Appendix

PURPOSE AND APPROACH

Why did we conduct the CCIS?

Goals:

1) Identify the most pressing immediate and long-term health needs created by the pandemic, including its social and economic consequences

2) Determine which populations have been most disproportionately impacted

.... in order to inform and prioritize resource deployment and policy actions

OVERVIEW OF CCIS APPROACH

- Conducted a self-administered online survey (Sept. and Nov. 2020) with over 33,000 adults and 3,000 youth respondents in the final sample
- Covered a wide range of topics specific to adults and youth respectively
    - Perceptions & experiences of COVID-19, Basic needs, Access to healthcare, Pandemic-related changes in employment, Mental health, Substance use, and Safety
- Available in 11 languages; additional focus groups also conducted in ASL
- Open ended questions captured previously unknown needs and barriers
- Weighted results to the state average, with different weights applied to youth and adult samples
- Recruitment via network of community-based organizations (CBOs)
- Employed a snowballing sampling strategy to ensure we reach key populations
    - eg. People of color, LGBTQ+ individuals, People with disabilities, Essential workers, People experiencing housing instability, Older adults, and Individuals living in areas hardest hit by COVID-19

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
- NEW: PERSONS WITH DISABILITIES SPOTLIGHT

POPULATION SPOTLIGHT: PERSONS WITH DISABILITIES

"The COVID-19 pandemic has… starkly exposed the heightened vulnerability and risks to persons with disabilities that is underpinned by entrenched discrimination and inequality. […] While many persons with disabilities have health conditions that make them more susceptible to COVID-19, pre-existing discrimination and inequality means that persons with disabilities are one of the most excluded groups in terms of health prevention and response actions and economic and social support measures, and among the hardest hit in terms of transmission risk and actual fatalities."

– United Nations Office of the High Commissioner for Human Rights

FRAMING MATTERS

Out-dated **dominant frames** about disability frame it as a problem with individual bodies/minds. According to this frame (also called the "medical model"[1]):

- Disability is an outcome of failed health care and public-health policies.
- People with disabilities are, by definition, unhealthy and have low quality of life.
- Differences in health outcomes are seen as a natural and expected result of biological differences.
- Interventions are focused on curing and preventing disabilities and "restoring" people to a state of non-disabled health.

1. WHO's World Report on Disability, 2011 (https://www.who.int/publications/i/item/9789241564182) ; The Institute of Medicine's consensus report The Future of Disability in America, 2007 (https://www.nap.edu/catalog/11898/the-future-of-disability-in-america); The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities, 2005 (https://www.ncbi.nlm.nih.gov/books/NBK44667/).

FRAMING MATTERS

More current **equity-focused frames** about disability see it as a combination of atypical bodies/minds with an environment that is designed by and for non-disabled people. According to this frame (one version of what is known as the "social model"[1]):

- People with disabilities are a demographic group whose bodies/minds reflect normal diversity and variation. They can be happy and healthy.
- Differences in health outcomes are more likely to be the result of societal ableism than natural biological differences.
- Interventions focus on reducing barriers to health and community participation.

1. WHO's World Report on Disability, 2011 (https://www.who.int/publications/i/item/9789241564182) ; The Institute of Medicine's consensus report The Future of Disability in America, 2007 (https://www.nap.edu/catalog/11898/the-future-of-disability-in-america); The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities, 2005 (https://www.ncbi.nlm.nih.gov/books/NBK44667/).

Ableism, like other oppressions, acts at multiple levels:

INTERNALIZED

- Suppressing own needs to avoid feeling like a burden
- Avoiding other people with disabilities to avoid being seen as similar to them

INTERPERSONAL

- Pity, condescension
- Scrutiny of who's "disabled enough"
- Withholding access to exert control

INSTITUTIONAL

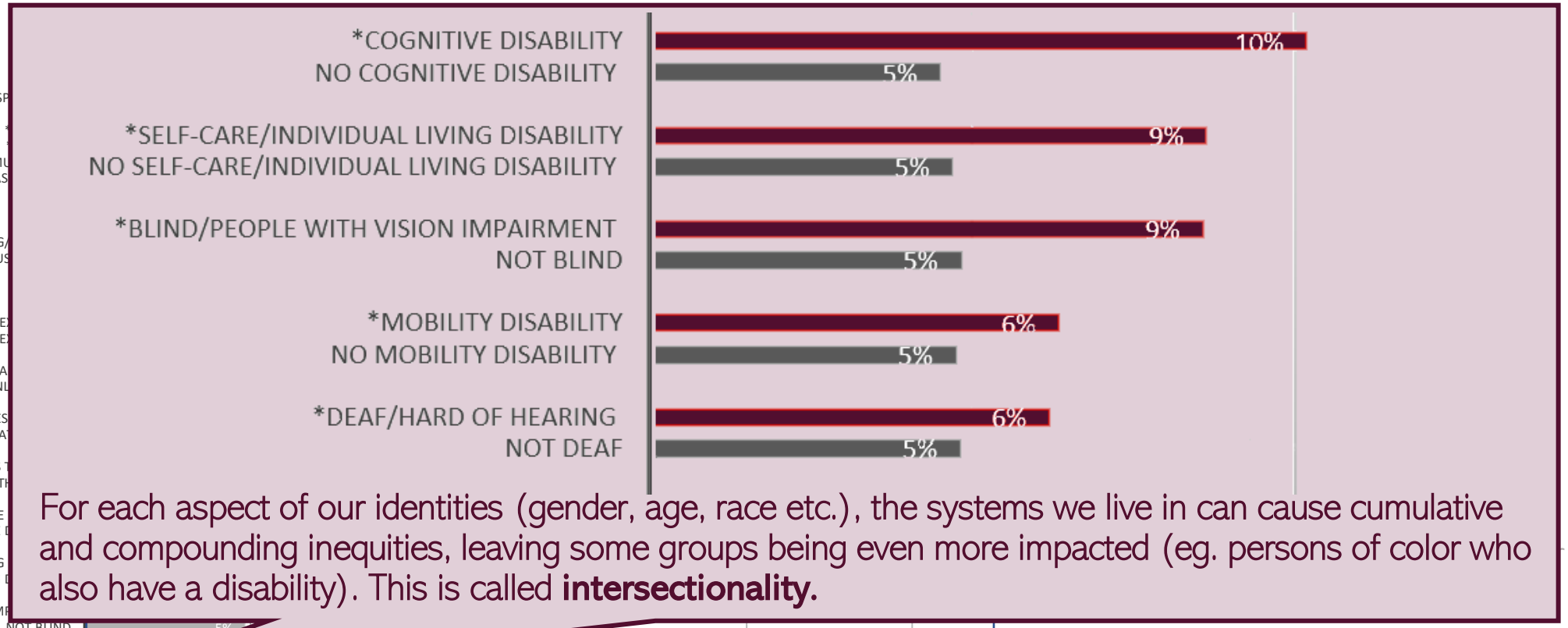
- Mandatory on-site work policies
- Patients with disabilities pressured to sign Do Not Resuscitate orders
- Laptop bans in classrooms

STRUCTURAL

- Financial penalties for marriage, work
- "Undue burden" clauses in civil-rights law
- Public charge restrictions in immigration policies

Ableism doesn't act alone.

MA Subpopulations Reporting Experiences of Discrimination based on Race/Ethnicity



For each aspect of our identities (gender, age, race etc.), the systems we live in can cause cumulative and compounding inequities, leaving some groups being even more impacted (eg. persons of color who also have a disability). This is called **intersectionality.**

school education, and those with disabilities

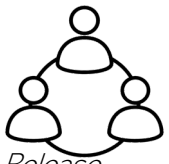
ABLEISM, DISABILITY & COVID-19

Limited systematic data on COVID-19 outcomes by disability status

Media messaging that "only people with pre-existing conditions" were at risk perceived as devaluing disabled lives

Prioritization of health care resources (e.g., ventilators) based on assumptions regarding quality of life

Increases in telehealth removes some barriers to health care & creates barriers to communication & assessing conditions or treatment plans



Disruption of support systems

COVID-19 swept through congregate settings (e.g., nursing homes); restrictions on movement from congregate settings limit independence and safety of residents

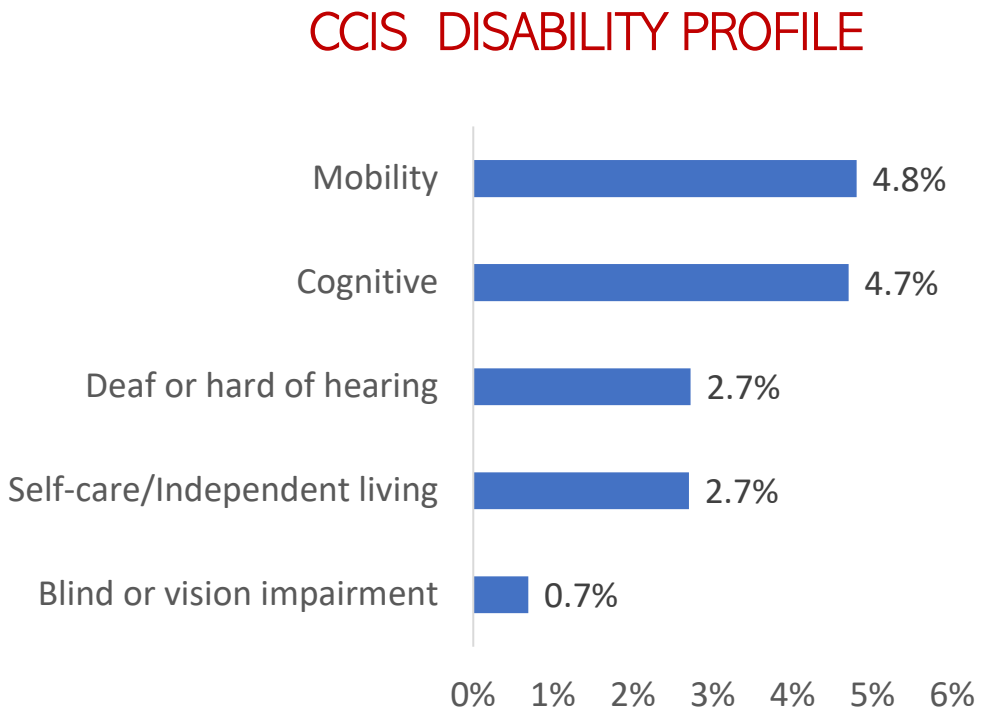
Barriers to following best practices for preventing virus exposure (e.g., handwashing, keeping 6 ft. distance, wearing masks)

Challenging to get COVID-19 accommodations for people with disabilities, whereas employers moved swiftly to make telecommuting possible

Fast changing COVID-19 information may not be adapted or accessible

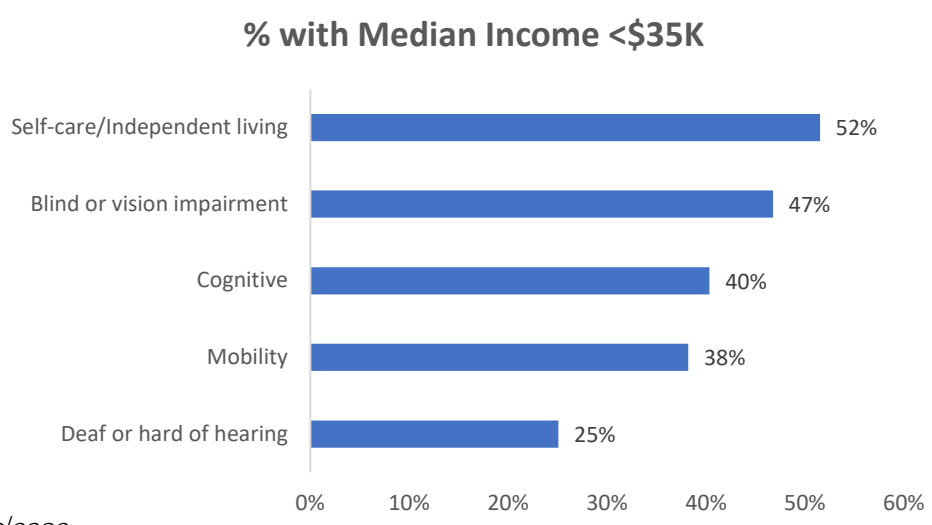
REACHING THE DISABILITY POPULATION IN MA CCIS

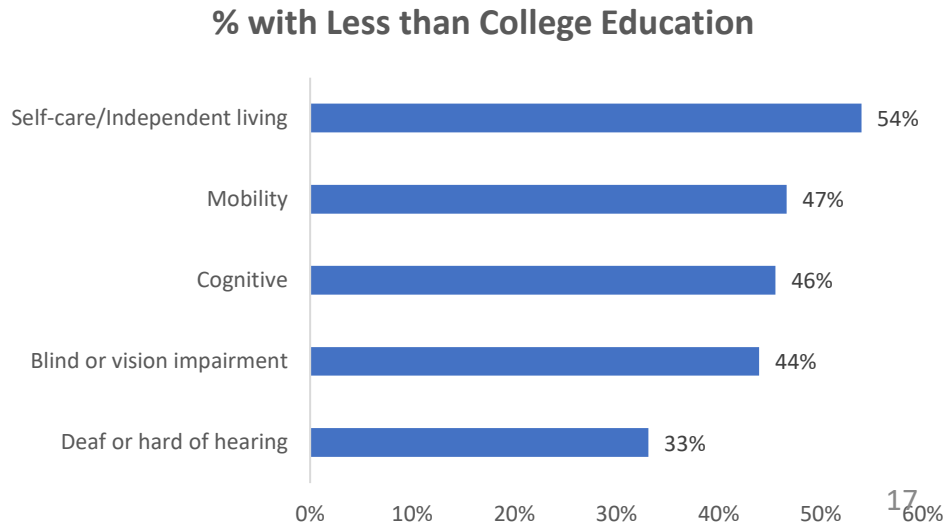
- **Over 4,100** CCIS participants had 1+ disability.
- While we did not directly sample residents <25 years of age and may not have reached many residents living in congregate settings, **CCIS allows us to examine the experiences of multiple disability subgroups.**
- **Focus groups conducted with deaf and hard of hearing residents (10 participants) to better understand experiences with COVID-19 mitigation, testing, and communication.**
- MA CCIS begins to fill an important gap in COVID-19 data by disability status.



SOCIOECONOMIC INEQUITIES AND DISABILITY

- While the Americans with Disabilities Act mandates equal educational and occupational opportunities and prohibits discrimination due to disability, **people with disabilities are more likely to have incomes below poverty and have lower levels of education than people without disabilities.**
- There are **socioeconomic differences** across disability subgroups.
- In the CCIS, one-quarter to half of respondents with a disability have incomes <$35K.
- About half of respondents with a self-care or independent living disability, mobility disability, or cognitive disability have less than a college education.





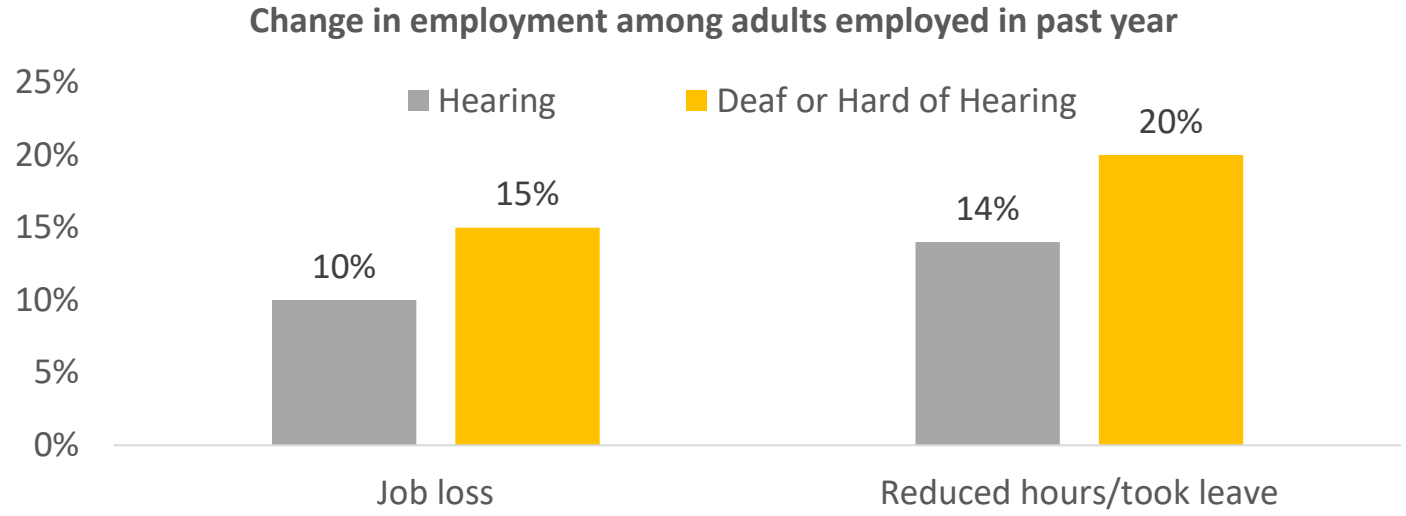
SPOTLIGHT
DEAF OR HARD OF HEARING

COMMUNICATION BARRIERS AMONG DEAF OR HARD OF HEARING POPULATION

- Deaf or hard of hearing focus group participants highlighted how practices to prevent virus transmission served as barriers to communication
  - *"I almost never use my voice, but now with masks, **sometimes I have to speak out loud to get people's attention,** and they all look at me like I'm an alien and I have to try and tell them I'm deaf."*
  - *"All of the grocery store workers know that I am deaf and **sometimes they will pull down their masks for a second so that I can see what they're saying.** Everyone seems more serious though when you can't see their faces. "*
  - *"There have been some challenges with repair people for our home and **having to communicate with pen and paper – hard to keep that distance in our home."***

JOB LOSS AND ECONOMIC STRAIN AMONG DEAF AND HARD OF HEARING RESPONDENTS

- Employed deaf or hard of hearing respondents are 1.5X* more likely to experience job loss and 1.4X* more likely to experience reduced hours or leave due to the pandemic.
- 4 in 10 (39%) deaf or hard of hearing respondents worry about paying for 1+ expenses or bills in the coming few weeks.
- Nearly 2 in 10 (18%) deaf or hard of hearing respondents have not gotten medical care needed since July 2020.



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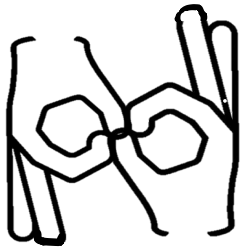
*Indicates compared to hearing respondents

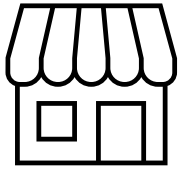
DEAF OR HARD OF HEARING & COVID-19

Face masks muffle sound and prevent lip reading, and may be hard to wear for people with behind-the-ear devices



People who need interpreters or other supports may be incorrectly affected by rules limiting visitors in medical settings

Telehealth visits are not always fully accessible (e.g., arranging for interpreter services)



Deaf people are less likely than hearing people to be hired for jobs, and more likely to lose those jobs in difficult times

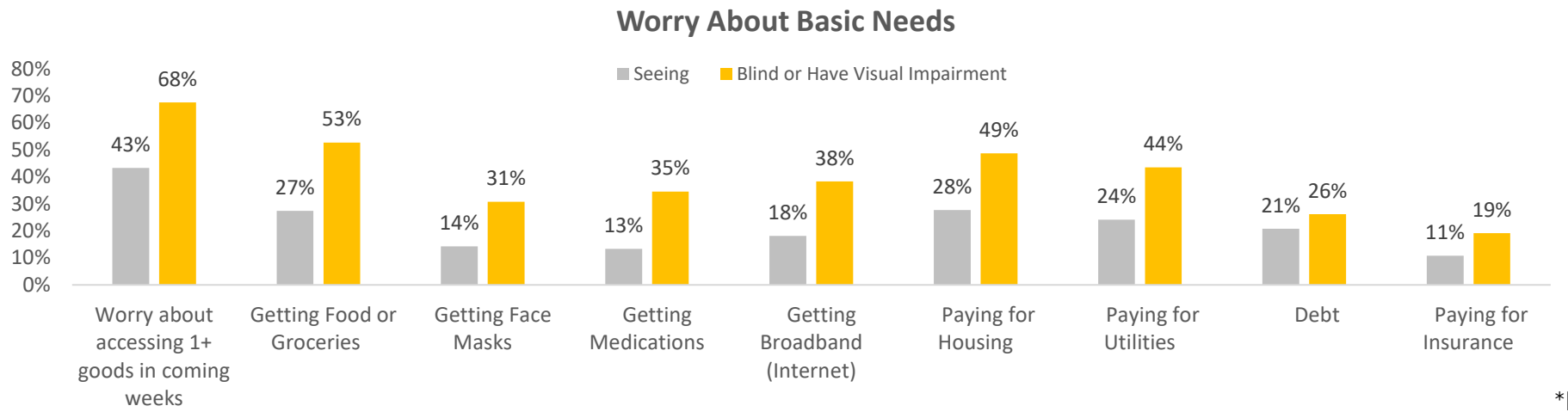
Urgent COVID-19 information may be disseminated in inaccessible formats first, and only made accessible to deaf or hard of hearing people later

Testing/vaccine providers may not know how to communicate with deaf people, or may be uncomfortable touching shared objects like pens and paper

SPOTLIGHT
BLIND OR VISION IMPAIRMENT

INEQUITIES IN COVID-19 PREVENTION PRACTICES AND BASIC NEEDS AMONG RESPONDENTS WHO ARE BLIND OR WHO HAVE A VISION IMPAIRMENT

- Respondents who are blind or who have a vision impairment are:
  - 1.2X* more likely to be "very" worried about getting infected with COVID-19.
  - 1.9X* more likely to not be able to keep 6 ft. distance when outside the home, compared to respondents who are not blind or have a vision impairment.
  - 1.9X* more likely to worry about getting food or groceries.
  - 2.1X* more likely to worry about getting broadband (internet).
  - 1.8X* more likely to worry about paying for housing.
  - 1.5X* more likely to report 15+ poor mental health days in past 30 days.



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*Indicates compared to seeing respondents

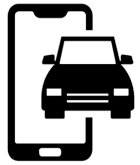
BLIND OR VISION IMPAIRMENT & COVID-19

Touch & tactile senses are important for routine activities

May need to be guided by holding someone's elbow; elbows used for sneezing & coughing

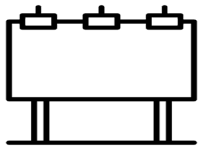
Difficult to locate hand sanitizer stations

Public transportation schedules reduced, may be crowded



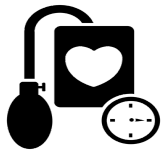
Difficult to arrange ride share services, need to sit in close proximity to driver

Telehealth visits not fully accessible

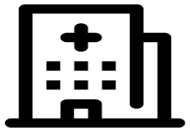


Best practices for virus prevention often visually conveyed

Getting groceries is more difficult: staff occupied with pick-up & delivery orders, items hard to find due to demand, cannot search multiple stores



Higher prevalence of comorbidities than general population, which increases risk of severe COVID-19



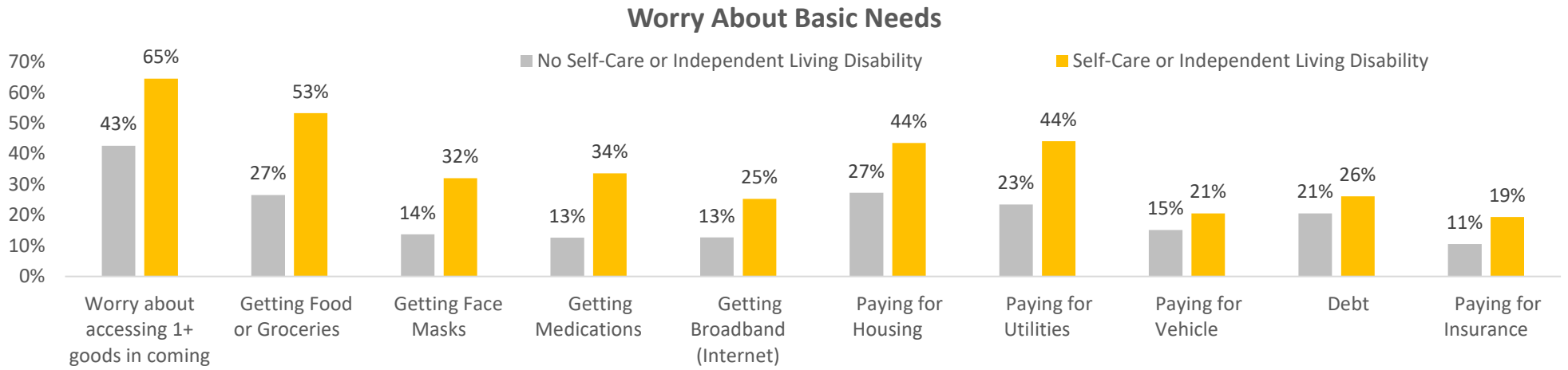
Elective surgeries were postponed, which may include eye surgeries

Drive-up testing is difficult if use transportation services

SPOTLIGHT
SELF-CARE OR INDEPENDENT LIVING DISABILITY

INEQUITIES IN MEETING BASIC NEEDS FOR RESPONDENTS WITH A SELF-CARE OR INDEPENDENT LIVING DISABILITY

- Respondents who have a self-care or independent living disability are:
  - 1.8X* more likely to be "very" worried about getting infected with COVID-19.
  - 2X* more likely to have not gotten medical care needed since July 2020.
  - 2X* more likely to worry about getting food or groceries.
  - 2.6X* more likely to worry about getting medications.
  - 2X* more likely to worry about getting broadband (internet).
  - 1.6X* more likely to worry about paying for housing.
  - 1.8X* more likely to report 15+ poor mental health days in past 30 days.



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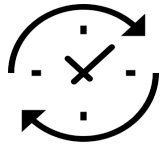
*Indicates compared to respondents who do not have a self-care or independent living disability

SELF-CARE OR INDEPENDENT LIVING DISABILITY & COVID-19

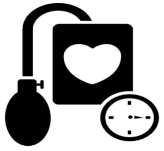


Rapid change to routine may strain day-to-day activities & support, stressful to adopt new behaviors

Support of family members or caregivers outside of household could increase risk of virus exposure (e.g., cannot fully distance)

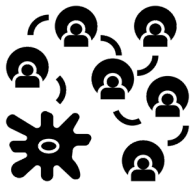
Finding reliable & safe in-home care may be more difficult (e.g., rotation of caregivers, staffing constraints due to illness or isolation)

Community-based supports (e.g., schools, day programs) interrupted



Higher prevalence of comorbidities than general population, which increases risk of severe COVID-19

Limitations on leaving home to prevent virus exposure



Congregate settings (e.g., nursing homes) had outbreaks linked with close quarters, shared living spaces, frequent staff changes

Reduced in-person visits with social & health care providers who may support disability management or other healthcare needs

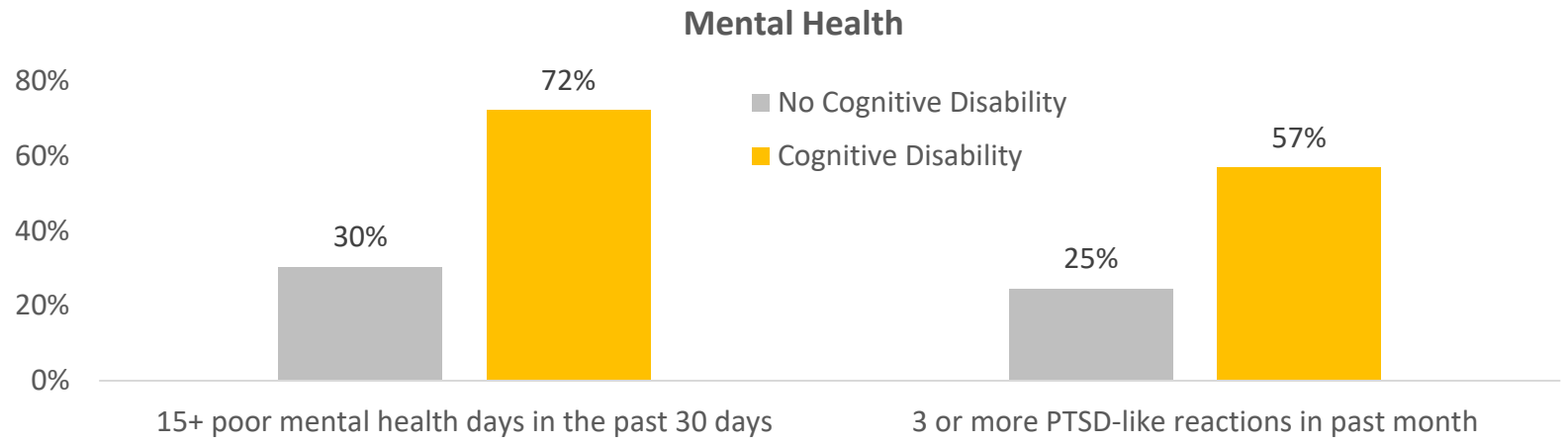
Drive-up testing inaccessible for users of public transit or paratransit services

Barriers to following best practices for preventing virus exposure (e.g., handwashing, keeping 6 ft. distance, wearing masks)

SPOTLIGHT
COGNITIVE DISABILITY

MENTAL TOLL OF COVID-19 AMONG RESPONDENTS WITH A COGNITIVE DISABILITY

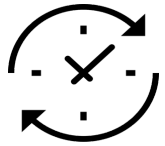
- Respondents who have a cognitive disability are:
  - 1.6X* more likely to be "very" worried about getting infected with COVID-19.
  - 2.1X* more likely to not be able to keep 6 ft. distance when outside the home.
  - 2X* more likely to worry about getting food or groceries.
  - 1.9X* more likely to worry about paying for housing.
  - 2.4X* more likely to report 15+ poor mental health days in past 30 days.
  - 2.3X* more likely to report 3+ PTSD-like reactions in the past month.



*Indicates compared to respondents who do not have a cognitive disability

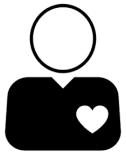
p<0.001

COGNITIVE DISABILITY & COVID-19



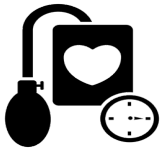
Rapid change to routine may strain day-to-day activities & support, stressful to adopt new behaviors

Support of family members or caregivers outside of household could increase risk of virus exposure (e.g., cannot fully distance)



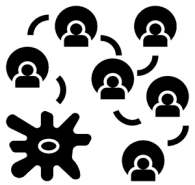
Finding reliable & safe in-home care may be more difficult (e.g., rotation of caregivers, staffing constraints due to illness or isolation)

Community-based supports (e.g., schools, day programs) interrupted



Some genetic factors linked with cognitive disability may increase risk of severe COVID-19

Limitations on leaving home to prevent virus exposure



Congregate settings (e.g., nursing homes) had outbreaks linked with close quarters, shared living spaces, frequent staff changes

Reduced in-person visits with social & health care providers who may support disability management

Drive-up testing is difficult if use transportation services

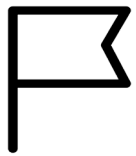
Barriers to following best practices for preventing virus exposure (e.g., handwashing, keeping 6 ft. distance, wearing masks)

COGNITIVE DISABILITY & COVID-19

Physical proximity to caregivers may be important for making routines manageable & predictable

COVID-19 restrictions & limits on usual routine, connections, supports may be stressful, contribute to externalizing behaviors

Disproportionately isolated before COVID-19, isolation increased after COVID-19



Abuse may be more difficult to detect by providers using remote communication or physical distancing

Cognitive impairments may limit processing of information communicated

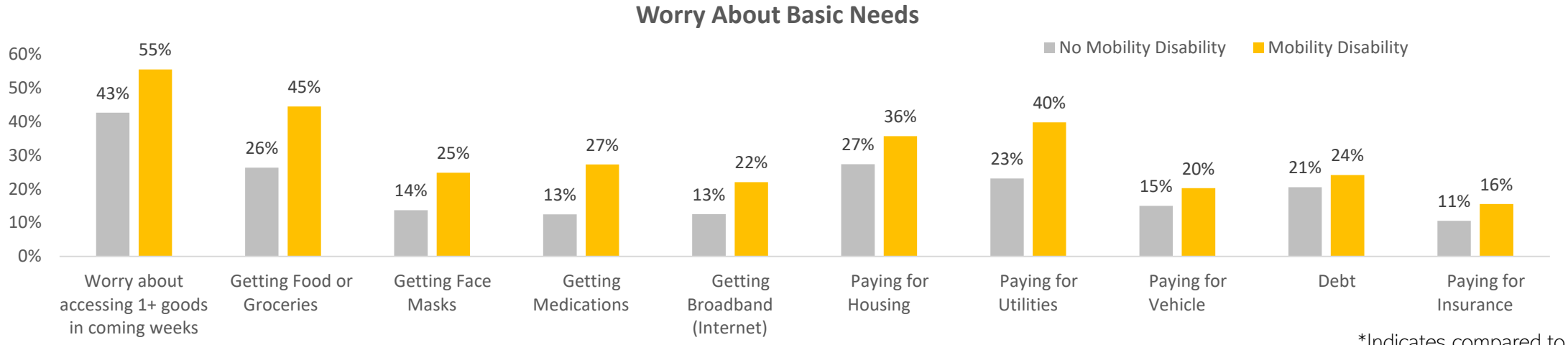
Deluge of information about COVID-19 may heighten anxiety, contribute to paranoid thinking and/or catalyze externalizing behaviors

May rely on others to process COVID-19 information & how to act upon information

SPOTLIGHT
MOBILITY DISABILITY

INEQUITIES IN BASIC NEEDS AMONG RESPONDENTS WITH A MOBILITY DISABILITY

- Respondents who have a mobility disability are:
  - **1.5X* more likely to be "very" worried about getting infected with COVID-19.**
  - **1.4X more likely to have not gotten medical care needed since July 2020.**
  - **1.7* more likely to worry about getting food or groceries.**
  - **2.2X* more likely to worry about getting medications.**
  - **1.8X* more likely to worry about getting broadband (internet).**
  - **1.3X* more likely to worry about paying for housing.**



*Indicates compared to respondents who do not have a mobility disability

p<0.001

MOBILITY DISABILITY & COVID-19

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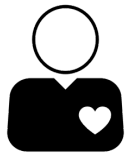
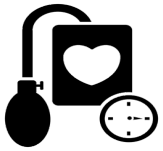


Finding reliable & safe in-home care may be more difficult (e.g., rotation of caregivers, staffing constraints due to illness or isolation)



Higher prevalence of comorbidities than general population, which increases risk of severe COVID-19

Reduced in-person visits with social & health care providers who may support disability management

Drive-up testing is difficult if use transportation services

Barriers to following best practices for preventing virus exposure (e.g., handwashing, keeping 6 ft. distance, wearing masks)

"Disabled people know what it means to be vulnerable and interdependent. We are modern-day oracles. It's time people listened to us."
- Alice Wong

FUTURE CCIS LIVE WEBINARS

Persons with Disability

December 15, 2021

10:00am –11:30am

Caregivers

Caregivers of adults with special needs and parents of children & youth with special healthcare needs

January 13, 2022

1:00pm – 2:30pm

You can register for these webinar events on our website at mass.gov/covidsurvey

For questions about these webinars, please email us at covid19survey@mass.gov