COVID-19 COMMUNITY IMPACT SURVEY:
Persons with Disabilities

Presented by:Nassira Nicola

Results as of June 8, 2021

REMINDER

This webinar is meant to be watched after you have already seen the <u>CCIS Introduction Webinar.</u>
The introduction contains important background information explaining how to interpret these results, how we did the survey, and how to frame these findings with a racial justice lens so that we can all turn the CCIS data into action!

Visit http://mass.gov/covidsurvey for more!

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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:

- Health Resources in Action (HRiA)
- John Snow International (JSI)
- 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.

PURPOSE AND INTENT

PERSONS WITH DISABILITIES

This webinar will share some key findings from the COVID-19 Community Impact Survey (CCIS) around how the pandemic has impacted persons with disabilities. The goal is that these findings:

- Inform immediate and short-term actions
- Identify ways to advance new, collaborative solutions with community partners to solve the underlying causes of inequities
- Provide data that stakeholders at all levels can use to "make the case" for a healthy future for ALL.

Remember to watch the CCIS Introduction Webinar for important background, tools, and tips to frame these findings with a racial justice lens to turn the CCIS data into action!

Visit http://mass.gov/covidsurvey for all things CCIS!

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

Dominant frames about disability see it as a problem with individual bodies/minds.

According to this frame (also called the "medical model"):

- 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.

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"):

- 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.

ABLEISM

Ableism: "A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence and excellence. These constructed ideas of normalcy, intelligence and excellence are deeply rooted in anti-Blackness, eugenics and capitalism.

This form of systemic oppression leads to people and society determining who is valuable or worthy based on people's appearance and/or their ability to satisfactorily produce, excel & 'behave.'"

- working definition developed by Talila "TL" Lewis, in collaboration with Dustin Gibson and other members of the community, 2019 (see https://www.talilalewis.com/blog/january-2021-working-definition-of-ableism for version updates and context)

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

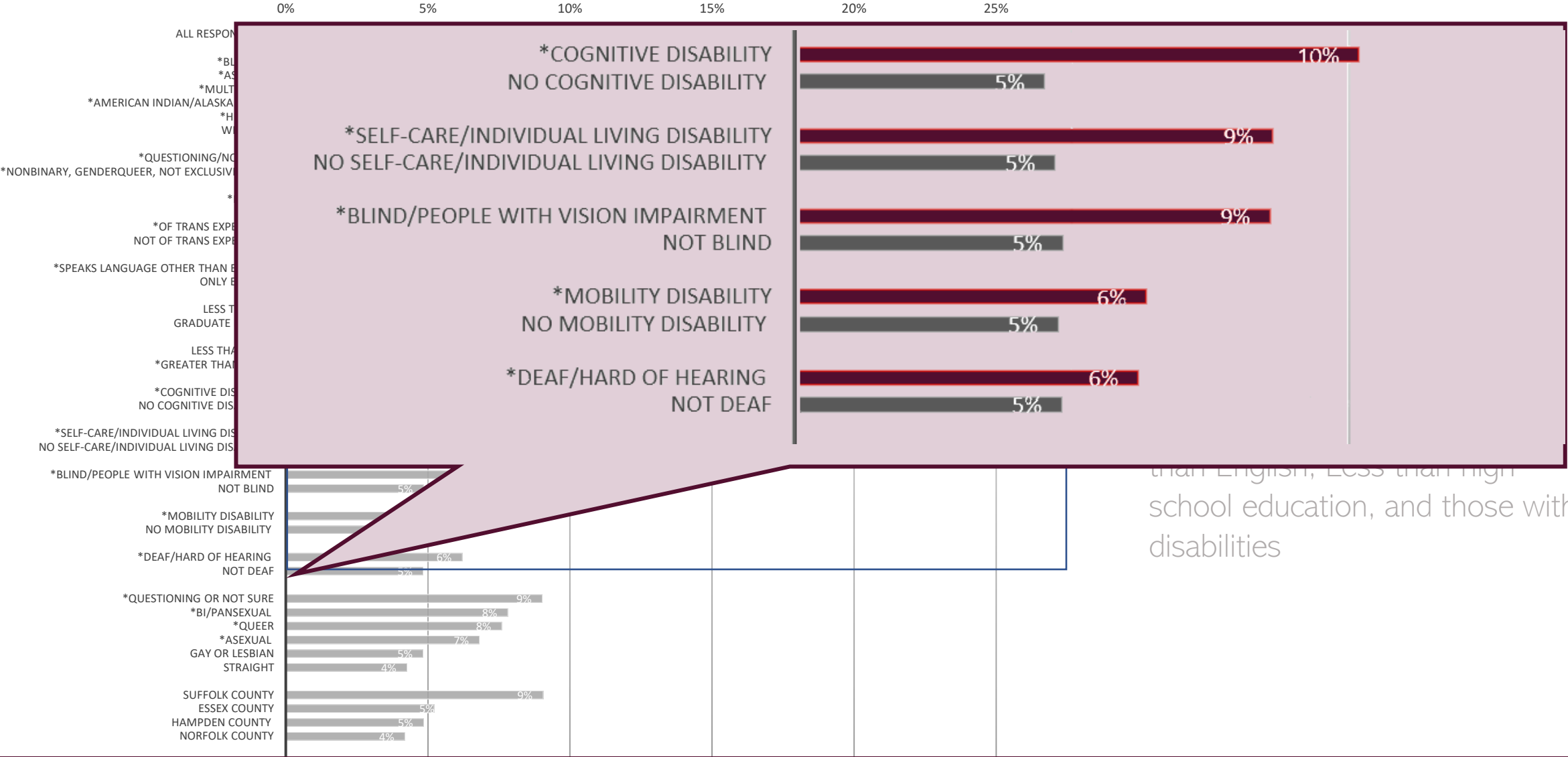• Laptop bans in classrooms

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 During COVID-19 Pandemic

0%   5%   10%   15%   20%   25%

ALL RESPON...
*BL...
*AS...
*MULT...
*AMERICAN INDIAN/ALASKA...
*H...
W...
*QUESTIONING/NO...
*NONBINARY, GENDERQUEER, NOT EXCLUSIV...
*...
*OF TRANS EXP...
NOT OF TRANS EXP...
*SPEAKS LANGUAGE OTHER THAN E...
ONLY E...
LESS T...
GRADUATE...
LESS THA...
*GREATER THA...
*COGNITIVE DIS...
NO COGNITIVE DIS...
*SELF-CARE/INDIVIDUAL LIVING DIS...
NO SELF-CARE/INDIVIDUAL LIVING DIS...

Callout detail:

Category	%
*COGNITIVE DISABILITY	10%
NO COGNITIVE DISABILITY	5%
*SELF-CARE/INDIVIDUAL LIVING DISABILITY	9%
NO SELF-CARE/INDIVIDUAL LIVING DISABILITY	5%
*BLIND/PEOPLE WITH VISION IMPAIRMENT	9%
NOT BLIND	5%
*MOBILITY DISABILITY	6%
NO MOBILITY DISABILITY	5%
*DEAF/HARD OF HEARING	6%
NOT DEAF	5%

*BLIND/PEOPLE WITH VISION IMPAIRMENT
NOT BLIND — 5%
*MOBILITY DISABILITY
NO MOBILITY DISABILITY
*DEAF/HARD OF HEARING — 6%
NOT DEAF — 5%

*QUESTIONING OR NOT SURE — 9%
*BI/PANSEXUAL — 8%
*QUEER — 8%
*ASEXUAL — 7%
GAY OR LESBIAN — 5%
STRAIGHT — 4%

SUFFOLK COUNTY — 9%
ESSEX COUNTY — 5%
HAMPDEN COUNTY — 5%
NORFOLK COUNTY — 4%

than English, Less than high school education, and those with disabilities

Ableism doesn't act alone.

Context	Impact	What we can do
LGBTQ members experience barriers to health due to **discrimination** and the lack of: • Insurance coverage • Technology needed for telehealth • Affirming accessible care • "I was denied care on the basis of being transgender and... disability accommodations and cannot find anyone to help me **so I can get the care I need**"		technology services: 1 ...dults technology ...that of
	7x) • 1 out 5 trans respondents reported delaying sexual/reproductive health care	Policy & organizational change • Train healthcare and social service providers on LGBTQ cultural competency[2]
In the CCIS, after cancelled delayed appointments, the top barriers LGBTQ adults identified for delayed care were: 1. Worried about getting COVID 2. Worried could not afford care/insurance wouldn't cover 3. No private place for phone call/video chat 4. No safe transportation to get to appt. 5. Didn't have good enough phone or internet connection.	• LGBTQ adults were up to 5.3x as likely to report never getting tested for COVID because they didn't know where to go	• Improve outreach of health services to LGBTQ youth and adults (e.g., through using social media and dating apps)[2]

"I was denied care on the basis of being transgender and disabled … or refusal to make disability accommodations and cannot find anyone to help me **so I can get the care I need**"

ABLEISM, DISABILITY & COVID-19

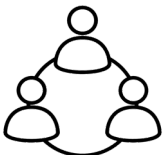Limited systematic data on COVID-19 outcomes by disability status

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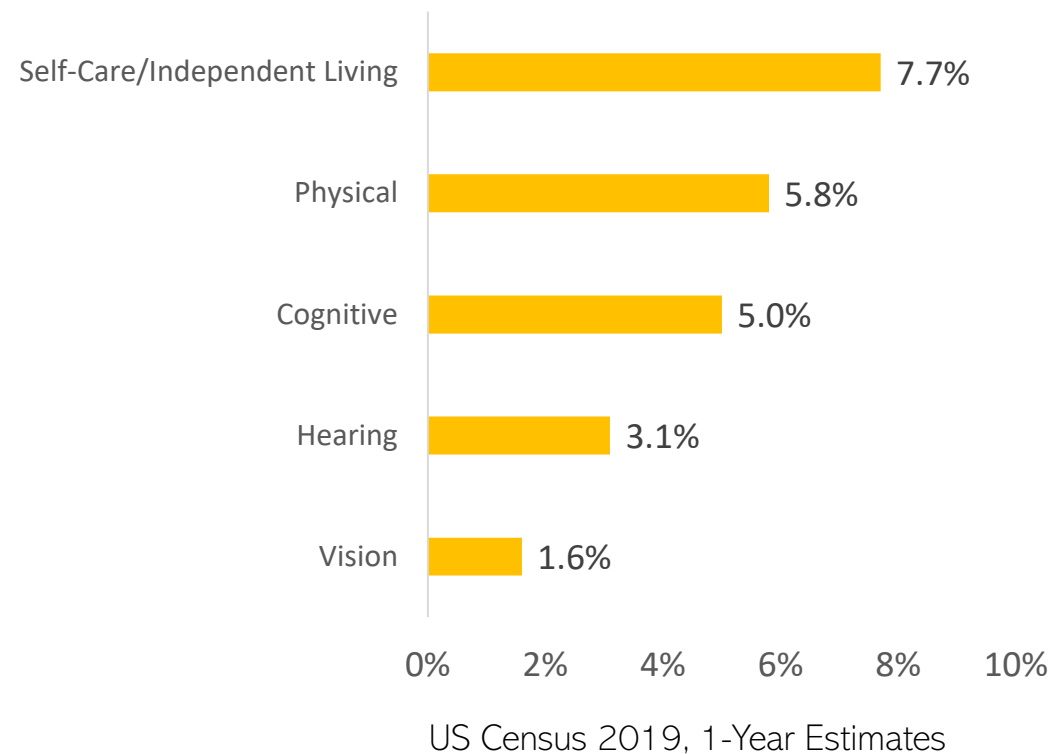
Fast changing COVID-19 information may not be adapted or accessible

DISABILITY POPULATION IN MASSACHUSETTS

- In Massachusetts, over **785,000 residents** have a disability, representing 11.5% of the non-institutionalized total population in Massachusetts.

- This number does not reflect people with disabilities who are incarcerated, in long-term care facilities, or otherwise living in institutional settings.
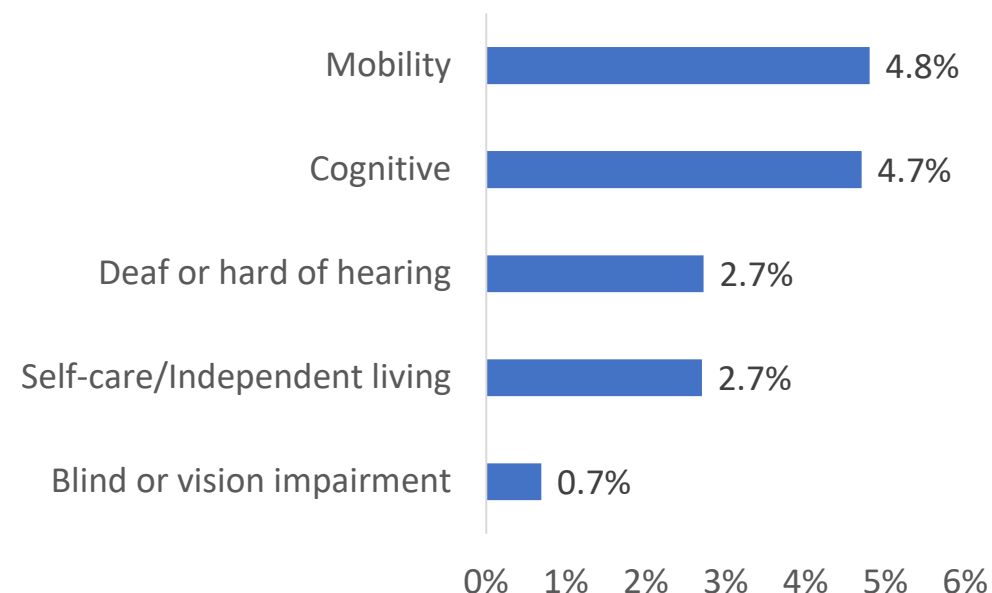
MASSACHUSETTS DISABILITY PROFILE

Category	Percentage
Self-Care/Independent Living	7.7%
Physical	5.8%
Cognitive	5.0%
Hearing	3.1%
Vision	1.6%

US Census 2019, 1-Year Estimates

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.
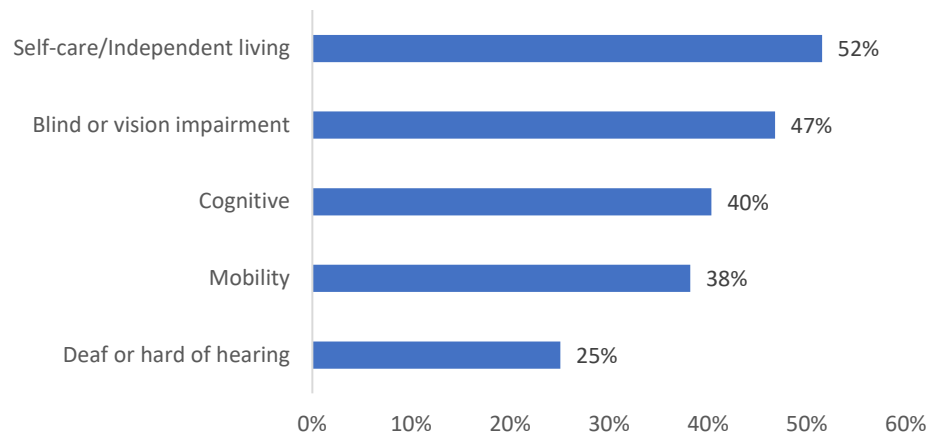
CCIS DISABILITY PROFILE

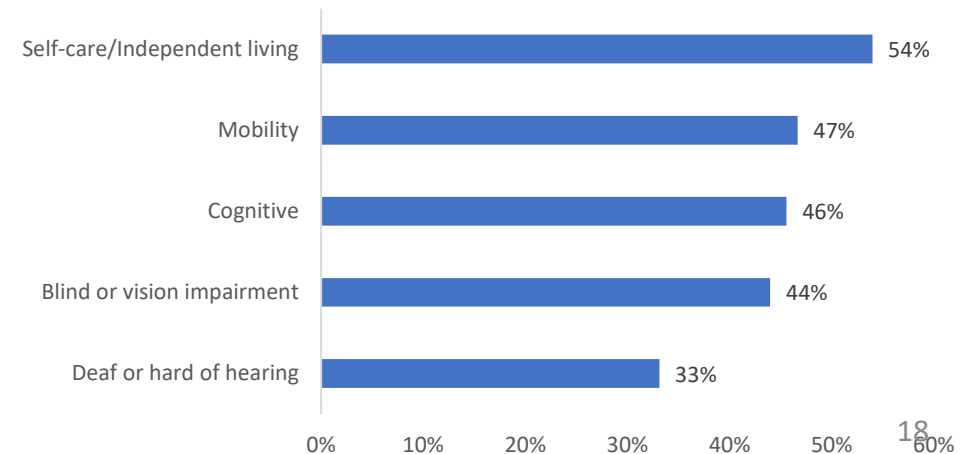| Category	Value
Mobility	4.8%
Cognitive	4.7%
Deaf or hard of hearing	2.7%
Self-care/Independent living	2.7%
Blind or vision impairment	0.7%

0% 1% 2% 3% 4% 5% 6%

SOCIOECONOMIC INEQUITIES AND DISABILITY

- While the American Disabilities Act ensures 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.
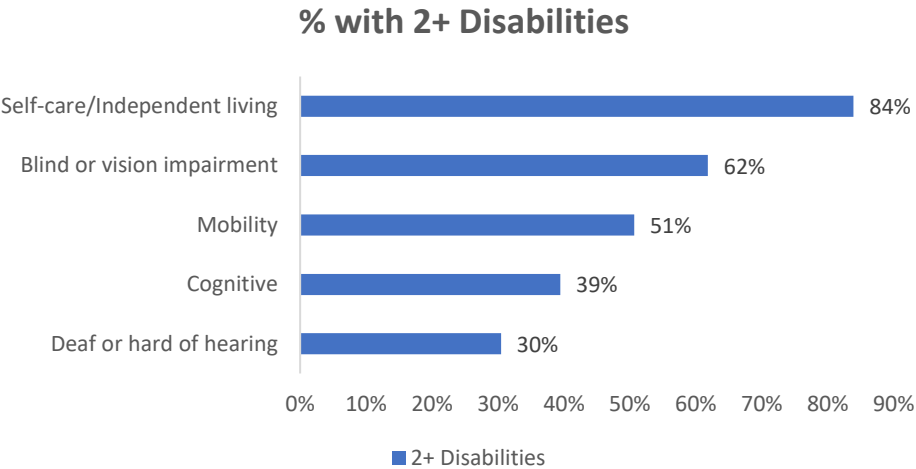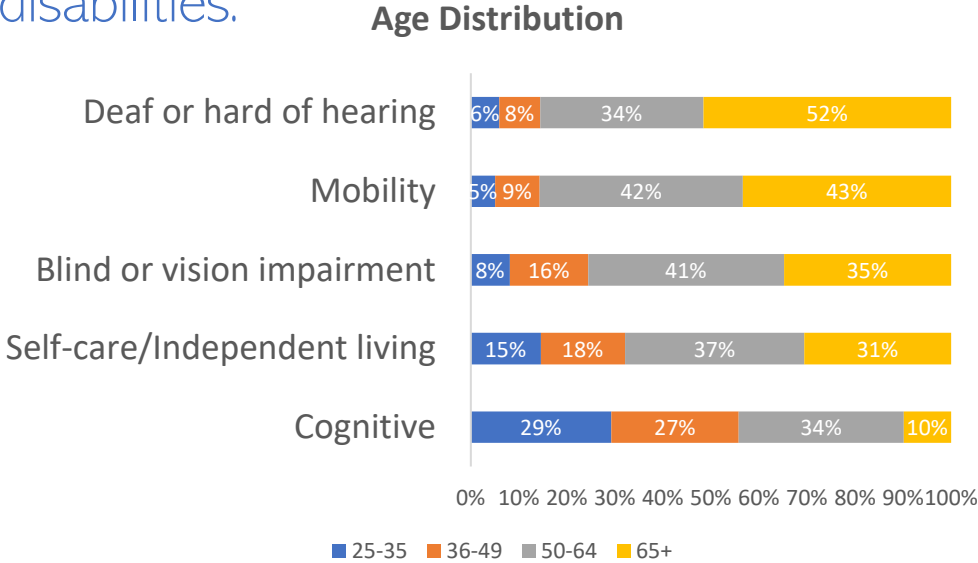
% with Median Income <$35K

Self-care/Independent living	52%
Blind or vision impairment	47%
Cognitive	40%
Mobility	38%
Deaf or hard of hearing	25%

0% 10% 20% 30% 40% 50% 60%

% with Less than College Education

Self-care/Independent living	54%
Mobility	47%
Cognitive	46%
Blind or vision impairment	44%
Deaf or hard of hearing	33%

0% 10% 20% 30% 40% 50% 60%

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DISABILITY: CONSIDERING MULTIPLE INTERSECTIONAL IDENTITIES

- While disability can occur at any age, disabilities are more common later in life.

- Age profiles differ by disability subgroups.

- Half (52%) of respondents who are deaf or hard of hearing are 65+ years of age, and nearly 1 in 3 (29%) respondents with a cognitive disability are 25-35 years of age.

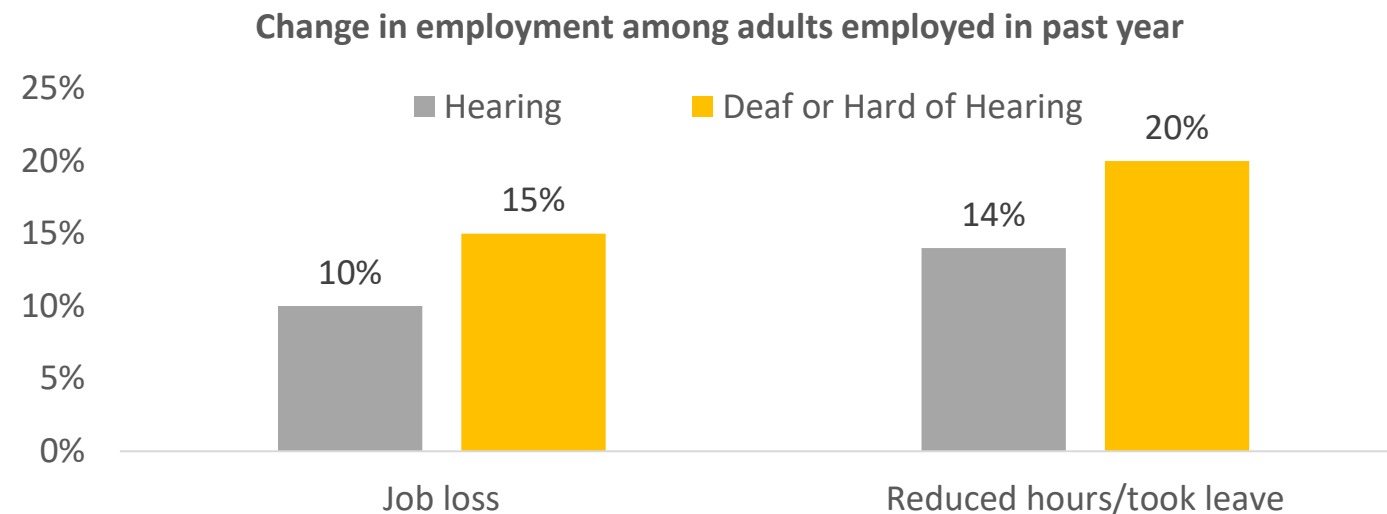- 8 in 10 (84%) respondents with a self-care or independent living disability have 2+ disabilities.

Age Distribution

Disability	25-35	36-49	50-64	65+
Deaf or hard of hearing	6%	8%	34%	52%
Mobility	5%	9%	42%	43%
Blind or vision impairment	8%	16%	41%	35%
Self-care/Independent living	15%	18%	37%	31%
Cognitive	29%	27%	34%	10%

■ 25-35 ■ 36-49 ■ 50-64 ■ 65+

% with 2+ Disabilities

Disability	2+ Disabilities
Self-care/Independent living	84%
Blind or vision impairment	62%
Mobility	51%
Cognitive	39%
Deaf or hard of hearing	30%

■ 2+ Disabilities

SPOTLIGHT
DEAF OR HARD OF HEARING

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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."***

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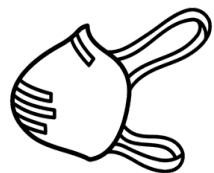# JOB LOSS AND ECONOMIC STRAIN AMONG DEAF AND HARD OF HEARING RESPONDENTS

- 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.

Change in employment among adults employed in past year

Legend: ■ Hearing ■ Deaf or Hard of Hearing

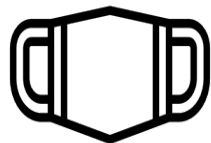|	Job loss	Reduced hours/took leave
Hearing	10%	14%
Deaf or Hard of Hearing	15%	20%

$p < 0.05$

*Indicates compared to hearing respondents
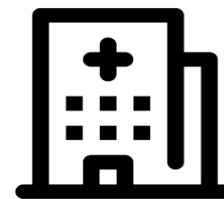
DEAF OR HARD OF HEARING & COVID-19

Face masks can reduce acoustic transmission & prevent lip reading for people with hearing loss

Face masks can be hard to wear and/or uncomfortable for people with hearing devices (e.g., hearing aid, cochlear implant)

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

Elective surgeries were postponed, which may include non-urgent ear surgeries

COVID-19 information may not be accessible to persons who are deaf or hard of hearing
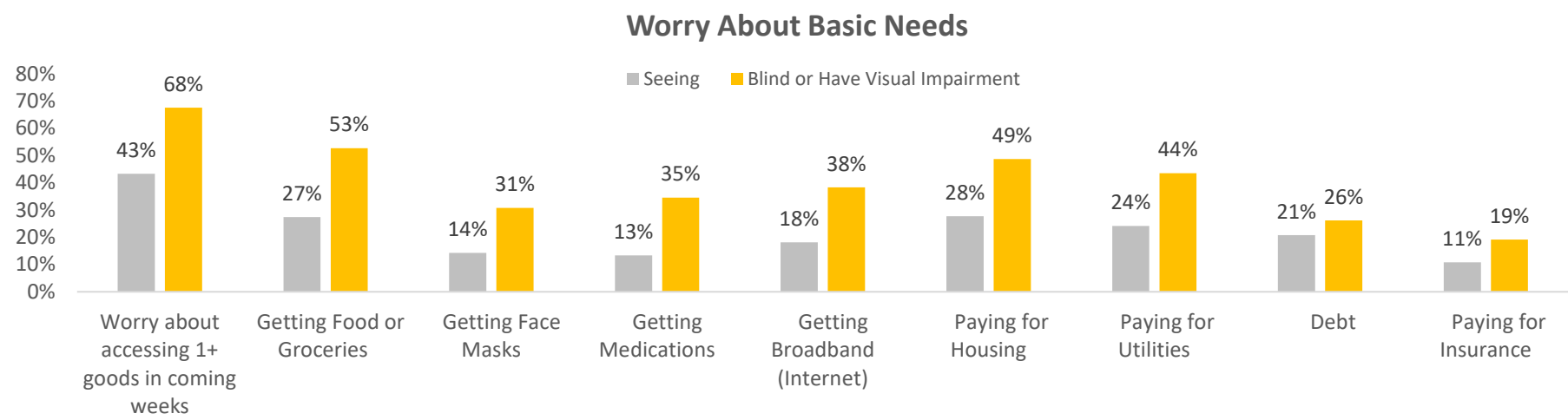
Drive-up testing is difficult if use transportation services

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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.

Worry About Basic Needs

■ Seeing   ■ Blind or Have Visual Impairment

Category	Seeing	Blind or Have Visual Impairment
Worry about accessing 1+ goods in coming weeks	43%	68%
Getting Food or Groceries	27%	53%
Getting Face Masks	14%	31%
Getting Medications	13%	35%
Getting Broadband (Internet)	18%	38%
Paying for Housing	28%	49%
Paying for Utilities	24%	44%
Debt	21%	26%
Paying for Insurance	11%	19%

p<0.05

*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

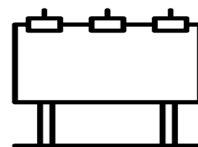Difficult to locate hand sanitizer stations

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

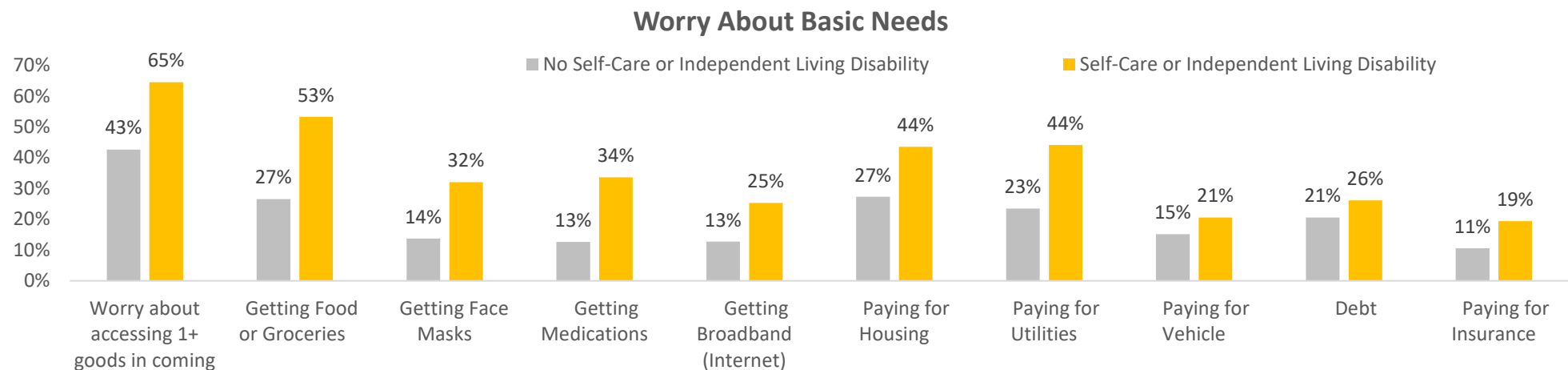Elective surgeries were postponed, which may include eye surgeries

Drive-up testing is difficult if use transportation services

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SPOTLIGHT
SELF-CARE OR INDEPENDENT LIVING DISABILITY

INEQUITIES IN MEETING BASIC NEEDS FOR RESPONDENTS WITH A SELF-CARE OR INDEPENENT 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.

Worry About Basic Needs

■ No Self-Care or Independent Living Disability   ■ Self-Care or Independent Living Disability

Category	No Self-Care or Independent Living Disability	Self-Care or Independent Living Disability
Worry about accessing 1+ goods in coming weeks	43%	65%
Getting Food or Groceries	27%	53%
Getting Face Masks	14%	32%
Getting Medications	13%	34%
Getting Broadband (Internet)	13%	25%
Paying for Housing	27%	44%
Paying for Utilities	23%	44%
Paying for Vehicle	15%	21%
Debt	21%	26%
Paying for Insurance	11%	19%

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p<0.001

*Indicates compared to respondents who do not have a self-care or independent living disability
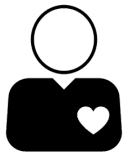
SELF-CARE OR INDEPENDENT LIVING DISABILITY & COVID-19

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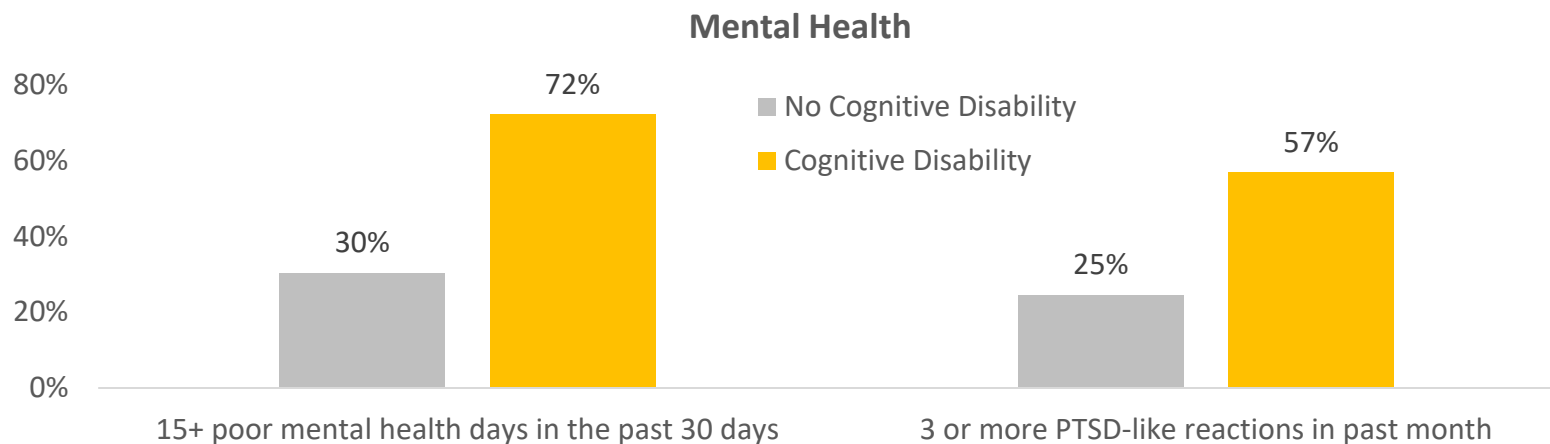
Barriers to following best practices for preventing virus exposure (e.g., handwashing, keeping 6 ft. distance, wearing masks)

SPOTLIGHT
COGNITIVE DISABILITY

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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.

Mental Health

	15+ poor mental health days in the past 30 days	3 or more PTSD-like reactions in past month
No Cognitive Disability	30%	25%
Cognitive Disability	72%	57%

*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-placed supports (e.g., day schools, respite centers) interrupted

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

Limitations on leaving supported living communities 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

Cognitive impairments may limit processing of information communicated

COVID-19 restrictions & limits on usual routine, connections, supports may be stressful, contribute to externalizing behaviors
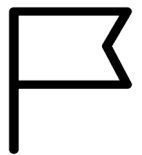
Deluge of information about COVID-19 may heighten anxiety, contribute to paranoid thinking and/or catalyze externalizing behaviors

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

May rely on others to process COVID-19 information & how to act upon information
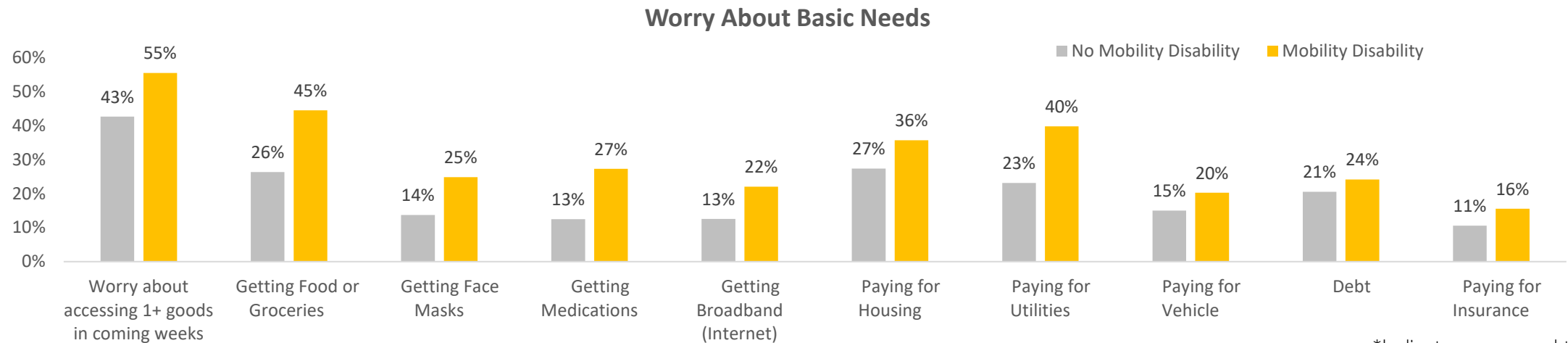
Abuse may be more difficult to detect by providers using remote communication or physical distancing

SPOTLIGHT
MOBILITY DISABILITY

- Respondents who have a cognitive 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.**

Worry About Basic Needs

No Mobility Disability / Mobility Disability

	Worry about accessing 1+ goods in coming weeks	Getting Food or Groceries	Getting Face Masks	Getting Medications	Getting Broadband (Internet)	Paying for Housing	Paying for Utilities	Paying for Vehicle	Debt	Paying for Insurance
No Mobility Disability	43%	26%	14%	13%	13%	27%	23%	15%	21%	11%
Mobility Disability	55%	45%	25%	27%	22%	36%	40%	20%	24%	16%

*Indicates compared to respondents who do not have a mobility disability
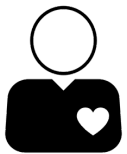
p<0.001

MOBILITY DISABILITY & COVID-19

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)

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

WANT TO KNOW MORE?

Visit http://mass.gov/covidsurvey for more information on how residents of Massachusetts have been impacted by the pandemic and how we can all work together to turn these data into action!