

# SPECIAL REPORT

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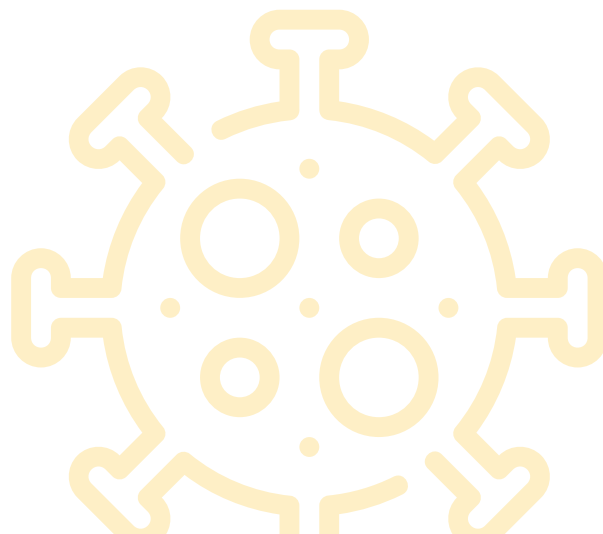
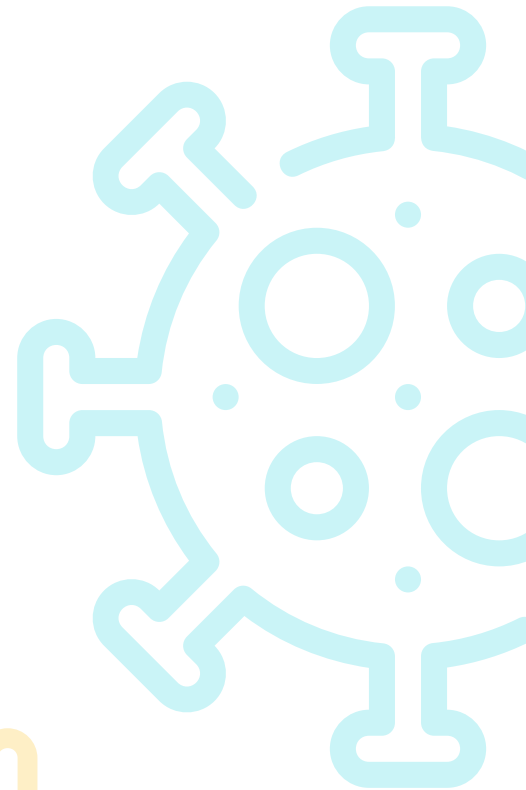
## COVID-19 and Autism

Impact on Needs, Health and Healthcare Costs

*March 2021*



autism speaks®



# A Year Disrupted

**The U.S. outbreak of the COVID-19 pandemic in March 2020 led to an immediate and widespread impact on people with autism.** While the coronavirus has touched people in every corner of the country and around the globe, for people with autism and their families, the effects of the pandemic have been profound. As we find in the following analyses, the basic needs, health and economic impacts of COVID-19 on people with an autism diagnosis are substantial, in some case more so than many other health conditions currently prioritized in public health policy. In particular, addressing food insecurity and accessibility of vaccines and vaccine information will be critical to supporting autistic people, who are bearing a substantial toll in terms of loss of life, health and costs of care. As we learn more about the health impacts of COVID-19 specifically for people with autism, both with and without other disabilities, we urge support for policies that protect this vulnerable population.


Over the last year, we monitored incoming requests to our Autism Response Team (team members specially trained to provide personalized information and resources to people with autism and their families), as well as feedback from community advocates and the work of scientists in the field to understand the needs and priorities of autistic people and their families during a rapidly evolving situation. When schools, communities, states and regions closed, children and adults with autism and their families experienced a cascade of disruptions – to critical services, healthcare, learning supports, employment and direct care for those with significant support needs.

People with autism of all ages and levels of support need were often not able to get necessary services, whether at a health facility or at school. These losses could ultimately impact their continued development and later outcomes in health, quality of life, education and employment. Many autistic adults lost employment and education opportunities in addition to routine supports to access those opportunities. Our organization produced, vetted and shared tools and resources for specific needs, according to the current stage of the pandemic, that people with autism and their families could use to navigate these massive changes to daily public life.

After our initial effort to address these needs got under way, the autism science community, including Autism Speaks, set out to understand where the community's needs have been greatest. By January 2021, most of what the field had learned about COVID-19's impact on autistic people was not specific to autism. Without evidence to show specific adverse health impacts of COVID-19 on autistic people, the federal Advisory Committee on Immunization Practices did not explicitly include people with autism in the first priority access groups to the vaccine authorized in December 2020. While some states have since widened priority groups to include people with disabilities in their state rollout plans, barriers in access to vaccines persist for the autism community and in racial and ethnic minority households. In a series of community surveys and analysis of other key data sources, our research reveals stark disparities in the health and well-being of autistic people in the U.S. due to COVID-19, particularly in minority communities.

We offer the following novel findings to contribute to a better understanding of our community's unique challenges a year into the pandemic, and to outline ways we can support those with autism moving forward. Autism Speaks is committed to serving the autism community through these challenging times.

Stay safe and healthy,



**Thomas Frazier, Ph.D.**  
Chief Science Officer



**Valerie Paradiz, Ph.D.**  
Vice President, Services and Supports



**Andy Shih, Ph.D.**  
Senior Vice President,  
Public Health and Inclusion



**Stuart Spielman, Esq.**  
Senior Vice President, Advocacy

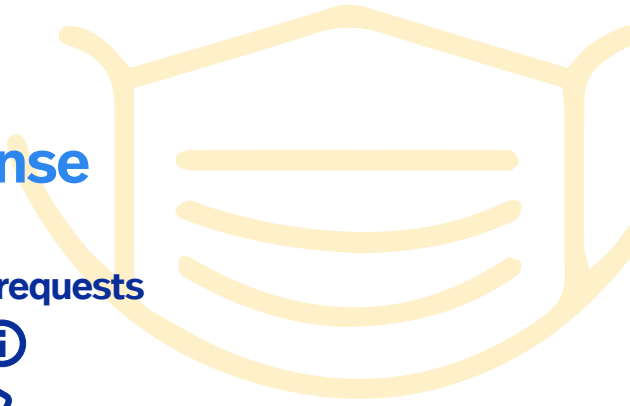
## COVID-19 IMPACTS ON THE AUTISM COMMUNITY

- Lack of access to healthcare and therapies
- Lack of access to education supports
- Disrupted routines
- Unemployment
- Challenges with mask-wearing, social distancing and other public health measures
- More food and housing insecurity, especially among minority households
- Adverse health outcomes from COVID-19 infection
- Barriers to accessing vaccines and overall vaccine hesitancy

# COVID-19 Needs and Our Response

## Saw significant increase in Autism Response Team requests for assistance during lockdown, focusing on

- *financial assistance*
- *education and IEP help*
- *behavioral resources*
- *family supports*



### Directly funded community needs through:

- more than **\$303,000 in 904 Autism Speaks Cares grants** to families, including additional funding secured from donors to meet a surge in financial need
- more than **\$600,000 in community grants** with a focus on recreational providers supporting access for traditionally underserved groups



### Successfully advocated in many states to allow access to a support person

for people with disabilities, including autism, when receiving health services to ensure they could participate in their healthcare decision-making



### Convened an Autism Research Community COVID-19 Task Force

to tap the rich knowledge and expertise of autism researchers, many of whose research was also on hold during the coronavirus outbreak



### Supported 2,600 contacts with COVID-19-specific needs

through our Autism Response Team, 50 percent of which sought financial support



### Hosted 26 state-level Advocacy webinars and 26 Services & Supports webinars with our Outreach team

to support individuals and families through sharing information and resources from federal and state governments as well as Autism Speaks



### Hosted provider and family webinars and family telementoring series

through the Autism Learning Health Network to support individuals, families and providers in continuing clinical care during the pandemic



### Successfully advocated for \$12.6 billion in emergency relief

for home and community-based services (HCBS), \$3 billion in special education funding and additional \$1,400 stimulus payments for dependents over the age of 16 included in the American Rescue Plan



### Produced videos, social stories and other critical supports

for autistic adults and children around mask-wearing, social distancing, adapting to new routines and other areas of need



### Built database to house and share 850 COVID-19 resources

for the autism community



### Joined Autism Society of America, Autism Science Foundation and other disability groups

in calling for priority access to COVID-19 vaccines for people with autism and other developmental disabilities



### Accelerated publication of 6 Caregiver Quick Tips videos

based on WHO Caregiver Skills Training program, to support learning and development through everyday home routines and play



### Supported extending the expanded telehealth services

for autism services and supports and other flexibilities established during COVID-19 pandemic



### Hosted an Autism and COVID Vaccines webinar

with the CDC, Autism Society of America and Autism Science Foundation to provide evidence-based vaccine information and support

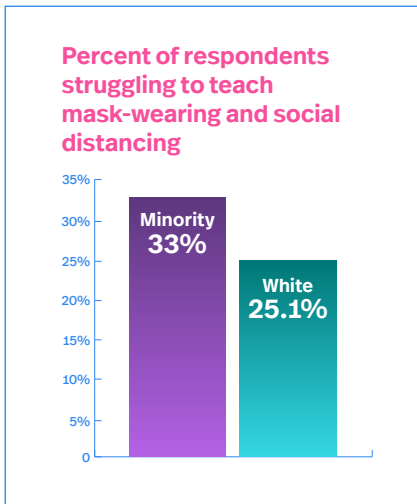


# COVID-19 Needs Assessment Survey

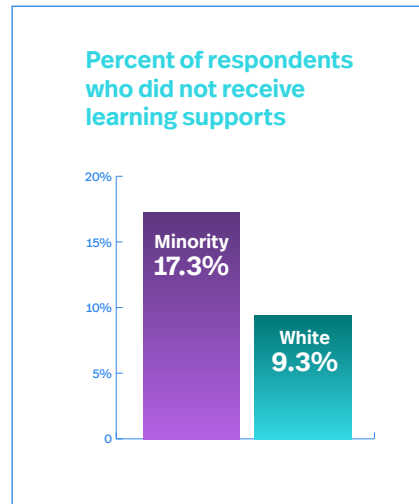
## Phase 1: May 2020

Two months into the pandemic, we surveyed people with autism and their families to find out how the pandemic is affecting them, in the first autism-specific COVID-19 survey to include a broad minority population. We asked about a range of challenges and found that people with autism and their families were struggling with new public health measures, education and having their basic needs met. Here's what we learned:

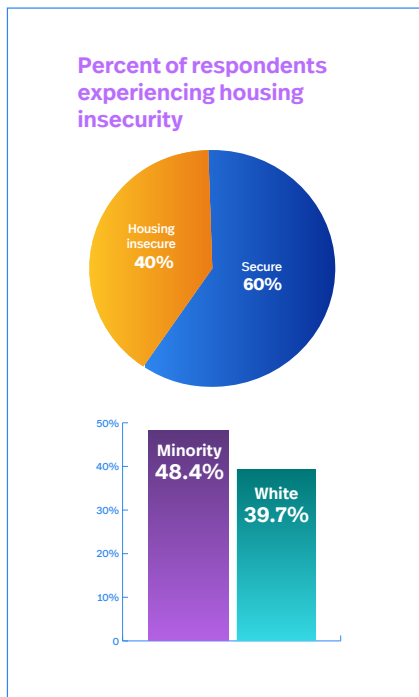
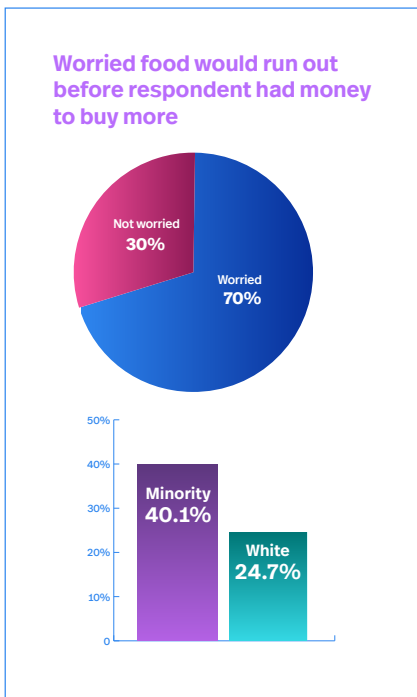
**FINDING:** Households of people with autism struggled with teaching health and safety behaviors.



**FINDING:** Households of people with autism struggled with receiving learning supports.



**FINDING:** Households of people with autism struggled with meeting basic needs like food and housing.



# COVID-19 Needs Assessment Survey

## Phase 2: December 2020

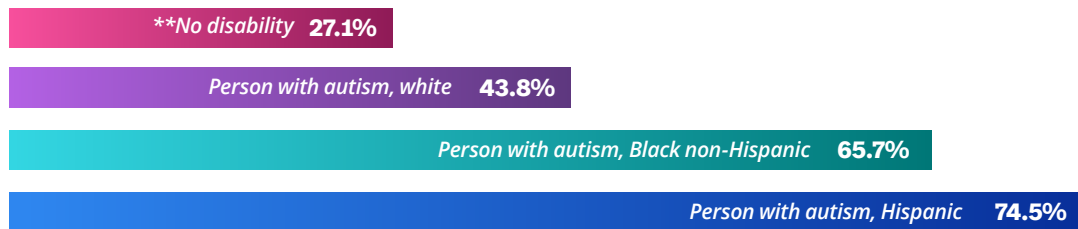
In November and December of 2020, we sent a follow-up survey to a larger group of recipients. This time, we asked even more detailed questions about how they were being affected by the pandemic, where they live and their situations. This helped us understand more about who is experiencing the most hardship due to COVID-19 so that we can focus our efforts on outreach and support into those communities. Here's what we learned:

**FINDING:** *Households of people with autism are experiencing significant food insecurity, especially minority households, compared to households with no disability.*

### HOUSEHOLD FOOD INSECURITY RATES BEFORE AND AFTER COVID-19

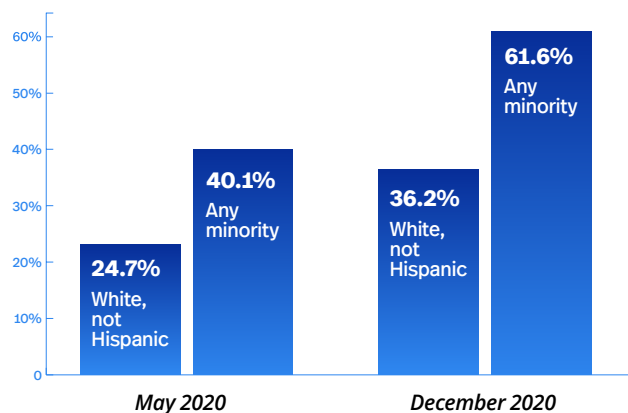


### HOUSEHOLD FOOD INSECURITY RATES, FALL 2020



**FINDING:** *Food insecurity, measured as worry about food running out before having money to buy more, worsened between May and December 2020 for households of people with autism, and substantially more so in minority households.*

### HOUSEHOLD FOOD INSECURITY INCREASES



Source except where noted: *Food Insecurity in Households of People with Autism Spectrum Disorder During the COVID-19 Pandemic, Autism Speaks, December 2020.*  
\*Source: Karpur A, Vasudevan V, Frazier T, Shih A, Lello A. *Food Insecurity in the Households of Children with Autism Spectrum Disorders and Intellectual Disabilities in the U.S.: Analysis of the National Survey of Children's Health Data 2016 - 2018. Autism. (in review).*  
\*\*Source: <https://disabilitycompendium.org/event>

**FINDING: Food insecurity impacts certain households of people with autism more:**

**FOOD INSECURITY BY INCOME**



**80%** of respondents <200% Federal poverty level were food insecure



**35.9%** of respondents >200% Federal poverty level were food insecure

**FOOD INSECURITY BY RACE**



**74.5%** of Hispanic households with autism were food insecure



**65.7%** of Black non-Hispanic households with autism were food insecure



**43.8%** of white households with autism were food insecure

**FOOD INSECURITY BY NEIGHBORHOOD TYPE**



**64.9%** of urban households with autism were food insecure



**62.1%** of rural households with autism were food insecure



**41.3%** of suburban households with autism were food insecure

**FOOD INSECURITY BY SUPPORT LEVEL**



**58.6%** of households with significant support needs were food insecure



**49.1%** of households with moderate support needs were food insecure



**43.5%** of households with few support needs were food insecure



# COVID-19 and Autism: Health and Economic Impact

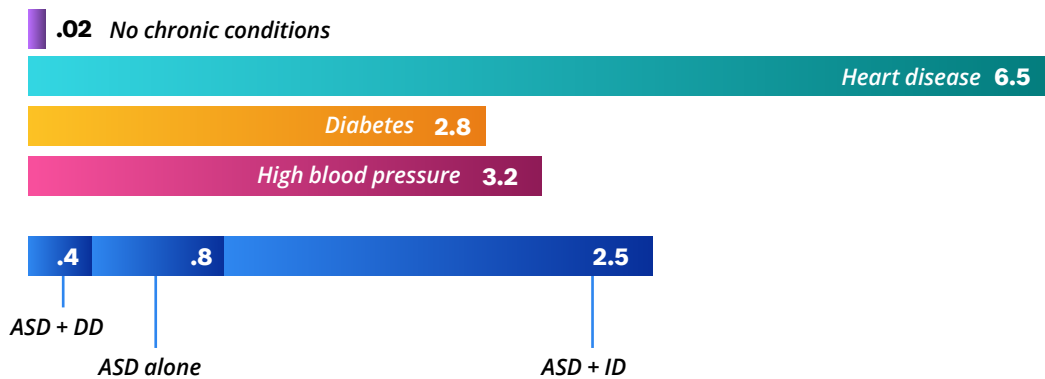
## Analysis of Private Health Insurance Claims Data

When deciding about priority access to the COVID-19 vaccines, officials used evidence showing risks for death and severe disease based on certain factors like health conditions and exposure risks. Much of what we know about the health risks of COVID-19 for autistic people are not specific to autism. Instead, we've learned over the last year that people with autism who live in residential settings with many other people, which we call congregate facilities, are more likely to contract COVID-19, much like older people in nursing homes. Also, people with autism have higher rates of underlying health conditions that put them at risk for severe disease if they get COVID-19. Some states have found people with intellectual disability, some of whom also have autism, may have a greater risk of dying from COVID-19 if they become infected. For people who need direct support, that also comes with greater exposure risk because service providers often see multiple people in a day or a week and close contact is unavoidable.

Without data to show a greater risk specifically for people with autism, people with an autism diagnosis were not explicitly included in the first priority group recommendations. To fill this gap, Autism Speaks partnered with FAIR Health, a nonprofit collector of private hospital insurance claims data. Using their dataset about COVID-19 hospitalizations, we set out to uncover the health impacts of COVID-19 on people with autism and related conditions. Here's what we learned.

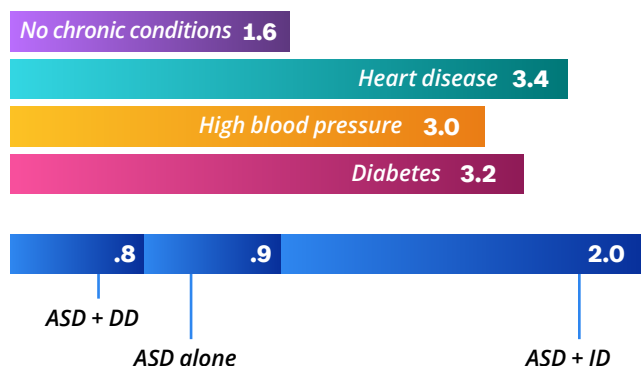
**FINDING: A greater percentage of people with autism, alone or with intellectual or developmental disability, died from COVID-19 than people with no chronic conditions.**

### DEATH FOLLOWING HOSPITALIZATION FROM COVID-19



**FINDING: People with autism and intellectual disability had higher COVID-19 infection than people with no chronic conditions, and just slightly lower than those with other chronic conditions.**

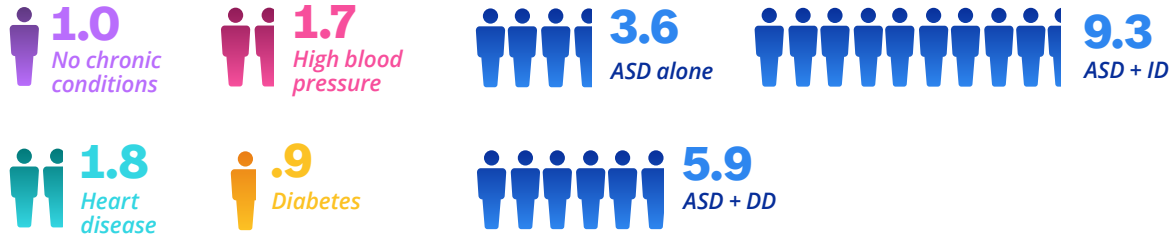
### PREVALENCE OF COVID-19 INFECTION



Even though people with autism had lower prevalence of COVID-19 infection compared with people with other health conditions, they had substantially higher risk for hospitalization when they did have COVID-19 infection.

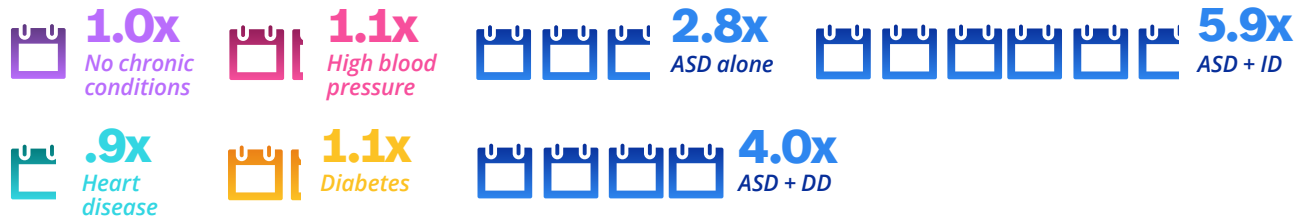
**FINDING:** People with autism, alone or with intellectual or developmental disability, were substantially more likely than those with other chronic conditions to be hospitalized with COVID-19. People with autism and intellectual disability were the most likely to be hospitalized.

**LIKELIHOOD TO BE HOSPITALIZED FROM COVID-19**



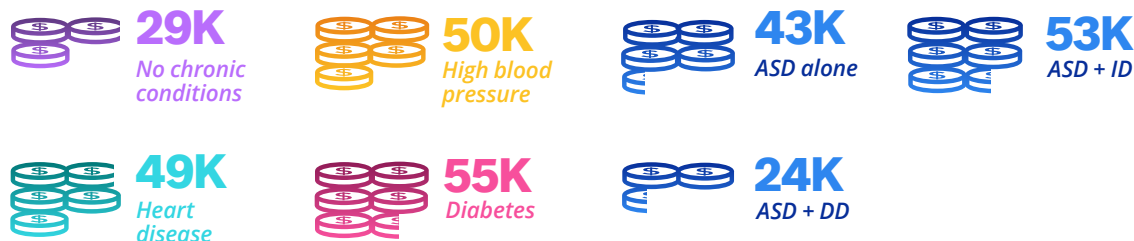
**FINDING:** People with autism, alone or with intellectual or developmental disability, were all more likely than those with other chronic conditions to have a longer than average hospital stay with COVID-19 infection. People with autism and intellectual disability were the most likely group to have a longer than average hospital stay.

**LIKELIHOOD TO HAVE A LONGER THAN AVERAGE HOSPITAL STAY FROM COVID-19**



**FINDING:** People with autism, alone or with intellectual disability, were among the top five groups with above-average charges for a hospital stay with COVID-19 infection. People with autism and intellectual disability had the third-highest average hospital charges among hospitalized patients with COVID-19.

**AVERAGE (MEDIAN) CHARGE FOR HOSPITAL STAY FROM COVID-19**





# What's Next?

Autism Speaks is continuing to monitor the impact of COVID-19 on our community and advocate for ways to improve the health, well-being and quality of life for people with autism and their families through sound research, targeted services and supports, and advocacy at the state and federal level.

## *In 2021, Autism Speaks will support the autism community by:*

- Working to encourage officials to equitably implement discretionary COVID-related funding in the American Rescue Plan to support people with autism and their families
- Supporting students with autism to receive the resources and tools necessary to recover and access learning opportunities and educational services
- Supporting prioritization of people with autism for vaccine access
- Supporting increased availability and reliable access to approved vaccines and accessible, evidence based information for people with autism, their caregivers and their service providers
- Supporting additional measures to address food insecurity and leverage school and community infrastructure to deliver food resources where our community is accessing free food
- Providing solutions to address employment disparities for autistic workers
- Supporting Home- and Community-Based Services and related programs that support autistic adults receiving needed services in their communities

