

## COVID-19 and the Autism Community: Impact and Lessons Learned

COVID-19 (coronavirus disease 2019) is an infectious disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Since its discovery in Wuhan, China, in December 2019, COVID-19 has rapidly spread around the world and was declared by the [World Health Organization \(WHO\)](#) as a global pandemic on March 11, 2020. COVID-19 can cause severe flu-like symptoms and has led to significant loss of life. Over one million people have died from the disease in the United States alone, and over 6.5 million have died worldwide. The COVID-19 pandemic has changed the world in profound ways, and people around the globe adjusted everyday living to limit the spread of the virus, causing both social and economic disruptions, including loss of livelihood and increased symptoms of depression, anxiety, insomnia, and stress.

For the autism community, the pandemic has posed additional concerns and hardships as individuals on the autism spectrum and people with disabilities in general have been reported to be at increased risk of contracting COVID-19 and experiencing additional mental health and daily living challenges due to sudden changes in routine and loss of needed services. The pandemic exacerbated existing shortages of health care providers, educators, and other direct care workers who interact with autistic individuals and provide services. Stay-at-home orders also increased strain on family caregivers and reduced opportunities for respite. On a more positive note, the COVID-19 pandemic has provided an opportunity to learn about what kinds of accommodations are feasible and work for the autism community during public health emergencies. These lessons can be applied not only to future public health crises and natural disasters but also in the immediate future to ensure that the autism community has access to more effective and improved services and supports to improve health and well-being.

### Impact of COVID-19 on Physical and Mental Health

[COVID-19 symptoms](#) include fever or chills, cough, shortness of breath or difficulty breathing, and fatigue, among many others. Symptoms can range from mild to severe. The [Centers for Disease Control and Prevention \(CDC\)](#) defines severe outcomes as hospitalization, admission to the intensive care unit (ICU), intubation or mechanical ventilation, or death. While [age](#) is the strongest predictor for severe disease, other factors such as certain underlying health conditions and living in congregate settings can also increase the risk of COVID-19 infection and severe outcomes. For example, intellectual and developmental disabilities (IDD),<sup>1, 2</sup> attention-deficit/hyperactivity disorder (ADHD),<sup>3</sup> depression,<sup>4</sup> and schizophrenia spectrum disorders<sup>3</sup> have all been shown to lead to higher risk for severe COVID-19 outcomes. Additionally, studies show that adults with IDD living in congregate settings are at greater risk of contracting COVID-19 compared to the general population.<sup>5</sup> A recent [report](#) by the National Council on Disability examined several of the negative impacts of the COVID-19 pandemic on people with disabilities, including the high death toll among individuals with disabilities living in congregate settings, and called for the strengthening of supports available through Home and Community Based Services waivers and a “Community Living Bias” to protect individuals with disabilities from being disproportionately endangered in future public health emergencies.

Individuals on the autism spectrum may be at increased risk of COVID-19 infection and hospitalization as they often have co-occurring ADHD, IDD, or other physical and mental health conditions and may live in congregate settings.<sup>6-8</sup> Indeed, one study conducted in Israel found higher rates of COVID-19 infection and greater odds for hospitalization for autistic men but not women.<sup>9</sup> A study using data from one of the

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United States' largest databases of private insurance claim records found that individuals with autism and intellectual disability were nine times more likely to be hospitalized following COVID-19 infection compared to those without autism and intellectual disability.<sup>10</sup> However, more research is needed on whether these results are generalizable to autistic individuals across the United States and what specific factors lead to increased risk for COVID-19, controlling for gender, co-occurring conditions, and differences in housing. As we move towards the next phase of the pandemic, it will be important to assess which individuals on the autism spectrum are at higher risk of contracting COVID-19 and severe disease and how to minimize risk and infection.

Some individuals infected with SARS-CoV-2 also experience long-term health effects known as "long COVID." Commonly reported symptoms of long COVID include fatigue that interferes with daily life and symptoms that worsen with physical or mental exertion. In addition, long COVID is associated with respiratory, cardiovascular, neurological, and digestive symptoms. These symptoms can last anywhere from weeks to years and are more common in individuals with severe COVID-19 illness or underlying health conditions prior to COVID-19. A preliminary study indicates that a history of anxiety disorder is associated with higher risk for long COVID.<sup>11</sup> Given that many autistic individuals have co-occurring anxiety and other conditions, it will be important to conduct epidemiological research to determine whether individuals on the autism spectrum are at increased risk for long COVID. Research to identify biological and molecular markers is also important to accurately diagnose long COVID and provide needed treatments and supports, particularly for individuals on the autism spectrum who may not be able to clearly communicate their symptoms.

In addition to how COVID-19 directly impacts autistic individuals, it is important to consider how COVID-19 infection during pregnancy may contribute to possible autism development in the offspring. Previous studies have shown that maternal immune activation and prenatal infection can increase the odds of developing autism.<sup>12, 13</sup> Viruses such as Zika, Influenza A, and Cytomegalovirus are already known to affect brain development in offspring.<sup>14</sup> Maternal COVID-19 infection increases risk of preterm births and neonatal intensive care unit admissions,<sup>15</sup> though vertical transmission of SARS-CoV-2 from the mother to the fetus is rare.<sup>15, 16</sup> A study with 222 mothers who tested positive for COVID-19 during pregnancy early in the pandemic found that their children were more likely to receive a neurodevelopmental diagnosis in the first year after birth.<sup>17</sup> However, it is unclear if severity of COVID-19 disease is associated with neurodevelopmental outcomes or how vaccines (which were not available at the time of the study) or new SARS-CoV-2 variants may affect these results. Since SARS-CoV-2 is a new virus, it is also unknown how COVID-19 may impact child development beyond the first year. Future longitudinal studies with larger study populations are needed to determine whether and how prenatal infection and maternal infection may impact neurodevelopment and/or development of autism in the offspring.

During the pandemic, the issue of healthcare rationing and discrimination against people with disabilities in prioritization for healthcare came into the spotlight. Devaluation of the lives of people with disabilities has often been used as a rationale to de-prioritize them for intervention when availability is limited<sup>18</sup>. Healthcare resources were scarce at the beginning of the pandemic, and many places implemented Crisis Standards of Care (CSC) in an attempt to allocate resources fairly. A review of CSC from 29 states in the US found that half listed equity as a guiding principle, and approximately 66% said that decisions should not factor in disability, race, ethnicity, and other identity-based factors.<sup>19</sup>

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Internationally, a review of 21 guidelines from other countries found that only one explicitly precluded using disability as an exclusion criterion for care.<sup>20</sup> Additionally, a literature review of public preferences for allocation of scarce medical resources found bias against giving preference to patients with disabilities or frailty and that approaches based on egalitarian principles received the least amount of support.<sup>21</sup> These attitudes and guidelines highlight some of the discrimination and ableism faced by individuals with disabilities, including individuals on the autism spectrum. Individuals with disabilities were also unable to access vaccination earlier in the pandemic due to lack of consideration for accommodations to enable disability access. In the case of autism, however, the CDC and many community organizations such as the Eagles Autism Foundation and the Autism Society developed autism/sensory-friendly vaccination clinics to facilitate access for autistic individuals and their families to COVID-19 vaccines. Eventually, sensory-friendly vaccine clinics were launched in many locations across the nation in an example of what can be accomplished through awareness and community partnerships. In the future, policies surrounding allocation of scarce resources and access to care must have equity as a major component so that all individuals can be provided with life-saving care, regardless of ability or disability.

### COVID-19 Mitigation Efforts and the Autism Community

COVID-19 mitigation efforts have mainly focused on three methods: vaccination, the wearing of face masks, and physical distancing. While these methods are effective at limiting the spread of COVID-19, guidance on proper mitigation efforts over the course of the pandemic has changed rapidly and can be difficult to follow, particularly for individuals with intellectual and other disabilities. In addition, for some people with disabilities, mask-wearing presented a challenge for sensory reasons, mental health-related reasons, or due to an intellectual disability. For future public health emergencies, public health authorities should ensure that new policies surrounding mitigation efforts and public health plans are developed in partnership with people with disabilities and the welfare of all vulnerable groups are considered during the development process. Accommodations should be developed for those who may for reasons of their disability be unable to wear a mask or a certain type of mask. Alternative mitigation strategies or accommodations should be put in place during planning. Information surrounding mitigation efforts also must be accessible for everyone, including those with intellectual and other disabilities and in other underserved communities.

Vaccination is currently the primary method to prevent COVID-19 infection and severe disease. A survey of autistic adults found that 78% of respondents reported having received or planning to receive a COVID-19 vaccine, with 55% having received at least one dose.<sup>22</sup> This was higher than the 42% vaccination rate in the total population at the time, indicating that autistic adults were more likely to be receptive to the COVID-19 vaccine as compared to the general population. However, despite these high numbers and numerous studies showing the safety and efficacy of COVID-19 vaccines,<sup>23</sup> anti-vaccine rhetoric continues to drive vaccine hesitancy.<sup>24</sup> Among those not planning on receiving a COVID-19 vaccine, most were concerned about vaccine safety and about one-third reported they were not worried about contracting COVID-19.<sup>22</sup> In addition, a survey of parents of children on autism spectrum found that only 35% of parents intended to vaccinate their child against COVID-19.<sup>25</sup> These parents reported a higher level of belief in vaccine harm compared to the national average. Additional research is needed on whether these survey results are representative of the autism community across the United States and whether there have been any changes in attitude with time. Given that autistic individuals may be at higher risk of COVID-19 infection and severe disease, it will also be crucial to understand how to

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combat misinformation surrounding COVID-19 and vaccine safety and efficacy to promote vaccine uptake among those who are hesitant and at risk. Collaborative efforts to make vaccines and available treatments accessible for autistic people who may have sensory or executive functioning difficulties that make it hard to make or get to vaccination appointments will also be critical for COVID-19 mitigation in the autism community.

Since the start of the pandemic, public health authorities around the world have advocated, and at times mandated, the use of face masks to limit the spread of COVID-19. A cloth mask can lower the odds of contracting COVID-19 by 56% in indoor public settings, and an N95 or KN95 respirator can lower the odds by 83%.<sup>26</sup> However, face masks can affect recognition of facial expressions,<sup>27</sup> making social interactions more difficult, especially for autistic individuals. Additionally, face masks may not be well tolerated by those on the autism spectrum, particularly those with sensory difficulties. Children on the autism spectrum may not understand why face masks are necessary and therefore have challenges in wearing face masks. While a handful of studies have explored how to improve tolerance of face coverings for children on the autism spectrum,<sup>28-31</sup> more research is needed to evaluate how to improve tolerance for face masks among both children and adults. Further research is also needed to develop, improve, and evaluate additional tools to overcome the sensory and social communication limitations of face masks.

In addition to vaccination and face masks, physical distancing and limiting contact with individuals who may be infected by SARS-CoV-2 has played a critical part in containing COVID-19. However, this has arguably had the largest effect on everyday life. Efforts to limit in-person contact led to the closure of schools and many businesses. For many autistic individuals and their families, this has meant the loss of or reduced access to diagnostic and screening services, in-school services, housing and support services, and healthcare services.<sup>32-34</sup> Families reported that children on the autism spectrum experienced a loss in developmental progress and communication and learning skills and an increase in challenging behaviors during this time.<sup>33, 35</sup> In addition, the pandemic led to increased caregiver stress and feelings of isolation and loneliness and other mental health challenges for many autistic individuals and their families.<sup>36-38</sup>

While research has explored the short-term impact of the COVID-19 pandemic on the autism community, it will be important to monitor how the pandemic affects service access and the mental and physical health of people on the autism spectrum and their families in the long term. Future research is needed to assess the long-term impacts of the COVID-19 pandemic on autism traits, including social development, learning, and communication. In addition, studies are needed on how social isolation in early childhood may affect autism traits and quality of life outcomes. As the pandemic has progressed, research is needed to evaluate the long-term effects of the pandemic on mental health, including feelings of isolation and loneliness, depression, and suicidality. Studies are also needed on how to better support mental health and promote resilience in autistic individuals and their families, including how to alleviate caregiver stress, for the duration of the COVID-19 pandemic and in future public health emergencies. In addition, autistic individuals may have settled into a “pandemic routine” and may be anxious at returning to the physical workplace or school as pandemic restrictions lift. Therefore, research on how to reduce anxiety and ensure a smoother transition is also necessary.

Economic hardship has also been reported as individuals on the autism spectrum and caregivers reported loss of employment and heightened food insecurity.<sup>33, 39</sup> The pandemic also highlighted the

disparities faced by those in underserved communities, as people with lower income and members of racial and ethnic minorities have an even more difficult time accessing needed support and healthcare services.<sup>33</sup> Importantly, research is needed on how to improve equity and access to services, care, and supports for all individuals across the autism spectrum and across the lifespan, particularly for individuals and families from underserved communities. Research is also needed to fully evaluate the impacts of the pandemic and extract lessons learned that can be applied to future national or global disruptions of a similar nature. Efforts by government bodies to plan for future public health emergencies must include consideration of individuals with disabilities. The establishment of the [National Advisory Committee on Individuals with Disabilities and Disasters](#) within the U.S. Department of Health and Human Services is a step in this direction that will help ensure planning to meet the needs of people with disabilities in future disasters and public health emergencies.

### Remote Technology and Accessibility During the Pandemic

The COVID-19 pandemic allowed the development of a grand global experiment with remote technologies to help maintain continuity of activities and services, especially during earlier days during the pandemic when people in many countries were encouraged or required to stay home to reduce the spread of the virus. For people with disabilities, remote technology enabled the continuation of some services and supports throughout the pandemic. For example, telehealth services allowed for the continued diagnosis and screening of children with autism.<sup>40-42</sup> Additionally, some healthcare providers used telehealth platforms to provide needed services for individuals on the autism spectrum.<sup>33, 34, 43</sup> Schools also took advantage of virtual platforms to allow children to continue receiving educational instruction, and some workplaces also shifted to remote work to allow for physical distancing and prevent the spread of COVID-19.

Some autistic individuals have indicated that remote schooling and work have been a welcome change, as it allows for more control over individual environments and fewer sensory and social challenges.<sup>44</sup> However, remote options did not benefit all individuals on the autism spectrum. Some individuals on the autism spectrum, including some living in care facilities, and their families may not have access to the technology necessary for remote school, work, and telehealth.<sup>33, 44</sup> Others found that the shift to a remote environment increased isolation, disrupted previously established routines, and caused anxiety and stress.<sup>44</sup> Still others indicated that telehealth services and virtual classrooms did not achieve the same level of effectiveness as in-person appointments and education.<sup>33, 35, 41, 44</sup> For others, however, use of remote technologies and options to telework increased opportunity for inclusion and engagement in work and connection with colleagues and friends<sup>38</sup>. Some people with disabilities reported being more at ease in a remote environment where they could control sensory inputs and felt reduced social stress<sup>45</sup>.

As remote technologies continue to develop and be used, it will be necessary to increase access to stable internet connections and the hardware and software necessary to participate in and take advantage of virtual opportunities and communities. Additionally, research is needed to determine if telehealth services are just as effective as healthcare services and supports delivered in-person and how to best close any gaps in efficacy. Educational research is also needed to ensure that students receiving remote education are not at a disadvantage compared to students in the classroom. Continued innovations are necessary to take advantage of new remote technologies to improve services delivery for the autism community to maximize positive outcomes.

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Equally important, in-person services need to be available and safely accessible to individuals for whom remote options were not feasible or did not work well. Some in-home support services personnel and direct support staff personnel left the industry during the pandemic, leading to workforce shortages. Efforts are needed to attract and train additional staff so that home- and community-based services can resume and provide individuals on the autism spectrum with the services they need. These services are more critical than ever as some autistic individuals have lost caregivers due to COVID-19 and are now left with no support at home. Addressing the workforce shortages and delivering services and supports more efficiently will greatly improve the health and well-being of individuals on the autism spectrum.

With increased vaccine uptake in the general public, mitigation efforts have lessened, and mask mandates have been lifted in most settings. However, community transmission of COVID-19 remains at medium to high rates. This has forced many individuals on the autism spectrum who have autoimmune issues or other co-occurring conditions to remain at home and in physical isolation to protect themselves from severe disease. As we continue to navigate this transition period out of the pandemic, it is important to consider how to make in-person interactions in schools and communities safe for individuals with co-occurring conditions. Additionally, remote options must continue to be available when possible to accommodate those who may not be able to take advantage of in-person services and supports.

### The Impact of the COVID-19 Pandemic on Autism Research

In addition to its direct impact on individuals on the autism spectrum and their families, the COVID-19 pandemic also caused significant disruptions in scientific research. Many universities shut down research labs and halted studies and clinical trials with human subjects to comply with physical distancing requirements during at least part of the pandemic. Training modules and classes also shifted to virtual delivery methods. Research that continued largely shifted to focus on COVID-19-related experiments. These changes resulted in a sharp decline in the amount of time scientists spent on research early in the pandemic, and investigators initiated fewer new projects in 2020 compared to previous years, indicating the pandemic may have long-lasting effects on scientific research.<sup>46</sup> Indeed, the upcoming *2019-2020 IACC Autism Research Portfolio Analysis Report* found a \$20 million decrease in total autism funding from 2019 to 2020, which was due to less funding towards new autism projects.

Early career researchers and trainees have borne the brunt of the impact of the pandemic on autism research, citing fewer training opportunities, fewer chances to network and establish meaningful collaborations and mentorships, lack of funding and resources, and a decrease in the number of open positions for those on the job market.<sup>47, 48</sup> Increasing the amount of available funding for autism researchers, allowing funding extensions for current projects, providing institutional support, and adjusting tenure and promotion requirements can alleviate some of the strain felt by early career researchers and trainees. Implementing these changes will be necessary to prevent “a lost generation” of researchers who could greatly improve the health and well-being of people on the autism spectrum.

### Summary

The COVID-19 pandemic has impacted every part of life. The autism community may be especially vulnerable to COVID-19 infection and severe health outcomes due to common co-occurring conditions. However, autistic individuals may have difficulties with mitigation efforts such as getting vaccinated and wearing face masks due to sensory and other issues. Physical distancing also comes with its own

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challenges as it causes disruptions in needed services and leads to feelings of isolation and loneliness. While remote options such as telehealth and virtual schooling are viable and preferred for some members of the autism community, others have trouble adjusting or find that remote services are less effective compared to in-person interactions. Autism research has also suffered as scientists had to shut down experiments and halt clinical trials to comply with physical distancing requirements earlier in the pandemic, resulting in lowered productivity and fewer new projects, which may have long-lasting consequences. COVID-19 highlighted existing hardships and disparities experienced by the autism community. As the world emerges from the pandemic, policy makers and researchers must consider how to use the lessons learned during the pandemic to improve access to needed services and promote equity to improve health and well-being for all people on the autism spectrum across the lifespan.

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