

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 a million people have died from the disease in the United States alone. 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, and insomnia.

For the autism community, the effects of the pandemic may pose additional hardships as individuals on the autism spectrum may be at increased risk of contracting COVID-19 and experience additional mental health challenges due to sudden changes in routine and loss of needed services. The COVID-19 pandemic provides 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 quality of life.

COVID-19 and Physical 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),^{1, 2} attention-deficit/hyperactivity disorder (ADHD),³ depression,⁴ and schizophrenia spectrum disorders³ 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.⁵

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.⁶⁻⁸ Indeed, one study conducted in Israel found higher rates of COVID-19 infection and greater odds for hospitalization for autistic men but not women.⁹ A study using data from one of the nation's 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 disability¹⁰ 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.

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.^{11, 12} Viruses such as Zika, Influenza A, and Cytomegalovirus are already known to affect brain development in offspring.¹³ Maternal COVID-19 infection increases risk of preterm births and neonatal intensive care unit admissions,¹⁴ though vertical transmission of SARS-CoV-2 from the mother to the fetus is rare.^{14, 15} However, since SARS-CoV-2 is a new virus, it is unknown how COVID-19 impacts child development. Future longitudinal studies are needed to determine whether and how prenatal infection and maternal infection may impact neurodevelopment and development of autism in the offspring.

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 disabilities. For future public health emergencies, public health authorities should ensure that information surrounding mitigation efforts are accessible for everyone, including those with intellectual and other disabilities and in other underserved communities, and the welfare of all vulnerable groups need to be considered when developing new policies and public health plans.

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.¹⁶ 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,¹⁷ anti-vaccine rhetoric continue to drive vaccine hesitancy.¹⁸ 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-19.¹⁶ In addition, a survey of parents of children on autism spectrum found that only 35% of parents intended to vaccinate their child against COVID-19.¹⁹ 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 combat misinformation surrounding COVID-19 and vaccine safety and efficacy to promote vaccine uptake among those who are hesitant and at risk.

Since the start of the pandemic, public health authorities around the world have advocated and 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%.²⁰ However, face masks can affect recognition of facial expressions,²¹ making social interactions more difficult 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 to

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wearing face masks. While a handful of studies have explored how to improve tolerance of face coverings for children on the autism spectrum,²²⁻²⁵ 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 diagnostic and screening services, in-school services, housing and support services, and healthcare services.²⁶⁻²⁸ 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.^{27, 29} 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.³⁰⁻³²

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 was also reported as individuals on the autism spectrum and caregivers reported loss of employment and heightened food insecurity.^{27, 33} 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.²⁷ 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.

Remote technology has enabled the continuation of some services and supports throughout the pandemic. For example, telehealth services allowed for the continual diagnosis and screening of children with autism.³⁴⁻³⁶ Additionally, some healthcare providers used telehealth platforms to continue providing needed services for individuals on the autism spectrum.^{27, 28, 37} Schools also took advantage of virtual platforms to allow children to continue to receive 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.³⁸ However, remote options did not benefit all individuals on the autism spectrum. Some individuals on the autism spectrum and their families do not have access to the technology necessary for remote school and work and telehealth.^{27, 38} Others found that the shift to a remote environment disrupted previously established routines and caused anxiety and stress.³⁸ Still others indicated that telehealth services and virtual classrooms did not achieve the same level of effectiveness as in-person appointments and education.^{27, 29, 35, 38}

As remote technologies continue to develop and be used, it will be necessary to ensure that everyone has access to stable internet connections and the hardware and software necessary to participate in and take advantage of the virtual opportunities. Additionally, research is needed to ensure that telehealth services are just as effective as healthcare services and supports delivered in-person. Educational research is also needed to ensure that students receiving remote education is not at a disadvantage compared to students in the classroom. Finally, continued innovations are necessary to take advantage of new remote technologies to improve services delivery for the autism community to enhance quality of life.

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. 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 scientists initiated fewer new projects in 2020 compared to previous years, indicating the pandemic may have long-lasting effects on scientific research.³⁹ Indeed, the *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 and 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.^{40, 41} 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 quality of life 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 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, 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 quality of life for all people on the autism spectrum across the lifespan.

References

1. Koyama, A.K., et al., *Severe Outcomes, Readmission, and Length of Stay Among COVID-19 Patients with Intellectual and Developmental Disabilities*. International Journal of Infectious Diseases, 2022. **116**: p. 328-330.
2. Friedman, C., *The COVID-19 pandemic and quality of life outcomes of people with intellectual and developmental disabilities*. Disability and Health Journal, 2021. **14**(4): p. 101117.
3. Liu, N., et al., *Genetic Predisposition Between COVID-19 and Four Mental Illnesses: A Bidirectional, Two-Sample Mendelian Randomization Study*. Frontiers in psychiatry, 2021. **12**: p. 746276-746276.
4. Li, T., et al., *Association of mental health with clinical outcomes in hospitalized patients with moderate COVID-19*. Journal of Affective Disorders, 2022.
5. Landes, S.D., et al., *Risk Factors Associated With COVID-19 Outcomes Among People With Intellectual and Developmental Disabilities Receiving Residential Services*. JAMA Network Open, 2021. **4**(6): p. e2112862.
6. Schott, W., S. Tao, and L. Shea, *COVID-19 risk: Adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions*. Autism, 2021. **26**(4): p. 975-987.
7. Rosen, T.E., et al., *Co-occurring psychiatric conditions in autism spectrum disorder*. International Review of Psychiatry, 2018. **30**(1): p. 40-61.
8. Tye, C., et al., *Characterizing the Interplay Between Autism Spectrum Disorder and Comorbid Medical Conditions: An Integrative Review*. Frontiers in Psychiatry, 2019. **9**.
9. Krieger, I., et al., *COVID-19 Morbidity Among Individuals with Autistic Spectrum Disorder: A Matched Controlled Population-Based Study*. Journal of Autism and Developmental Disorders, 2021.
10. Karpur, A., et al., *Brief Report: Impact of COVID-19 in Individuals with Autism Spectrum Disorders: Analysis of a National Private Claims Insurance Database*. Journal of Autism and Developmental Disorders, 2021.
11. Paraschivescu, C., et al., *Cytokine changes associated with the maternal immune activation (MIA) model of autism: A penalized regression approach*. PLOS ONE, 2020. **15**(8): p. e0231609.
12. Brown, A.S., *Epidemiologic studies of exposure to prenatal infection and risk of schizophrenia and autism*. Developmental Neurobiology, 2012. **72**(10): p. 1272-1276.
13. Elgueta, D., et al., *Consequences of Viral Infection and Cytokine Production During Pregnancy on Brain Development in Offspring*. Frontiers in Immunology, 2022. **13**.
14. Vila-Candel, R., et al., *Obstetric–Neonatal Care during Birth and Postpartum in Symptomatic and Asymptomatic Women Infected with SARS-CoV-2: A Retrospective Multicenter Study*. International Journal of Environmental Research and Public Health, 2022. **19**(9): p. 5482.
15. Michailidou, D., et al., *The impact of COVID-19 during pregnancy on maternal and neonatal outcomes: a systematic review*. EMBnet.journal, 2021. **26**(1): p. e969.

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16. Shea, L.L., et al., *Self-reported COVID-19 vaccination acceptance and hesitancy among autistic adults*. *Vaccine*, 2022. **40**(24): p. 3288-3293.
17. Asghar, N., et al., *Safety, efficacy, and immunogenicity of COVID-19 vaccines; a systematic review*. *Immunological Medicine*, 2022: p. 1-13.
18. Pullan, S. and M. Dey, *Vaccine hesitancy and anti-vaccination in the time of COVID-19: A Google Trends analysis*. *Vaccine*, 2021. **39**(14): p. 1877-1881.
19. Choi, K., et al., *Parent intentions to vaccinate children with autism spectrum disorder against COVID-19*. *Journal of Pediatric Nursing*, 2022. **63**: p. 108-110.
20. Andrejko, K.L., et al., *Effectiveness of Face Mask or Respirator Use in Indoor Public Settings for Prevention of SARS-CoV-2 Infection — California, February–December 2021*. *MMWR. Morbidity and Mortality Weekly Report*, 2022. **71**(6): p. 212-216.
21. Pazhoohi, F., L. Forby, and A. Kingstone, *Facial masks affect emotion recognition in the general population and individuals with autistic traits*. *PLOS ONE*, 2021. **16**(9): p. e0257740.
22. Halbur, M., et al., *Tolerance of face coverings for children with autism spectrum disorder*. *Journal of Applied Behavior Analysis*, 2021. **54**(2): p. 600-617.
23. Sivaraman, M., J. Virues-Ortega, and H. Roeyers, *Telehealth mask wearing training for children with autism during the COVID -19 pandemic*. *Journal of Applied Behavior Analysis*, 2021. **54**(1): p. 70-86.
24. Lillie, M.A., et al., *Increasing passive compliance to wearing a facemask in children with autism spectrum disorder*. *Journal of Applied Behavior Analysis*, 2021. **54**(2): p. 582-599.
25. Ertel, H.M., D.A. Wilder, and A.C. Hodges, *Evaluation of a Graduated Exposure Procedure to Teach Extended Mask Wearing in Various Settings to Children With Autism*. *Behavior Modification*, 2021: p. 014544552110495.
26. White, L.C., et al., *Brief Report: Impact of COVID-19 on Individuals with ASD and Their Caregivers: A Perspective from the SPARK Cohort*. *Journal of Autism and Developmental Disorders*, 2021. **51**(10): p. 3766-3773.
27. Wanjagua, R., et al., *Key learnings from COVID-19 to sustain quality of life for families of individuals with IDD*. *Journal of Policy and Practice in Intellectual Disabilities*, 2022. **19**(1): p. 72-85.
28. Jeste, S., et al., *Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions*. *Journal of Intellectual Disability Research*, 2020. **64**(11): p. 825-833.
29. Stadheim, J., et al., *A qualitative examination of the impact of the COVID-19 pandemic on children and adolescents with autism and their parents*. *Research in Developmental Disabilities*, 2022. **125**: p. 104232.
30. Charalampopoulou, M., et al., *Mental health profiles of autistic children and youth during the COVID-19 pandemic*. *Paediatrics & Child Health*, 2022. **27**(Supplement_1): p. S59-S65.
31. Nicholas, D.B., et al., *Mental health impacts of the COVID-19 pandemic on children with underlying health and disability issues, and their families and health care providers*. *Paediatrics & Child Health*, 2022. **27**(Supplement_1): p. S33-S39.
32. Bal, V.H., et al., *Early Pandemic Experiences of Autistic Adults: Predictors of Psychological Distress*. *Autism Research*, 2021. **14**(6): p. 1209-1219.
33. Karpur, A., et al., *Food insecurity in households of children with ASD in COVID-19 pandemic: A comparative analysis with the Household Pulse Survey data using stabilized inverse probability treatment weights*. *Disability and Health Journal*, 2022: p. 101323.
34. Stavropoulos, K.K.M., et al., *Exploring telehealth during COVID for assessing autism spectrum disorder in a diverse sample*. *Psychology in the Schools*, 2022.

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35. Spain, D., et al., *Autism Diagnostic Assessments With Children, Adolescents, and Adults Prior to and During the COVID-19 Pandemic: A Cross-Sectional Survey of Professionals*. *Frontiers in Psychiatry*, 2022. **13**.
36. Reisinger, D.L., et al., *Provider and Caregiver Satisfaction with Telehealth Evaluation of Autism Spectrum Disorder in Young Children During the COVID-19 Pandemic*. *Journal of Autism and Developmental Disorders*, 2022.
37. Aranki, J., et al., *Acceptance of Telehealth Therapy to Replace In-Person Therapy for Autism Treatment During COVID-19 Pandemic: An Assessment of Patient Variables*. *Telemed J E Health*, 2022.
38. Lipkin, M. and F. Crepeau-Hobson, *The impact of the COVID-19 school closures on families with children with disabilities: A qualitative analysis*. *Psychology in the Schools*, 2022.
39. Gao, J., et al., *Potentially long-lasting effects of the pandemic on scientists*. *Nature Communications*, 2021. **12**(1).
40. Kaku, S.M., et al., *Experiences of student and trainee autism researchers during the COVID-19 pandemic*. *Autism Research*, 2022. **15**(3): p. 413-420.
41. Harrop, C., et al., *A lost generation? The impact of the COVID -19 pandemic on early career ASD researchers*. *Autism Research*, 2021. **14**(6): p. 1078-1087.

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