

## A Pediatrician's Guide to Working with Children on the Autism Spectrum in Coronavirus Disease 2019 and Beyond: Retrospect and Prospect



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### Keywords

- Autism • COVID-19 • Pandemic • Health • Services • Vulnerable • Adapt • Resilience

### Key points

- The COVID-19 pandemic is an unprecedented event with observable consequences and devastating effects on autistic children and families, highlighting and broadening disparities in the care.
- Abrupt reduction in services and access to care during the pandemic compromised physical and mental health and led to missed intervention opportunities at critical times.
- However, many autistic children and providers demonstrated resilience in adapting to these challenges.

## INTRODUCTION

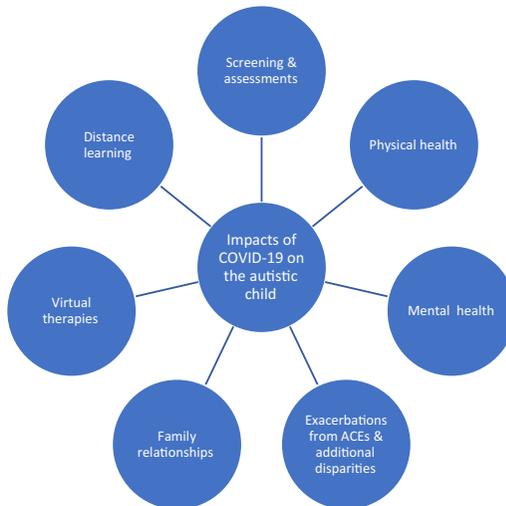
The coronavirus disease 2019 (COVID-19) pandemic is an unprecedented event with observable consequences and devastating effects on children and families.

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This global occurrence highlighted and broadened gaps and disparities in the care of children with developmental disabilities, while simultaneously catalyzing innovation. Initially not seen as direct victims of the disease, children are inherently vulnerable to the impacts of COVID-19, resulting in increased stress, anxiety, isolation, and health challenges. The impact is further amplified in autistic children and children with other neurodevelopmental considerations. These children are uniquely vulnerable due to communication impairments, comorbid medical disorders, poor adaptability, and reliance on therapeutic interventions. Abrupt reduction in services and access to care during the pandemic led to compromised physical and mental health and missed opportunities for intervention at critical times, which may have profound consequences further down the road [1]. There are, however, bright spots in this story, because many autistic children demonstrated resilience in their abilities to adapt to these challenges. It is important to examine the effects that the pandemic triggered, address deficiencies, and recognize new opportunities to improve systems of care to prepare for unforeseen futures. This review outlines the impacts of the first year and a half of the pandemic on autistic children and provides tools for professionals, recognizing the ever-evolving nature of the situation (Fig. 1).

### CAVEATS ABOUT THE STATE OF THE SCIENCE

This article reviews findings from the available published scientific literature, combined with clinical experience from the trenches during the first year and a half of the COVID-19 pandemic to generate comprehensive recommendations for practitioners serving autistic individuals and their families during



**Fig. 1.** The multidimensional impact of COVID-19 on autistic children. ACE, adverse childhood event.

times of crisis. It is important to note that the research literature at this time is incomplete, evolving, and has significant gaps in key areas. Generating ways of examining these groups through creative and nontraditional means is an important public health priority within this field, and as a result, many of the available studies oftentimes involved smaller and narrower sample sizes. Clinical experience as medical and mental health providers at a university-based medical institution supplemented the available literature to provide a thorough summary and meaningful recommendations on this topic.

## **MEDICAL CARE**

Early in the pandemic, most children did not seem to become severely ill from COVID-19 compared with adults [2], although the COVID-19 landscape is ever-changing with the emergence of new variants. However, analysis during the pandemic found that autistic children without comorbidities were hospitalized at much higher rates than other children, and even more so if they had autism with comorbid intellectual disability [3]. Comparatively, autistic children were hospitalized at higher rates than children with other medical problems including obesity and heart failure [3]. Hospitalizations of autistic children with COVID-19 were also longer than their neurotypical peers with increased risk of mortality [3,4].

These higher risks in the autistic population are likely multifactorial, including decreased ability to wear masks and convey symptoms and communication barriers limiting the ability to follow safety directions [4]. More severely impaired autistic individuals often live in group homes, placing them at greater risk for rapid viral spread [5]. Before the pandemic, autistic children were found to have poor cooperation and noncompliance in inpatient settings [6]. The use of insensitive techniques in pediatrics can inadvertently increase behavioral outbursts and complicate the ability to provide life-saving treatments, necessitating the use of chemical or physical restraints, which can further exacerbate aggressive behaviors [7]. Although some health care workers are receiving formal training on aggression and challenging behavior management, this is not yet standard of care and more research working with the pediatric autistic population, specifically, is needed [7–9]. Given these multi-tiered risk factors, autistic children must be recognized as a high-risk population for COVID-19.

During the initial part of the pandemic, the autistic community voiced fears of “health care rationing,” an example of which is prioritizing a neurotypical patient over a patient with a neurodevelopmental disorder should only one ventilator be available [10]. Many US states and several European countries issued crisis care guidelines at the pandemic’s peak, raising community concerns for exclusion of care in specific adult populations, such as individuals with disabilities and the elderly [11,12]. Such policies must receive critical evaluation, especially given the aforementioned heightened risk for hospitalization and death of the autistic population so that autistic patients are treated fairly and ethically.

Owing to scientific innovation and collaboration, at the time of this article, the US Food and Drug Administration (FDA) authorized 3 vaccines against COVID-19 [13]. Before the pandemic, autistic children were vaccinated at lower rates than neurotypical children [14]. Studies published after the pandemic's onset found that reasons for vaccine hesitancy in parents of autistic children included beliefs that vaccines led to autism and developmental plateaus [15,16].

However, a large study of autistic adults found higher rates of COVID-19 vaccination compared with age-matched controls, while acknowledging varying vaccine practices across countries and populations [17]. This higher rate could be due to many factors including parental oversight of autistic individuals and concern for more severe COVID-19 illness. A small study found no increased COVID-19 vaccine side effects, such as fever or fatigue, in autistic patients compared with nonautistic patients [18]. These data support favorable trends in combating the pandemic in autistic individuals, and providers should continue to refer to FDA recommendations regarding updates on vaccination age cutoffs and booster doses to best protect autistic patients.

*Autistic children should be considered a high-risk population for medical complications of COVID-19, due to factors predisposing them to infections and difficulties with inpatient hospitalizations. Given these risks, standardized interventions to address behaviors complicating hospital stays should be investigated and implemented even beyond the pandemic. Policies in times of crises must be critically evaluated for ethical care of a neurodiverse population. Although vaccination has historically been a contentious subject in the autistic community, efforts to prioritize COVID-19 vaccination in autistic patients should be encouraged.*

## TELEHEALTH

Owing to physical distancing measures and parental fears, a steep drop in pediatric well-child and sick visits was observed during the pandemic and telehealth quickly became an important mode of patient interaction [19]; this required providers to overcome technological barriers to access, insurance repayment logistics, and concerns regarding HIPAA compliance. Sometimes providers enjoyed this method of interaction, as telehealth offered a window into patients' home environments, offering unique insight into care previously unavailable [20].

Some families even preferred telehealth appointments, with parents not wanting to miss time from work and minimizing transportation barriers [21].

However, there were drawbacks to this modality of patient care with technology utilization challenges and loss of personal perspectives with telemedicine [22]. Providers experienced discomfort with diagnostic reliability, due to lack of in-person physical examinations, lack of play observations, and difficulties in screening for mental health disorders over telehealth calls. Despite increased use of telemedicine, a developmental-behavioral study of preschoolers found that most medication initiations and changes still took place in the in-person setting [23]. These findings suggest ongoing telehealth should

continue to remain an option, but that a hybrid model is the best compromise between convenience and comprehensive care.

*The COVID-19 pandemic forced a dramatic shift toward telehealth models. Both providers and families found satisfaction and even benefit from telehealth appointments; however, in-person visits are still important for medication changes, severe behavioral concerns, families with technology limitations, and to verify certain therapeutic modalities.*

## **AUTISM SCREENING AND DIAGNOSIS**

With the drop in in-person pediatric visits during the early days of the pandemic, opportunities were missed for timely developmental screenings. It is accepted that for some children, autism can be reliably diagnosed by experienced clinicians by 14 months of age or earlier, and that children younger than 5 years show tremendous benefit from earlier intervention [24]. The early US data on autism identification during the pandemic highlights a multitiered challenge: decreased referral rates, increased wait times for evaluation, and decreased number of children receiving early intervention (EI) services, although there were notable gaps in the data available at this time [25,26].

Given these challenges, several groups developed new and modified existing approaches in autism screening and assessments. Typically, broadband level 1 screening tests, like the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F), are first line in identifying toddlers at risk for autism by screening all patients in primary care, compared with level 2 tools that rely on trained clinician's observations using a structured, play-based model and are typically given when a toddler is identified as at risk [27,28].

Although the specificity and sensitivity of level 1 screening tests are high in low-risk settings, a study before the pandemic found that combining level 1 screeners and level 2 screeners, such as the STAT (Screening Tool for Autism in Toddlers and Young Children), improved specificity and could streamline referrals and decrease wait times for diagnostic evaluations [29]. Research to validate these tools are ongoing, but preliminary data are very positive [30].

Furthermore, virtual validated tools could potentially be used to identify high-risk children for EI, enabling them to begin services in a timelier manner. Limited data currently exist to support this approach. However, if data from the pandemic can demonstrate strong psychometric properties and these methods are accepted by insurers, the COVID-19 pandemic may serve as a catalyst to use alternate virtual assessment tools, such as the SORF (Systematic Observation of Red Flags of Autism Spectrum Disorder) [31], TELE-ASD-PEDS [32], or the BOSA (Brief Observation of Symptoms of Autism) [33], which are opening the door for further diagnostic access. Use of these tools would afford earlier access to care and service to underresourced and rural communities, improving patient outcomes and health equity.

*During the COVID pandemic, screening for and referrals for formal assessment of autism decreased. There has been limited access to evaluations and EI in some parts of the country; this created opportunities for using innovative multitiered screeners for earlier autism*

*identification and developing new virtual assessment tools that are hoped to improve patient outcomes and lessen health disparities.*

## **SERVICES**

COVID-19 pandemic restrictions greatly reduced the delivery of critical therapeutic interventions needed by the autistic community [34]. Autistic children often receive various treatment interventions, which can include applied behavior analysis (ABA), speech therapy, occupational therapy, physical therapy, and cognitive behavioral therapy (CBT) [35]. These therapies are typically delivered in one-to-one in-person settings, either in the home or in clinics. These children can also receive interventions through their school districts, as outlined in their Individualized Education Programs (IEPs). Therapists work closely with families to address tailored goals, which can include building social, adaptive, and communication skills and coping with sensory and behavioral challenges. Families rely on their therapy teams to help them navigate challenges and set their children up for successful outcomes.

When the pandemic struck, delivery of many vital therapy services came to an immediate halt and families lost their support networks. Concurrently, therapists faced unprecedented practice regulations, restrictions, and closures [36], and one survey of ABA therapists reported decreased productivity and job insecurity [37]. Restructuring efforts to provide virtual services were deployed. Providing therapies via telehealth is not a new concept, as the World Federation of Occupational Therapists and Confederation for Physical Therapy has encouraged their providers for many years to offer telehealth programs [38,39]. During the pandemic's peak, therapy providers implemented nuanced decision-making models that considered the risks and benefits of restarting in-person therapies versus transitioning to teletherapies [40]. During this time of mass transition, many challenges with the virtual modality of therapy delivery arose including Internet connection issues, Web literacy gaps, and difficulties following therapists' instructions remotely [41]. In one study from the SPARK/Simmons Foundation community dataset of more than 97,000 autistic individuals, the benefits of teletherapy were perceived to be low and impacted by the lack of interactive play, peer-to-peer interactions, and reinforcers, which are hard to deliver remotely [42]. For many families, there was appropriate fear that the disruption in services would lead to a regression in skills and ultimately impact prognosis.

Despite these challenges, the rise of teletherapies in many settings is exciting given its potential to make therapies more accessible by decreasing time and costs related to travel. In one intervention model, in which virtual parental support and rehabilitation was provided, parents reported increased child growth and development and increased feelings of self-relevance, engagement, perceived support, and recognition [43]. Helpful parenting tips have emerged, including scheduling regular online consultations with therapy providers, maintaining online therapy, creating structured daily schedules and reinforcement systems, and scheduling daily child-appropriate activities [43].

As service providers explored optimal best practices when offering telehealth options, several virtual tools emerged. The acronym “VIRTUAL” was developed to highlight important domains needed to deliver effective teletherapy: Visual, Information, Relationships, Technology, Unique, Access, and Legal [44]. Innovative parent coaching programs that include counseling and support have also emerged. One program focused on teaching parents to implement simple token reward systems that were positively reinforcing for all [45]. Within CBT models, therapists adopted creative solutions to several challenges posed by the virtual session format, including expanding their virtual rapport-building activities, implementing virtual visual aids/handouts, and navigating distractions [46]. Noted advantages to virtual CBT sessions included some children engaging more from the comfort of their home, sharing aspects of their physical environment, and more flexibility in scheduling sessions [46]. The COVID-19 pandemic prompted both families and service providers to become creative in the ways autistic children receive services when in-person options are not possible.

*Vital therapy services for autistic children came to an immediate halt due to the COVID-19 pandemic, leaving families isolated and fearful. Virtual therapies were implemented, but not all patients were able to participate. Although virtual programs were expanded, special consideration was made to continue one-to-one therapies for some autistic children where virtual therapies were unrealistic. The COVID-19 crisis opened the door for opportunities to increase accessibility to services through virtual options that can be used even beyond the pandemic.*

## EDUCATION

To reduce the spread of COVID-19, schools closed globally in early 2020. Every US state closed its schools in mid-March 2020, and a US study found significant decreases in incidence of and mortality from COVID-19 in states where in-person schools remained closed [47]. Stay-at-home orders, which included school and nonessential business closures, were associated with decreased incidence of COVID-19 infections [48]. However, a study of schools that resumed in-person classes in fall 2020 found that the vast majority of students and staff members who contracted COVID-19 during the school year acquired their infections from exposures outside of school [49]. This finding suggests that interventions that fall short of school closures, such as canceling large gatherings, physical distancing, and masking, may have more effectively prevented COVID-19 spread than school closures. Although school closure focused on preventing deaths and avoiding overwhelming hospitals due to COVID-19 cases, models have demonstrated that the mass school closures will lead to higher years of life lost due to downstream impacts of educational losses than the estimated years of life saved from COVID-19 infections [50,51]. With the rise of new COVID-19 variants and lack of approved COVID-19 vaccines for younger children at this time, the risk of these factors must be weighed.

As the lockdown phase of the pandemic progressed, the US Department of Education released statements regarding providing special education and

evaluations during times of physical distancing [52]. Meanwhile, it became clear that distance learning jeopardized the upholding of the Individuals with Disabilities Education Act (IDEA) and providing Free and Appropriate Public Education (FAPE). Around the world, children's special education was discontinued during the pandemic [53]. As most schools transitioned online, the impact of distance learning on autistic children was varied and complex. A study exploring the core pandemic experiences of parents of autistic children found that families lacked tools to provide education at home, feared downstream implications of distance learning, and lamented the loss of attention that their children previously received in-person [54]. Behaviors such as noncompliance, inflexibility, and tantrums worsened with distance learning [55]. The Core Experiences Study demonstrated higher educational losses in students learning in virtual environments compared with peers learning in person [56], and more isolation and decreased physical activity [57]. Contrasted with these findings, some children benefited from the distance learning environment, became more relaxed while learning at home, developed independence, and built better relationships with their parents [58–60]. Although some parents reported preference for virtual learning, this type of education likely failed to meet children's socialization needs. Clinical experience found that in some cases, distance learning was so preferred that there was real fear and anxiety about returning to in-person learning. However, the options for home-charter schools and medical home programs would not adequately support the needs of children with higher support needs because neither program typically offers sufficient special education support.

These findings prompt many questions regarding the future of education for autistic children. If some parents have preference for and data support that students fare better with distance learning during the pandemic, is IDEA obligated to continue facilitating this option? What emerging lessons can be harnessed to provide the best education to autistic children? How will the education system catch up on the backlogs of IEPs? How will students be provided the opportunity to make up for what they lost, especially those in special education and those attending underserved schools? Although early studies are only beginning to highlight the educational impact of COVID-19 on students, time and future studies are needed to fully grasp the impact of the pandemic on education, especially the education of autistic children.

*In the autistic population, many children struggled with virtual learning during the pandemic, with limited or completely halted education and worsening of behaviors at home, whereas some benefited in many ways from distance learning at home. Further studies are needed to assess the full degree of impact on autistic children. Many more studies so far have been conducted of the neurotypical population, showing greater negative impacts of distance learning related to social determinants of health, and models showing higher years of life lost due to school closures than years of life saved by halting in-person education. The experience thus far has frankly led to more questions than answers about what is best educationally for autistic children moving forward, questions that should guide innovative thinking for education system structuring so that it can most benefit autistic children.*

## MENTAL HEALTH

Autistic children are at greater risk to psychological challenges during the COVID-19 pandemic than their neurotypical peers due to the nature of autism, which demands consistency and is highly associated with comorbid anxiety, depression, and attention-deficit/hyperactivity disorder. One study found increased aggression, behavioral outbursts, and regression more in the autistic population than in other children with neurodevelopmental considerations during the restrictions [55]. Anxiety and depression were highest among those with prepandemic psychiatric conditions, those who were younger, and those with fewer emotional contacts [55,61]. These effects were worse earlier in the pandemic and compounded by limited access to educational services [53,55]. When compared with neurotypical groups, there was a clear pattern that disrupted schedules and services were more problematic for autistic children compared with neurotypical subjects [61]. However, there were benefits found in some studies, wherein autistic adults reported enjoying isolation with reduced sensory and social overload [61].

Examining the utilization of the mental health emergency care system during the pandemic demonstrated an increase in mental health acuity, including increased suicide attempts [62,63]. Immediately after stay-at-home orders were enacted, the number of pediatric emergency department (ED) visits dropped, but over the next several months, whereas ED visits remained low, the proportion of ED visits for mental health crises increased dramatically, most notably in patients older than 12 years [63,64]. Patients with mental health conditions presented more severely during the COVID-19 pandemic and more frequently required admission to the hospital [65]. Unfortunately, in clinical experience, children were boarded in the ED for hours to days because inpatient psychiatric facilities were overwhelmed with patients due to the increase in acute mental health needs from COVID-19 [66].

With the reality of increased mental health needs during the pandemic, it is important to understand factors that aid in resilience. Having strong family function prepandemic and contact with the school system even indirectly were found to be protective [55,67]. In autistic adults' telehealth check-ins, telehealth with a therapist, journaling, maintaining a schedule, walking/exercise, and keeping in touch with family via phone/chat were critically important in coping during times of physical distancing [68]. Families reported that social stories, providing breaks, telehealth, hobbies, cooking, and virtual connections were helpful as well. These findings underscore the importance of targeting emotional regulation, continued services, social connection, and creating routine among the chaos. Understanding factors that support resilience are critical in offering tools moving forward.

*The growing literature suggests that the mental health of children declined during the COVID-19 pandemic, more significantly so in autistic children and those with pre-COVID-19 behavioral concerns. However, autistic individuals without service disruptions, with schedules, and with ongoing social support fared better. As this population reintegrates and the state of normalcy returns, providers should also watch for a spike in behaviors, because this will create another change in routines, new social demands, and sensory inputs.*

## **FAMILY RELATIONSHIPS**

The COVID-19 pandemic presented many challenges to the families of autistic children. Schools are an important influence in children's lives because many autistic children receive services in the school setting, thrive in a structured and organized classroom, and benefit from the opportunities in school to socialize with peers [69,70]. The loss of in-person education significantly disrupted the lives of autistic children, and in many cases placed more pressure and stress on families to make up for these losses. More time spent in restricted spaces at home with fewer resources, such as being limited to the same toys, can exacerbate children's restricted interests, thus worsening autism symptoms and challenging family dynamics. Parents had difficulties setting limits on play and screen time, leading to more conflict in parent-child relationships [71]. Parents of autistic children are already at heightened risk for mental health problems such as stress, depression, and anxiety, which was likely exacerbated during the pandemic, due to decreased access to respite care and increased demands in the home environment [72]. Emerging data during the pandemic found that children were at increased risk for abuse in the home in the setting of parental job loss [73]. The mental health of parents and children were linked during COVID-19, so when parents struggled, children were more likely to struggle, and vice versa [74].

Despite these challenges, some families saw benefits in certain domains for their children that improved family dynamics. For example, some children experienced less stress due to the decreased social demands and decreased academic pressures of distance learning [60,75]. However, this was less likely to be the case for families in which their child had behavioral or learning difficulties. Half of the parents in one small study reported their children being happier and calmer during quarantine [76]. Not having to endure battles over homework completion, for instance, during the first 6 months of homeschooling, reduced parent and child stress levels and conflict. During the pandemic and the period of remote learning, children were allowed to honor their rhythms of sleep/wake cycles, eating, and physical activity in a way that was more individually beneficial rather than having to meet the needs of an entire student body, which could reduce overall stress load in the home.

*Disrupted routines and changes presented opportunities for innovation in families with autistic children during the pandemic. Families that were able to implement routines in the home environment, adequately limit children's exposure to screens or restricted interests, continue to expose their children to social environments, and reduce challenges that children face in the in-person school environment, such as teasing, bullying, and academic stressors, may have created an optimal home life for autistic children.*

## **CONSIDERATION OF FURTHER EXACERBATIONS FROM DISPARITIES AND ADVERSE CHILDHOOD EVENTS**

It is important to consider how the disparities that many autistic children experience may have exacerbated the negative impacts the pandemic had on them. Before the COVID-19 crisis, families of autistic children and children with

developmental disabilities were at higher risk for food insecurity [77]. One study reported worsening of behaviors during the pandemic in autistic children from lower-income families and families who were food insecure [78]. During the pandemic, minority populations were found to have increased rates of food insecurity compared with nonminorities [79,80]. Consideration of these multiple factors is important because the pandemic likely created a situation of potentially compounding effects and multiple vulnerabilities for autistic children and their families.

The educational crisis during the COVID-19 pandemic exacerbated already present disparities in learning opportunities for children. Less participation in virtual learning activities was found in students in poverty [81] and students in rural communities [82]. Families with monetary means were able to provide innovative solutions to educate their children during times of school closures, such as paying out of pocket for educated adults to lead “pods” of students in a neighborhood [83]. Meanwhile a digital divide and worsening achievement gaps became apparent for students from low-income families who experienced limited access to digital equipment and Internet [84]. The implications of these findings for autistic children must be considered, especially given the additional challenges they faced with distance learning as mentioned previously.

These considerations are important due to the strong relationship between autism diagnosis and a higher number of adverse childhood events (ACEs) [85]. ACEs are a set of 10 potentially traumatic events occurring in childhood that have been linked to health problems in adulthood [86]; this is likely due to the families of autistic children being particularly vulnerable to financial difficulties, parental divorce/separation, and household mental illness/substance abuse. In addition to delayed diagnosis, the average age of entry into autism services was delayed in patients with higher ACE scores [87]. Given these baseline statistics, the COVID-19 pandemic has likely compounded these disparities further and has placed autistic children at higher risk for negative outcomes, although no study on this has been published at this time.

*Families of autistic children have faced compounding vulnerabilities during the pandemic. The challenges of distance learning led parents to unique and discriminatory ways of coping, often serving only those with greater economic means and exacerbating already present educational disparities. It will be important for health care professionals to offer support and resources to families and to screen for ACEs and for further research to be conducted regarding these topics.*

## **THE PEDIATRICIAN’S TOOLBOX FOR AUTISM CARE IN CORONAVIRUS DISEASE 2019 AND BEYOND**

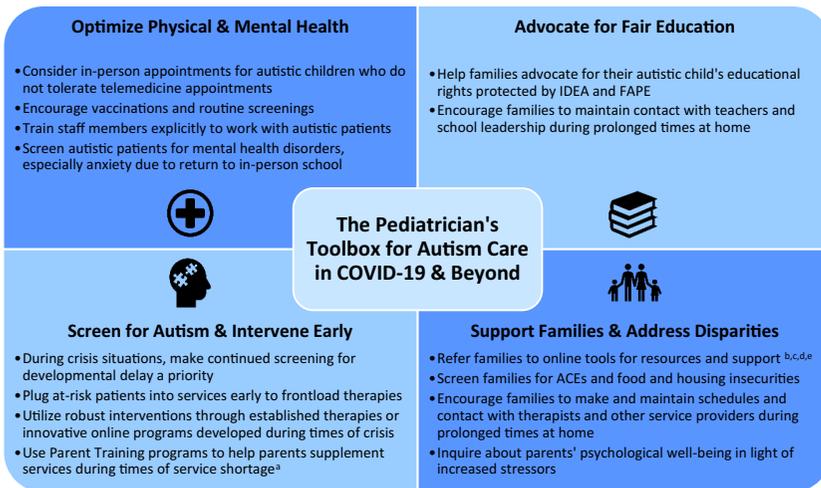
For the general pediatrician, it is important to understand the complex impact of the COVID-19 pandemic on autistic patients and their families, recognizing that every family experienced challenges and possibly even found some pleasant surprises along the way. During office visits physically or virtually,

families should be asked open endedly about their experiences and check-in on their well-being. In addition, families should be helped to navigate challenges faced with their child's education and service interventions. The expansion of the use of telemedicine brings new opportunities for innovative ways to screen and diagnose patients and decrease wait times.

Advocacy for children and challenging of potentially unethical policies will be needed to lessen disparities and provide care with equity.

During the pandemic, several online services were augmented or created to provide information about autism and tips for care. Many intervention programs were adapted and are now available as caregiver-delivered programs, increasing caregivers' abilities to support their children over the long-term. Webinars and resources were created to help parents encourage prosocial behaviors at home, including Baby Navigator, Autism Speaks, Triad Family First, and Help is in Your Hands (Fig. 2). These services are hoped to outlive COVID-19 pandemic as useful educational tools for parents and a bridge to services.

When autistic children and their families are exposed to unforeseen circumstances, such as the COVID-19 pandemic, pediatricians can help in many ways as a primary point of contact for these families during difficult times. Fig. 2 is the Pediatrician's Toolbox for care of the autistic child based on the early findings and needs that have come to light during the COVID-19 crisis. Through all the darkness of this pandemic there is hope and possibility for improvement in care for autistic patients.



**Fig. 2.** A pediatrician's toolbox for autism care in coronavirus disease 2019 and beyond. Web tools: <sup>a</sup>*Autism Speaks Parent Training*: <https://www.autismspeaks.org/covid-19-information-and-resources-families#ParentTraining>; <sup>b</sup>*Baby Navigator*: [babynavigator.com](http://babynavigator.com); <sup>c</sup>*Autism Speaks*: [autismspeaks.org](http://autismspeaks.org); <sup>d</sup>*TRIAD Families First Program*: [vk.vumc.org/vk/triad/fam/](http://vk.vumc.org/vk/triad/fam/); <sup>e</sup>*The AAP Parenting Website*: <https://www.healthychildren.org/English/Pages/default.aspx>.

## DISCLOSURE

The authors have nothing to disclose.

## CLINICS CARE POINTS

- This paper reviewed the available literature up until the time of submission, which was incomplete and developing, and notably most available studies involved small sample sizes
- Autistic children with COVID-19 were hospitalized more frequently and for longer periods than their neurotypical peers
- COVID-19 vaccination in autistic patients should be encouraged given their higher risk for more severe illness
- The pandemic forced a dramatic shift toward telehealth models, and while both providers and families found benefit in telehealth appointments, in-person visits are still important for medication changes, severe behavioral concerns and families with technology limitation
- The COVID-19 pandemic led to a fall in screening for and referrals for formal assessment of autism, simultaneously creating opportunities for utilizing multi-tiered screeners for earlier autism identification and the development of virtual assessment tools
- Therapy services for autistic children came to a halt due to the COVID-19 pandemic, and while virtual therapies were implemented, not all patients were able to participate
- In the autistic population, while many children struggled with virtual learning during the pandemic, with limited or completely halted education and worsening of behaviors at home, some benefited in many ways from distance learning at home; further studies are needed to assess the full degree of impact of virtual learning on autistic children
- The challenges of distance learning led parents to unique ways of coping, often serving only those with greater economic means and exacerbating already present disparities
- Utilization of routines and reduction of challenges that autistic children face in the in-person school environment, such as bullying and social stressors, may have created an optimal home life for autistic children during the pandemic
- When autistic children and their families are exposed to unforeseen circumstances, such as the COVID-19 pandemic, pediatricians can help as the primary point of contact for these families during difficult times, including pointing them to online resources and engaging in advocacy

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## References

- [1] White LC, Law JK, Daniels AM, et al. Brief Report: Impact of COVID-19 on individuals with ASD and their caregivers: A perspective from the SPARK cohort. *J Autism Dev Disord* 2021;51(10):3766–73.

- [2] CDC. COVID data tracker: demographic trends of COVID-19 cases and deaths in the US reported to CDC. Atlanta (GA): US Department of Health and Human Services, CDC; 2021. Available at: <https://covid.cdc.gov/covid-data-tracker/#demographics>.
- [3] Karpur A, Vasudevan V, Shih A, et al. Brief report: Impact of COVID-19 in individuals with autism spectrum disorders: Analysis of a national private claims insurance database. *J Autism Dev Dis* 2021; <https://doi.org/10.1007/s10803-021-05100-x>.
- [4] Oakley B, Tillmann J, Ruigrok A, et al. COVID-19 health and social care access for autistic people: European policy review. *BMJ Open* 2021;11(6):e045341.
- [5] Landes SD, Turk MA, Formica MK, McDonald KE, Stevens JD. COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disabil Health J* 2020;13(4):100969.
- [6] Johnson NL, Rodriguez D. Children with autism spectrum disorder at a pediatric hospital: a systematic review of the literature. *Pediatr Nurs* 2013;39(3):131–41. Available at: <https://pubmed.ncbi.nlm.nih.gov/23926752/>.
- [7] Dalton EM, Herndon AC, Cundiff A, et al. Decreasing the use of restraints on children admitted for behavioral health conditions. *Pediatrics* 2021;148(1):e2020003939.
- [8] Matuska G, Gallagher A. The needs of people with intellectual disabilities and autism during the pandemic: Making the invisible visible. *Nurs Ethics* 2020;27(7):1487–9.
- [9] Mitchell MJ, Newall FH, Sokol J, et al. Simulation-based education for staff managing aggression and externalizing behaviors in children with autism spectrum disorder in the hospital setting: pilot and feasibility study protocol for a cluster randomized controlled trial. *JMIR Res Protoc* 2020;9(6):e18105.
- [10] den Houting J. Stepping out of isolation: Autistic people and COVID-19. *Autism Adulthood* 2020;2(2):103–5.
- [11] Scully JL. Disability, disablism, and COVID-19 pandemic triage. *J Bioeth Inq* 2020;17(4):601–5.
- [12] Epstein S, Campanile J, Cerilli C, et al. New obstacles and widening gaps: A qualitative study of the effects of the COVID-19 pandemic on U.S. adults with disabilities. *Disabil Health J* 2021;14(3):101103.
- [13] COVID-19 Vaccines. US Food and Drug Administration. 2021. Available at: <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines>. Accessed October 30, 2021.
- [14] Zerbo O, Modaressi S, Goddard K, et al. Vaccination patterns in children after autism spectrum disorder diagnosis and in their younger siblings. *JAMA Pediatr* 2018;172(5):469–75.
- [15] Goin-Kochel RP, Fombonne E, Mire SS, et al. Beliefs about causes of autism and vaccine hesitancy among parents of children with autism spectrum disorder. *Vaccine* 2020;38(40):6327–33.
- [16] Bonsu NEM, Mire SS, Sahni LC, et al. Understanding vaccine hesitancy among parents of children with autism spectrum disorder and parents of children with non-autism developmental delays. *J Child Neurol* 2021;36(10):911–8.
- [17] Weinstein O, Krieger I, Cohen AD, et al. COVID-19 vaccination among individuals with autism spectrum disorder: A population-based study. *Res Autism Spectr Disord* 2021;89.
- [18] Brondino N, Bertoglio F, Forneris F, et al. A pilot study on covid and autism: Prevalence, clinical presentation and vaccine side effects. *Brain Sci* 2021;11(7):860.
- [19] Crawley E, Loades M, Feder G, et al. Wider collateral damage to children in the UK because of the social distancing measures designed to reduce the impact of COVID-19 in adults. *BMJ Paediatr Open* 2020;4(1):e000701.
- [20] Knutsen J, Wolfe A, Burke BL, et al. A systematic review of telemedicine in autism spectrum disorders. *Rev J Autism Dev Disord* 2016;3:330–44.
- [21] Burke BL Jr, Hall RW, Section on Telehealth Care. Telemedicine: Pediatric applications. *Pediatrics* 2015;136(1):e293–308.

- [22] Simacek J, Elmquist M, Dimian AF, et al. Current trends in telehealth applications to deliver social communication interventions for young children with or at risk for autism spectrum disorder [published online ahead of print, 2020 Oct 12]. *Curr Dev Disord Rep* 2020;1–9.
- [23] Harstad E, Shults J, Barbaresi W, et al. Preschool attention-deficit/hyperactivity disorder and telephone medication management at developmental-behavioral pediatric network sites. *J Dev Behav Pediatr* 2021;42(6):481–4.
- [24] Landa RJ, Gross AL, Stuart EA, et al. Developmental trajectories in children with and without autism spectrum disorders: The first 3 years. *Child Dev* 2013;84(2):429–42.
- [25] Delayed Interventions: Early Indicators of the Pandemic’s Impact on Infants and Toddlers. Advocates for children of New York. 2021. Available at: [https://www.advocatesforchildren.org/custom\\_search?amp=](https://www.advocatesforchildren.org/custom_search?amp=). Accessed October 31, 2021.
- [26] The Impact of COVID-19 on Early Intervention: How States can Support our Youngest Learners. The Education Trust. 2021. Available at: <https://edtrust.org/wp-content/uploads/2014/09/The-Impact-of-COVID-19-on-Early-Intervention-How-States-Can-Support-Our-Youngest-Learners-May-2021.pdf>. Accessed October 31, 2021.
- [27] Robins DL, Casagrande K, Barton M, et al. Validation of the modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics* 2014;133(1):37–45.
- [28] Brewer N, Young RL, Lucas CA. Autism screening in early childhood: Discriminating autism from other developmental concerns. *Front Neurol* 2020;11:594381.
- [29] Khowaja M, Robins DL, Adamson LB. Utilizing two-tiered screening for early detection of autism spectrum disorder. *Autism* 2018;22(7):881–90.
- [30] Berger NI, Wainer AL, Kuhn J, et al. Characterizing available tools for synchronous virtual assessment of toddlers with suspected autism spectrum disorder: A brief report. *J Autism Dev Disord* 2021; <https://doi.org/10.1007/s10803-021-04911-2>.
- [31] Dow D, Day TN, Kutta TJ, et al. Screening for autism spectrum disorder in a naturalistic home setting using the systematic observation of red flags (SORF) at 18-24 months. *Autism Res* 2020;13(1):122–33.
- [32] Corona L, Hine J, Nicholson A, et al. TELE-ASD-PEDS: a telemedicine-based ASD evaluation tool for toddlers and young children. Vanderbilt University Medical Center; 2020. Available at: <https://vkc.vumc.org/vkc/triad/tele-asd-peds>.
- [33] Lord C, Dow D, Holbrook A, et al. Brief observation of symptoms of autism (BOSA). *Western Psychological Services*; 2020.
- [34] Masi A, Mendoza Diaz A, Tully L, et al. Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents. *J Paediatr Child Health* 2021;57(5):631–6.
- [35] Lord C, Elsabbagh M, Baird G, et al. Autism spectrum disorder. *Lancet* 2018;392(10146):508–20.
- [36] Litke N, Daniel T, Wallacher S, et al. Einfluss der COVID-19 Pandemie auf die ambulante physiotherapie [Impact of the COVID-19 pandemic on outpatient physical therapy in Germany]. *Z Evid Fortbild Qual Gesundheitswes* 2021;165:58–67.
- [37] Jimenez-Gomez C, Sawhney G, Albert KM. Impact of COVID-19 on the applied behavior analysis workforce: Comparison across remote and nonremote workers. *Behav Anal Pract* 2021;1–10; <https://doi.org/10.1007/s40617-021-00625-0>.
- [38] Jacobs K, Cason J, McCullough A. The process for the formulation of the international telehealth position statement for occupational therapy. *Int J Telerehabilitation* 2015;7(1):21–32.
- [39] Report of the WCPT/INPTRA Digital Physical Therapy Practice Task Force. World Physiotherapy. 2020. Available at: <https://world.physio/sites/default/files/2020-06/WCPT-INPTRA-Digital-Physical-Therapy-Practice-Task-force-March2020.pdf>. Accessed August 11, 2021..
- [40] degli Espinosa F, Metko A, Raimondi M, et al. A model of support for families of children with autism living in the COVID-19 lockdown: Lessons from Italy. *Behav Anal Pract* 2020;13(3):550–8.

- [41] Camden C, Silva M. Pediatric telehealth: Opportunities created by the COVID-19 and suggestions to sustain its use to support families of children with disabilities. *Phys Occup Ther Pediatr* 2021;41(1):1–17.
- [42] Shorey S, Tiang Lau LS, Tan JX, et al. Families with children with neurodevelopmental disorders during COVID-19: A scoping review. *J Pediatr Psychol* 2021;46(5):514–25.
- [43] Provenzi L, Grumi S, Gardani A, et al. Italian parents welcomed a telehealth family-centered rehabilitation programme for children with disability during COVID-19 lockdown. *Acta Paediatr* 2020;110(1):194–6.
- [44] Colombo RA, Wallace M, Taylor R. An essential service decision model for ABA providers during crisis. *Behav Anal Pract* 2020;13:306–11.
- [45] LeBlanc LA, Lazo-Pearson JF, Pollard JS, et al. The role of compassion and ethics in decision making regarding access to applied behavior analysis services during the COVID-19 crisis: A response to Cox, Plavnick, and Brodhead. *Behav Anal Pract* 2020;13(3):604–8.
- [46] Kalvin CB, Jordan RP, Rowley SN, et al. Conducting CBT for anxiety in children with autism spectrum disorder during COVID-19 pandemic. *J Autism Dev Disord* 2020; <https://doi.org/10.1007/s10803-020-04845-1>.
- [47] Auger KA, Shah SS, Richardson T, et al. Association between statewide school closure and COVID-19 incidence and mortality in the US. *JAMA* 2020;324(9):859–70.
- [48] Lyu W, Wehby GL. Comparison of estimated rates of coronavirus disease 2019 (COVID-19) in border counties in Iowa without a stay-at-home order and border counties in Illinois with a stay-at-home order. *JAMA Netw Open* 2020;3(5):e2011102.
- [49] Zimmerman KO, Akinboyo IC, Brookhart MA, et al. Incidence and secondary transmission of SARS-COV-2 infections in schools. *Pediatrics* 2021;147(4):e2020048090.
- [50] Christakis DA, Van Cleve W, Zimmerman FJ. Estimation of US children’s educational attainment and years of life lost associated with primary school closures during the coronavirus disease 2019 pandemic. *JAMA Netw Open* 2020;3(11); <https://doi.org/10.1001/jamanetworkopen.2020.28786>.
- [51] Zimmerman FJ, Anderson NW. Association of the timing of school closings and behavioral changes with the evolution of the coronavirus disease 2019 pandemic in the US. *JAMA Pediatr* 2021;175(5):501–9; <https://doi.org/10.1001/jamapediatrics.2020.6371>.
- [52] Office for Civil Rights & Office of Special Education and Rehabilitative Services. Addressing the risk of COVID-19 in preschool, elementary and Secondary Schools while serving children with disabilities. US Dept of Education; 2020.
- [53] Mutluer T, Doenyas C, Aslan Genc H. Behavioral implications of the COVID-19 process for autism spectrum disorder, and individuals’ comprehension of and reactions to the pandemic conditions. *Front Psychiatry* 2020;11:561882.
- [54] Tokatly Latzer I, Leitner Y, Karnieli-Miller O. Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism* 2021;25(4):1047–59.
- [55] Colizzi M, Sironi E, Antonini F, et al. Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: an online parent survey. *Brain Sci* 2020;10(6):341.
- [56] Verlenden JV, Pampati S, Rasberry CN, et al. Association of children’s mode of school instruction with child and parent experiences and well-being during the COVID-19 pandemic — COVID experiences survey United States, October 8 pandemic — COVID experiences survey, United States, October 8–November 13, 2020. *MMWR* 2021;70(11):369–76.
- [57] Takaku R, Yokoyama I. What the COVID-19 school closure left in its wake: Evidence from a regression discontinuity analysis in Japan. *J Public Econ* 2021;195:104364.
- [58] Pesch MH, Julian MM, Munzer TG. Reflections on children with developmental and behavioral challenges who are thriving while sheltering in place. *J Dev Behav Pediatr* 2020;41(7):506–7.
- [59] Meral BF. Parental views of families of children with autism spectrum disorder and developmental disorders during the COVID-19 pandemic. *J Autism Dev Disord* 2021; <https://doi.org/10.1007/s10803-021-05070-0>.

- [60] Mumbardó-Adam C, Barneé-López S, Balboni G. How have youth with Autism Spectrum Disorder managed quarantine derived from COVID-19 pandemic? An approach to families perspectives. *Res Dev Disabil* 2021; 110:103860.
- [61] Oomen D, Nijhof AD, Wiersema JR. The psychological impact of the COVID-19 pandemic on adults with autism: a survey study across three countries. *Mol Autism* 2021;12; <https://doi.org/10.1186/s13229-021-00424-y>.
- [62] Hill RM, Rufino K, Kurian S, et al. Suicide ideation and attempts in a pediatric emergency department before and during COVID-19. *Pediatrics* 2021;147(3); <https://doi.org/10.1542/peds.2020-029280>.
- [63] Leeb RT, Bitsko RH, Radhakrishnan L, et al. Mental health-related emergency department visits among children aged <18 years during the COVID-19 pandemic — United States, January 1–October 17, 2020. *MMWR* 2020;69(45):1675–80.
- [64] Gill PJ, Mahant S, Hall M, et al. Reasons for admissions to US children's hospitals during the COVID-19 pandemic. *JAMA* 2021;325(16):1676–9.
- [65] Krass P, Dalton E, Doupnik SK, Esposito J. US pediatric emergency department visits for mental health conditions during the COVID-19 pandemic. *JAMA Netw Open* 2021;4(4):e218533.
- [66] Hoffmann JA, Duffy SJ. Supporting youth mental health during the COVID-19 pandemic. *Acad Emerg Med* 2021; <https://doi.org/10.1111/acem.14398>.
- [67] Penner F, Hernandez Ortiz J, Sharp C. Change in youth mental health during the COVID-19 pandemic in a majority Hispanic/Latinx US Sample. *J Am Acad Child Adolesc Psychiatry* 2021;60(4):513–23.
- [68] Ameis SH, Lai MC, Mulsant BH, et al. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. *Mol Autism* 2020;11; <https://doi.org/10.1186/s13229-020-00365-y>.
- [69] Golberstein E, Wen H, Miller BF. Coronavirus disease 2019 (COVID-19) and mental health for children and adolescents. *JAMA Pediatr* 2020;174(9):819–20.
- [70] Shattuck PT, Orsmond GI, Wagner M, Cooper BP. Participation in social activities among adolescents with an autism spectrum disorder. *PLoS One* 2011;6(11); <https://doi.org/10.1371/journal.pone.0027176>.
- [71] Fitzpatrick SE, Srivorakiat L, Wink LK, Pedapati EV, Erickson CA. Aggression in autism spectrum disorder: Presentation and treatment options. *Neuropsychiatr Dis Treat* 2016;12:1525–38.
- [72] Keenan BM, Newman LK, Gray KM, et al. Parents of children with ASD experience more psychological distress, parenting stress, and attachment-related anxiety. *J Autism Developmental Disord* 2016;46(9):2979–91.
- [73] Lawson M, Piel MH, Simon M. Child maltreatment during the COVID-19 pandemic: Consequences of parental job loss on psychological and physical abuse towards children. *Child Abuse Negl* 2020;110(Pt 2):104709.
- [74] Bate J, Pham PT, Borelli JL. Be my safe haven: Parent-child relationships and emotional health during COVID-19. *J Pediatr Psychol* 2021;46(6):624–34.
- [75] Liu G, Wang S, Liao J, et al. The efficacy of WeChat-based parenting training on the psychological well-being of mothers with children with autism during the COVID-19 pandemic: Quasi-experimental study. *JMIR Ment Health* 2021;8(2); <https://doi.org/10.2196/23917>.
- [76] Forrest DL, Kroeger RA, Stroope S. Autism spectrum disorder symptoms and bullying victimization among children with autism in the United States. *J Autism Dev Disord* 2020;50:560–71.
- [77] Karpur A, Vasudevan V, Lello A, et al. Food insecurity in the households of children with autism spectrum disorders and intellectual disabilities in the United States: Analysis of the National Survey of Children's Health Data 2016–2018. *Autism* 2021; <https://doi.org/10.1177/13623613211019159>.

- [78] Panjwani AA, Bailey RL, Kelleher BL. COVID-19 and behaviors in children with autism spectrum disorder: disparities by income and food security status. *Res Dev Disabil* 2021;115:104002.
- [79] Fitzpatrick KM, Harris C, Drawve G, Willis DE. Assessing food insecurity among US adults during the COVID-19 pandemic. *J Hunger Environ Nutr* 2020;16(1):1–18.
- [80] Dubowitz T, Dastidar MG, Troxel WM, et al. Food Insecurity in a Low-Income, Predominantly African American Cohort Following the COVID-19 Pandemic. *Am J Public Health* 2021;111(3):494–7.
- [81] Hash PM. Remote learning in school bands during the COVID-19 shutdown. *J Res Music Educ* 2020;68(4):381–97.
- [82] Onyema EM, Eucheria NC, Obafemi FA, et al. Impact of coronavirus pandemic on education. *J Educ Pract* 2020;11(No. 13); <https://doi.org/10.7176/jep/11-13-12>.
- [83] Carpenter D, Dunn J. We're all teachers now: Remote learning during COVID-19. *J Sch Choice* 2020;14(4):567–94.
- [84] Goudeau S, Sanrey C, Stanczak A, et al. Why lockdown and distance learning during the COVID-19 pandemic are likely to increase the social class achievement gap. *Nat Hum Behav* 2021;5(10):1273–81.
- [85] Rigles B. The relationship between adverse childhood events, resiliency and health among children with autism. *J Autism Dev Disord* 2017;47(1):187–202.
- [86] Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experiences (ACE) Study. *Am J Prev Med* 1998;14(4):245–58.
- [87] Berg KL, Acharya K, Shiu CS, et al. Delayed diagnosis and treatment among children with autism who experience adversity. *J Autism Dev Disord* 2018;48(1):45–54.