

Short Communication

The impact of the COVID-19 pandemic on children with autism spectrum disorders

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Abstract. In the unprecedented disruption and social isolation of the COVID-19 pandemic, families around the world are faced with questions of how their children can thrive in these conditions. On top of the ubiquitous challenges for all children, this public health crisis imparts unique difficulties for children with special health needs. We identify children with Autism Spectrum Disorder (ASD) as being particularly vulnerable to negative impacts of the COVID-19 pandemic. In this paper, we examine why children with ASD are uniquely vulnerable, recommend strategies to mitigate these stressors for children with ASD and their parents, explore the potential challenges of reintegration into society as conditions improve, and examine the obligations of healthcare and community stakeholders to support these families.

Keywords: Autism Spectrum Disorder, COVID-19 pandemic, social isolation, childcare strategies

1. Introduction

Although children have fortunately carried a lower disease burden from COVID-19, it is apparent that they are experiencing adverse effects from the pandemic [1,2]. The suspension of in-person education, extracurriculars, social activities, and routine healthcare threaten children's physical and mental wellbeing. Families around the world are faced with questions of how to best support their children under these conditions. The pandemic has been even more disruptive for those with special health needs. Children with Autism Spectrum Disorder (ASD) are particularly vulnerable to negative consequences of the COVID-19 pandemic. In this paper, we describe these challenges and propose strategies for parents and healthcare providers invested in the wellbeing of these children.

2. Children with ASD as a vulnerable population

The COVID-19 pandemic has disproportionately affected persons with special needs, including children with autism spectrum disorder (ASD) (Table 1) [3–5]. The disruption in their usual medical care is likely to result in an increase in missed autism diagnoses as children aged 18 to 24 months may have their well-child visits and ASD screening postponed or cancelled [6,7]. Yet, delayed ASD treatment has been shown to severely worsen behavioral and cognitive outcomes [7,8]. Additionally, ASD often co-occurs with physical disabilities, including epilepsy and cerebral palsy, which may increase risk of severe complications from COVID-19 [9,10].

Hallmark features of ASD put children with ASD at greater risk for being negatively impacted by the COVID-19 pandemic. Children with autism have difficulties with social communication, and therefore thrive most when they are immersed in caring, supportive environments that gently challenge their social development (often through school, play dates, and therapies, described below). Thus the very nature of social isolation during the COVID-19 pandemic makes this virtually impossible to do with anyone other than immediate

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Table 1
Challenges faced by children with ASD and their caregivers before and after the COVID-19 pandemic

Existing challenge	New challenge	Short-term consequence	Long-term consequence
Completing diagnostic ASD testing following screen during well-child visit	Completing initial ASD screen when children may not be attending well-child visits	Delayed screening will lead to delayed diagnostic ASD testing and delayed treatment	There are critical periods of development in which therapies can make the most difference – delayed long-term treatment can lead to worsened cognitive, language, and behavioral outcomes
Co-occurrence with disabilities and autoimmune disorders	Increased risk of severe complications from COVID19 infection due to autoimmune disorder	Further treatment and careful care required, especially during the COVID19 pandemic	Globally worse future health outcomes, including mortality
Attending speech therapy, occupational therapy, and ABA services in school and at office	Providing ABA services, therapy, and other educational lessons at home without specialists' help while working from home and/or homeschooling other children	Decreased access to quality therapy and increased stress placed on parents/caregivers	Decreased regular access to in-person quality therapy, which can lead to worsening long-term behavioral outcomes and failure to develop skills
Paying for ABA services, which are usually at least partially covered by insurance	Paying for online ABA services, which may not be covered by insurance, and which requires a computer and home internet access	Financial burden, made worse by economic uncertainty during the pandemic	Foregoing therapies entirely due to cost, which can lead to worse long-term behavioral outcomes

family members. Children with ASD also do best when daily routines are predictable [11]. However, COVID-19 has eliminated all such predictability. Those with ASD may communicate their distress to the uncertainties of the pandemic through aggression, tantrums, or refusals to engage in daily activities. While physical activity can provide a calming and regulating effect, they may not have access to indoor or outdoor spaces for such activities. Additionally, picky eating and oral aversion can be an existing challenge for children with ASD that may be exacerbated by the unavailability of their favorite food at a restaurant or in the grocery store. Also, mandated masks are especially bothersome to any child who experiences sensory sensitivities and may not understand the reasoning for them.

Unfortunately, therapies that normally mitigate these challenges are also limited during this time. The gold standard therapy for many children with ASD is called applied behavior analysis (ABA) therapy. Therapists employ ABA to understand the underlying reason for challenging behaviors and identify actionable steps for the families to prevent them. ABA is often intensive, occurring 15–25 hours/week for many, depending on their age and needs. This therapy targets social, communication, and academic skills through positive reinforcement. There are many logistical barriers to delivering ABA services and other therapies for ASD (speech and occupational therapy) without considering the challenges the stay-at-home instructions present (Table 1) [12]. In-person social interactions are also key naturalistic interventions for children with ASD

that are a benefit of school in addition to more specific modalities such as speech therapy, social skills groups, or smaller classroom settings [13,14]. Given social distancing executive orders in many states, therapy in the classroom and at the doctor's office must be delivered in the home instead. Unfortunately, many ABA therapy centers do not include online programming [1]. Even if it were offered, these services may not be covered by insurance and often rely heavily on parents to deliver therapy. Furthermore, many children may not have the capacity to effectively engage in a virtual environment due to attention challenges or difficulty transferring skills learned on the computer screen to in-person activities and social situations.

The economic downturn causing lay-offs, furloughs, and pay cuts has also resulted in loss of insurance benefits for many families [15]. Though Medicaid is an option, there are additional barriers to access given long wait times and temporary closures at Community Mental Health agencies across the country [16]. Out-of-pocket costs for ABA therapy are untenable for the vast majority of families. Furthermore, shifting the responsibility for therapy primarily to parents is not a feasible expectation for many families, particularly those with limited resources who will likely encounter greater barriers to engaging in therapy (less financial latitude, greater likelihood of essential service work, and more responsibilities as home-based caregivers for other family members). This deepens the developmental gap between those with adequate resources and those without. Structural disparities may also make it impossible for

Table 2
Recommendations for modification of ASD care due to stay at home orders during the COVID19 pandemic

Typical comprehensive ASD care	Modified social-distancing ASD care	Opportunities for support from healthcare system
Speech therapy, occupational therapy, and ABA services provided by 1-on-1 tutors	Speech therapy, occupational therapy, and ABA services provided by caregivers	Access to online ABA services and therapy, including resources such as laptops, covered by insurance
Naturalistic and structured therapy provided in-person with peers at school	Naturalistic therapy provided through in-person interaction with other(s) in home	Access to classes for caregivers and face-to-face support for caregivers with providers and therapists
Reinforcers appropriately provided when needed to incentivize social behaviors	Token-based economy to balance lack of access to certain reinforcers (e.g., specific food that may not be available) and free access to other reinforcers in the home	Access to necessary reinforcers through insurance
Routine maintained by regularly-scheduled school, activities, and therapy	Routine maintained by blocks of activity (such as meals, walks, and household chores) with clear transitions set with timer or location in the house	Access to resources such as sample schedules from providers and therapists

services to be effectively delivered in the home setting, as not all families have an available computer or internet access.

3. Recommended strategies to mitigate distress

Each caregiver has the best understanding of what works for the child and family. There is no one-size-fits-all approach. Thus, the recommendations provided here are meant to serve as a starting point (Table 2), and may vary by age (e.g.: more intensive interventions for younger children or those with more severe symptoms versus more social skills-based and naturalistic interventions for older children). Given the abrupt change in daily life, challenging new behaviors or behavioral regressions might arise as a mechanism of coping or communication. Understanding the motivation behind these behaviors is key to mitigating them – which often occurs through ABA therapy. This approach has been successfully implemented in Italy, which has developed the infrastructure to administer ABA therapy via telemedicine. In this program, children are provided ABA therapy of different intensity based on their needs [17]. Verbally interactive children receive direct daily sessions with an ABA “tutor” via telehealth using PowerPoints and shared screens. The tutor and family meet twice a week to assess progress. For preschool-age and minimally verbal children, parent coaching systems consist of daily parent coaching and child interaction sessions.

If ABA therapy is unavailable, positive reinforcement may be the most powerful behavioral tool; however, this can be time-consuming. Normally while at home, children are given free access to items and ac-

tivities without being required to complete a task beforehand. In addition, parents are given a basic program of maintenance to prevent significant skill loss [17]. However, these regular reinforcement options are now limited (e.g.: ability to go to the store or pool). Some recommend using a loose token-based economy, where a desired activity should be completed before children are able to “shop” for tokens or rewards (e.g.: stickers, opportunities for tablet play) during the day. To optimize efficacy, it is important to structure reinforcement activities where the child is frequently successful and earns tokens. Other strategies include mixing harder tasks with easier (more preferable) ones that can help children accomplish the less-preferred tasks with more success, which could be accomplished using a “first-then” statement and pairing with a visual picture. For example, a parent may ask a child to “first complete one page of schoolwork in the morning (show picture of schoolwork), then they get to feed the family pet (show picture of pet)” [18].

Other behavioral approaches include creation of a visual daily schedule, which can be as simple as a paper with written/drawn activities [19]. Structuring days into blocks of activities based on primary needs (such as meals and naps) can help maintain consistency. Some have suggested making transitions clear with timers. Independent activity can be extremely useful for providing parent relief during stay-at-home orders. This might be followed by a time that is more parent-intensive (e.g.: crafts, baking), as young children may have trouble tolerating long stretches of independent work. If families have the latitude, one particular skill that may be helpful for high-functioning children with ASD is to include activities that naturally incorporate social goals (e.g.: writing letters to peers, setting aside time to call rela-

tives, and playing board games which can encourage turn-taking and reciprocity). For families interested in other educational resources, Dr. Sally Rogers created an app called “Help is in your Hands” containing videos, lessons, and worksheets that promote social, play, and language skills [20].

4. Management of parental stress

The stress, anxiety, and disruption for children with ASD brought on by the pandemic is also experienced by parents [15]. The majority of U.S. parents report that financial concerns due to the pandemic are interfering with their ability to parent [21]. Some parents are essential workers with limited options for childcare. Others report an increase in conflict with their children, using harsh words, and physical punishment that would not normally be implemented [21]. Clinicians and specialists advising families might have opportunities to underscore and validate the unprecedented stressors families face, while helping parents problem-solve and empowering their self-efficacy and self-care. One resource addressing the unique stressors for parents of children with ASD includes Acceptance and Commitment Therapy, which promotes psychological flexibility and self-care [22]. Another longitudinal randomized controlled trial showed that parents following the Early Start Denver Model had greater improvements in distress and parental-child dysfunctional interactions [23].

5. Reintegration into society

It remains unclear when children can safely resume their usual educational and recreational activities. These uncertainties create difficulties in planning future routines, especially for parents of children with ASD. Waves of viral spread and reimplementing of stay-at-home orders are possible, bringing more unpredictable change [24]. The loss in social-emotional and language practice and progress that have occurred during this time may make re-engagement with peers more challenging. Furthermore, as the nation plans a gradual return to daily activities and economic re-opening, continuous adjustment to new routines may lead to a stressful changing environment and exacerbate behaviors specific to ASD. As the conditions of the pandemic change, parents will face uncertainties about how to proceed: should they transition their children with ASD slowly back into society with other community members, risk-

ing re-entry only to later return to quarantine conditions? Or instead should they wait until they are reassured that the pandemic is definitively contained and make one slow transition? Parents may not get a choice in the matter; they may need to return to work, whether or not their children are impacted by continued school closures. Also they may be forced to employ childcare workers unfamiliar with the child or ASD, adding a new component to the already stressful environment. In the inevitable circumstance that some parents do not have the financial or social resources for childcare, the reopening of workplaces will only worsen the deep and pervasive structural inequities they already face [25].

6. Conclusion

Children with ASD are a particularly vulnerable population in the COVID-19 pandemic due to the potential for exacerbation of ASD symptoms, limited access to therapy, and the overwhelming responsibility placed on their caregivers. The medical community (healthcare providers, behavioral specialists, and others) has an obligation to aid families with ASD as they navigate this time [26–28]. Even without the pressures of COVID-19, parents face many obstacles in obtaining high quality care (Table 1) [29,30]. Yet, it is these very services which enable children with ASD to thrive and contribute in positive ways [31,32]. Because they are more adversely affected by prolonged social isolation, communities should consider allowing children with ASD to take priority in returning to school when safe [4,33]. Healthcare providers can promote children’s wellbeing by providing online resources and advocating for structural changes that support families [34,35]. From a public health standpoint, policymakers can optimize funding for the mental health, material, and financial supports for stressed families. Schools should be provided the resources and training to deliver services to children with ASD in formats that can be adapted to the challenges of a pandemic. Collaboration among individual and community stakeholders is instrumental in helping children with ASD and their families thrive during a public health crisis.

Conflict of interest

The authors have no conflict of interest to report.

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