

# The Experience of Parents of Children with Autism Spectrum Disorder During the COVID-19 Pandemic: A Qualitative Analysis

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## Research Article

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# Abstract

Families with children with autism spectrum disorder (ASD) face a unique set of challenges with the rise of the COVID-19 pandemic and shelter-in-place related to a diverse set of issues, including explaining COVID-19 and safety precautions in a comprehensible way, building structure in home for e-learning to take place, and guiding children back into social situations and the community. We sought to obtain direct feedback through semi-structured interviews from fifteen parents of children and adolescents from a non-public school for children with level 2 and 3 ASD to both develop an initial guide for families, teachers and clinicians caring for children with ASD and to create awareness in the community about the challenges presented by COVID-19 and shelter-in-place.

## Introduction

“It’s stressful,” a phrase that anyone can relate to during this Coronavirus (COVID-19) pandemic, but which rings especially true for parents of children with Autism Spectrum Disorder (ASD). Parenting stress is higher in children with ASD (versus stress in parents with typically developing children and children with developmental disabilities; Estes et al. 2013), and this baseline stress is exacerbated by the enormous changes occurring due to this pandemic and the shelter-in-place requirement. On top of jobs and typical daily duties, parents are being asked to become around the clock babysitters, teachers and therapists for their children with ASD. Due to the unprecedented nature of the changes to family life occurring during the COVID-19 pandemic and the dearth of research on this topic, we implemented this qualitative study to identify the range of experiences occurring in families of children and adolescents with ASD.

From the start of the COVID-19 pandemic and well into the foreseeable future, families with children with ASD face unique sets of challenges. As autism is a spectrum, not all families will face the same challenges, and those who do face similar challenges will experience them in varying degrees. In such a heterogeneous population there is no one size fits all prescription. However, through this study we aim to identify some general challenges and highlight strategies families are currently using to address the unique experiences of supporting a child with ASD amidst a worldwide pandemic.

## Methods

This study was approved by the UCSF CHR on April 30, 2020. Parents of children and adolescents from a non-public school or children with level 2 and 3 ASD were recruited through an email from the school director and interested families were contacted by the study team. The study consisted of a parent semi-structured phone interview. The parent interviews were comprised of 18 to 24 questions, as some were optional/skipped as the relevance of a question sometimes depended on the student’s communication capabilities. The questions followed a template that asked about the following topic areas: general COVID-19 experiences and concerns, changes in the child’s mood and behavior, changes in parent mood

and behavior, and coping/advice. Post-data collection, quotes and descriptions were reviewed and grouped into thematic areas.

## Results

Parent interviews (n=15) lasted between 27 to 57 minutes and were conducted from May 4 to May 14 (seven to eight weeks into shelter-in-place). The students of the parents who participated ranged in age from 11 to 21. All parents included in analysis had a child with ASD.

## Discussion

### Discussions Surrounding COVID-19 & Safety Precautions

*"We got three picture frames [into the social story] and then he lost interest...the pictures were too high level of communication."*

*"[The school] had a story book that I read to him. [I'm] not so sure he comprehended it. I basically said that we can't go outside for a little while. I visually showed him by coughing."*

The first challenge that arose for these families was how to explain the COVID-19 pandemic and safety precautions to their children with ASD. With receptive and expressive language skills often being lower in an ASD population (Maljaars et al. 2012), parents had to get creative with their explanations. Many schools and ASD organizations recommended the use of social stories. Social stories break down challenging and confusing situations into digestible parts by using simple language and visual aids. The goal of social stories is to help individuals with ASD "understand and interact appropriately in social situations" (Ali and Frederickson 2006). Social stories should be individualized to meet the students' needs and interest in order to increase engagement and understanding (Gray and Garand 1993). Many families reported using social stories, but the success rates varied.

Although news sources are typically the main source of information about COVID-19, The Child Mind Institute recommends limiting children's exposure to the news as it may lead to increased anxiety which can trigger a multitude of related anxiety provoked behaviors (Dyson 2020). Some parents reported not wanting to tell their child about the "scary parts" of the virus, such as "it [causes] a lot of deaths." One reported that "there's no real reason to try and tell [my child] there's a virus out there" as this child has low receptive language. Conversely, there are children who are watching the news and forming their own opinions on the current socio-political climate. Somewhere in between those two ends of the spectrum lay the children who were able to grasp that it's a "bad virus." Many of those families have gotten the point across by explaining that they can't leave their home to partake in their usual activities, such as school or extracurriculars. A common difficulty that arose due to the children's varying receptive skills was the ability to explain the uncertainty of when the pandemic would be over and when the children would be able to return to their normal day activities. As evident, there are many ways to explain COVID-19 and

safety precautions to children with ASD, and parents must use the tools available and their best judgement to figure out what will best meet their child's language abilities, and emotional well-being.

## **Transitions**

*"[My child] thrives in routine— knowing exactly what goes on in his school day is a source of comfort. He loves his school and receives so much support. That just stopping quickly without any logical explanation, he knew it wasn't spring break or summer break so it didn't make sense that huge structure was all the sudden gone."*

The next challenge families faced was transitions; transitioning into a shelter-in-place lifestyle, and transitioning from one activity to the next. For children with ASD, transitions and changes in routine can feel very disruptive. This can lead to severe behavior problems such as crying, heightened aggressiveness and refusal to transition (Schreibman et al. 2000). When transitions normally occur in the lives of children with ASD, priming and warnings are utilized to ease the child into the change (Flannery and Horner 1994; Schreibman et al. 2000). However, with the abruptness of the shelter-in-place enactment, there was not ample time to implement appropriate transition tools.

While some parents reported their children adapted without a major fuss, thinking of it as school break/vacation, other parents reported their children were disturbed by the transition. Other parents also reported that their children immediately felt the effects of a broken routine— missing the travel to school, the structure of classes, teachers, and friends. Some even reported that their child's mood and behavior immediately changed, in which some children were angry, confused, sad, and displayed more hyperactivity.

To make transitions easier, Stoner et al. (2007) suggest understanding what works best for the child, planning in advance, and communicating openly and honestly. Understanding and communicating can be achieved using the strategies discussed in the section above; use engaging tools that can effectively get the message across at a communication level that works for your child. Planning in advance may seem difficult in a time of uncertainty, but one parent suggests giving far-out deadlines that your child can look forward to. For example, her child was disappointed and perseverating on being unable to go to summer camp this year, so she redirected her child's attention by having him block out "summer camp" in his 2021 calendar.

## **Social Skills**

*"I resumed care providers because [my child was] getting very depressed... They come a couple days a week and take him to his friends' apartment... He's very social."*

*"At school [my child gets] more interactions because he's there with them for many hours versus short burst."*

With the transition into e-learning, there was less opportunity for children to interact in person with their peers. Children with ASD prior to shelter-in-place already reported higher levels of loneliness and a lack of peer support compared to typically developing children (Bauminger and Kasari 2000). Without being in a supportive classroom setting surrounded by peers, loneliness especially in a time of stress, may be exacerbated. Family members also provide a social context and support for children with ASD, however, interacting with members outside of one's family (peers, teachers, strangers) plays a large role in a child's social development and exploration.

There are some safe modes of communication that children can engage in social activity with their peers. For those students who were uninterested in the visual cues of video conferencing, Discord, an audio-only application was utilized. One father reported being "blown away" by his sons' ability and desire to write emails to other extended family members. Parents recommended different ways their child remained connected with their communities: Doing activities (such as cooking, dancing, or playing 20 questions) over video conference with social groups (or individuals) the child was previously involved with, and driving by other students houses for short, socially distant conversations. One parent mentioned that the therapist engages the students over a video game platform to promote conversation among peers. Although in-person interactions with peers are unlikely during COVID-19, there are some ways around it.

## **E-learning**

*"There's frustration of knowing I'm not a teacher, husbands not, and ABA therapist isn't a teacher, and were all trying, but it's so hard."*

*"I need to check in on him to find out whether he's progressing or whether he's lost interest and I need to re-engage him with the process. Most of our day is a staccato progression towards his assignments."*

E-learning helped reinstitute some structure into the children's lives, but parents would be asked to assist the learning at home, a job normally primarily handled by teachers and aids. Along with e-learning came an assortment of new challenges. There are those who still have work and must balance a work from home schedule while assisting their children, and those who have become unemployed, which is accompanied with an entirely different slew of stressors. Many parents expressed the need to be constantly supervising and facilitating their child to have them engage in their work. Conversely, sometimes a child would be so engrossed in an activity that the child would get visibly frustrated when the parent tried to help transition to the next activity. Transitioning from one activity to another can be hard for a child with ASD but creating structure in the student's daily routines can help the transitions run smoothly.

## **Structure**

*"He's shown more independence– haven't had to tell him to come down and do things. The schedule is good... [He's] managing his own time."*

Implementing a daily schedule looks different for each family. For those children with more severe ASD, visual schedules, such as laminated pictographs (ex. toothbrush, books) arranged in a particular order best met the child's needs. One parent worked with the teachers to create videos of daily routines so that the child could watch and learn from models to set expectations for the day. Another student has "a big board where everything is mapped out for the week" and has his own checklist for each day. Before starting classes, one child spends 30 minutes writing out his schedule in 30-minute time blocks. Alternatively, some students rely on more of an internal clock as routines have been so engrained, they know that when they wake up they should make a cup of tea, or at two o'clock it's time for reading. Whether the daily schedule is explicit or part of a natural circadian rhythm, families have expressed many benefits that coincide with setting expectations through schedules.

Schedules help create structure and fill time for the children, even if they aren't fully engaging with the activities planned. For example, one child wakes up every morning and participates in an exercise class. Although he doesn't fully participate in the movements, the mother reports it's an "anchor...to feel like 'okay, here we are in a new day.'" Many parents felt like structure makes both their own and children's lives more enjoyable.

## **Rigidity**

*"We were gung-ho with structure and working on school, but over time we've asked him to do less to avoid conflict and stress with him."*

*"[My child's] sister is back from college. She has her own coping skills, she just disappears."*

Not only did schedules have to change, but physical environments and relationships were also restructured due to shelter-in-place. One telltale characteristic of ASD is being rule ridden and boundary driven (Poljac et al. 2017). To put it simply, "home should stay at home and school should stay at school" was a sentiment felt by many of the students.

This rigidity has made it difficult for parents to implement e-learning. To combat this, one family mentioned designating a specific work area in the child's room as to physically separate school and home. While this works for some families, others report that the boundary is more than physical; the idea of "doing schoolwork at home violates a rule set in [my child's] head". One parent reported that trying to take on the role of a teacher created an unpleasant parent-child relationship, so they decided to stop pushing with academics all together. Focusing on creating structured environments can make the family feel as if "autism controls their daily lives" (DeGrace 2004). Sometimes focusing too much on the needs of the child with ASD can force the family to relegate the needs of other family members and decrease family participation in activities (DeGrace 2004; Larson 2006). Therefore, it's important to strive for a balance of structure that maximizes the family's productivity and happiness as a whole.

## **COVID-19 Related Stress**

*"[I am] very concerned because from a sensory perspective he hasn't learned to wear a mask. I don't know how he can tolerate it. It's not comfortable. And he doesn't understand social distancing."*

*"I can't take him to the grocery store because he'll scare somebody by getting too close to them."*

*"I feel stressed and concerned because he can't do social distancing so he's under house arrest basically."*

There are also some concerns that arise when shelter-in-place restrictions begin to lift. The CDC suggests that as a part of safe social distancing practices, people should stay six feet apart and wear a mask. This may cause some additional difficulties for those with ASD. Children with ASD are more likely to violate personal space than typically developing children (Kennedy and Aldophs 2014). Awareness of personal space is necessary when outside of the home to minimize the transmission of germs. Additionally, many people with ASD experience sensory sensitivity, and more specifically, in this case, tactile defensiveness (Ornitz and Ritvo, 1976). Tactile defensiveness is the inability to tolerate certain tactile materials. Children with ASD may feel discomfort wearing masks over their faces when in the community, which may lead to issues for the family when trying to enter establishments that require masks. Furthermore, failure to comply with the CDC's social distancing rules combined with a lack of understanding from the community about the challenges children with ASD may face, can lead to further stigma of the disorder.

To address the issues of masks, one mother created masks out of the characters her children liked to increase the likelihood they would wear them. In general, a few families expressed the need to ease the children back into society by having the school or community put on small preparation events where children could learn and practice COVID-19 safety precautions. Examples include having the teachers write social stories about the importance of wearing masks, as well as having their students practice wearing masks for short periods of time, over Zoom lessons with them and the students' therapist. Community talks and disseminating information regarding the challenges children with ASD might face due to the coronavirus is integral to decreasing stigmatization.

Lastly, please see Table 1 for a compilation of additional parental stressors that are important to be aware of.

## **Positive Changes**

*"He must have clipped his nails by himself. I didn't know he could do that."*

*"[He] might be a little happier. [He's] much more easy going because he's not on 'a treadmill,' on a strict schedule and tired."*

With the challenges that arise for children with ASD via e-learning, many families have decided to focus their efforts towards working on life skills. With more time at home, it has been easier for children to get into the routine of doing chores. Some families have noticed an increase in initiation when it comes to chores, such as doing laundry, or clipping one's own nails. Parents attribute the positive improvements in life skills to routine and being present and able to provide reminders.

As parents demand less academically, there were also some positive externalities that coincided with the shelter-in-place environment. Many parents reported a decrease in their child's anxiety and negative behaviors that are typically provoked by anxiety. There were reports of less self-injurious behaviors, such as hitting oneself when frustrated. Additionally, one parent reported that they had been experiencing "less blow up incidents at home than at school". Not only did some parents observe a decrease of problem behaviors, but some also noticed an increase in positive mood and behavior. One parent describes her child as "more affectionate... relaxed and not stressed out". Some parents spoke to the child's relaxed mood making it easier to get along with other family members. Another aspect parents have been happy about is that there was more transparency on their child's progress in school, even though that meant they were spending more of their own time aiding their child with schoolwork.

## **Parent Coping**

*"[I do] a really good meditation practice and use mindfulness techniques. It melts stress right off of me."*

*"I've seen a therapist. So for any anxieties, I don't take them out on my family."*

Although we predict parent stress to be heightened during these trying times, we also recognize that there are ways for parents to combat and positively cope with daily stressors. Pottie and Ingram (2008), identified five coping responses that can heighten a parents' mood: social support, positive refraining, problem focused, emotional regulation and compromise coping. Simultaneously, they identified four coping responses that decreased positive mood: escaping, blaming, withdrawal and helplessness.

Parents communicated both positive and negative coping techniques. Parents listed the following as coping responses to COVID-19: Exercising (walking, biking, yoga), meditation, praying, reading the newspaper, creative outlets (art, cooking, baking), attending virtual groups to connect with the community, self-care (taking a bath, doing nails, online shopping), having a glass of wine (or two), creating a private time/space (with or without spouse) away from the children to relax, and talking to family, friends, coworkers, and even counselors or therapists. For families who had more than one caregiver in the house, a few parents suggested the idea of "switching back and forth on rest breaks to not get too overwhelmed." One parent who was overwhelmed and found it hard to make time for herself said she was "laid out flat from this." Another parent mentioned that she finds herself yelling at her child when stress becomes overwhelming. Finding positive ways to decompress can be beneficial for both the parent and child.

## **Parent Advice**

*"Generic advice is tough. What may fit 'person a' may not fit 'person b.'"*

*"We try and do more relaxed rewards on the weekends—Friday night we pick a place to go get take out... he really enjoys that."*

One topic that parents provided varying responses on was how much structure to employ for their child with ASD. Although providing structure is recommended for children with ASD, having a balance and allowing the child some choice in routine can also be beneficial to increase flexibility and reduce rigidity. For example, one mother said that every morning her child starts the day with lessons, but her child gets to choose which one he would like to do first (ex. academic versus music lesson). The amount of structure one's child needs varies, but the families provided some good examples on how to make daily routines more enjoyable.

Many parents mentioned that they look for daily pleasures. They advise letting the children enjoy themselves (for example, by allowing them to play outside on the trampoline), and to reflect on the precious moments one has with their child. Many parents mentioned that it's important to remember that they are not typically teachers or therapist for their children; thus, they should give themselves leeway if things aren't going perfectly, and not let these new roles create too much of a shadow on one's relationship with the child. Some parents also mentioned that no matter how hard things get, it's important to stay strong for the family and child, and seek help from friends, family, coworkers, and mental health professionals when needed. Parents recommended allowing extra caregivers (such as grandparents or ABA therapist) into the home if it can be done in a safe manner. Another parent mentioned finding ways to delegate responsibilities to the student, so that parents can have a break, and so the student can feel a sense of independence from the parents like they would at school.

As evident, there are many challenges for families with children with ASD during COVID-19 and shelter-in-place. Transitioning back into the community with the phasing out of shelter-in-place will also be accompanied with stressors, but one can make it a little easier for these families by educating oneself on the difficulties those with ASD face and providing solicitude. While spreading awareness about the challenges of COVID-19 is important to help end the stigmatization of ASD, one parent also reminds others to "be compassionate— we want to give whoever we're dealing with the benefit of doubt, because this is stressful for everyone."

## **Limitations And Future Directions**

This study provides insight into both the challenges and potential solutions to the numerous complex issues that arise when parenting children with ASD during a pandemic. Although the parents provided a wealth of information regarding their COVID-19 and shelter-in-place experiences, the study was limited by the relatively small sample size. Future researchers could consider larger samples and quantitative approaches to coding the interview responses. We hope that this initial report provides useful suggestions for families and teachers while increasing awareness and support regarding the magnitude of this challenge for families affected by ASD.

## **Declarations**

**Consent to participate:**

The participants consented to participate through an informed consent process approved by the UCSF CHR on April 30, 2020

### Competing interests:

The authors declare no competing interests.

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## Tables

**Table 1** *Additional Parent Stressors*

<p><b>Missing Opportunity to Learn/ Aging out of program</b></p>	<p>“Great family, nice home, and great set up, but he’s getting older and his neuroplasticity is starting to firm up—we are missing a window of growth.”</p> <p>“They’re never going to go back to school. I don’t know how long this is sustainable. We’re going to start seeing regression. Half an hour of video on computer is not going to do it.”</p> <p>“[My child was supposed to] focus on life skills and vocational inspiration. The school hasn’t been able to get to those things. If [shelter-in-place] continues on, I’m concerned it will take him longer to get ready to do some of those things.”</p>
<p><b>Problems with E-learning</b></p>	<p>“[E-learning is] significantly worse. It does not replace the 1 on 1, the physically being right there, at all. He does fine with 30-minute meetings, but it’s the whole day of it that has been so instrumental in his growth.”</p> <p>“Private sessions were reduced to half an hour because being in front of the screen is impractical.”</p> <p>“He’s visually defensive so he has a hard time focusing on the screen. In person it’s hard to get him to look at you. He peers with his eyes so it’s not an ideal situation for him. He’s much better 1v1”.</p> <p>“He’s very tactile and sensory seeking. Needs to be able to lean in and feel things. Needs someone there, hand over hand, guiding him to do [work].”</p> <p>“When we’re doing e-reading, we would all interrupt each other causing [my child] to participate less.”</p> <p>“What is the expectation of e-learning... A lot of the times they’ll tell us things are optional, but on an academic level, I want to see progress, so when I have an IEP we can advocate that he’s still getting an education that can’t be matched at a public school.”</p> <p>Parents have also observed that implementing certain lessons and therapies over the phone do not translate as they do in person. For example, the occupational therapist will typically adjust the student’s posture, which is not feasible over a video conference.</p>
<p><b>Parents Facilitating/ Supervising E-learning</b></p>	<p>“It seems to be a nonstop workload” (for children and parents).</p> <p>“We are constantly on.”</p> <p>“[My child] can’t sit through a session without someone being next to him to keep him motivated and get him through.”</p>
<p><b>Social Skills</b></p>	<p>“You just can replace human interaction with zoom.”</p> <p>“Face to face is much better for socialization.”</p> <p>“At [school]...they had something they called ‘a coffee shop.’ They learned not only about the money and how to make [coffee], but also about interacting with people.”</p> <p>“They occasionally talk on discord, but that is just voice... visual cues don’t matter to him and he doesn’t really look at people.”</p>
<p><b>Eloping</b></p>	<p>“We don’t let him go anywhere. During lockdown we added a security system on the gates. There are two ways in/out and it’s hard to have eyes on him at every second... We are so afraid that he’s going to elope.”</p>
<p><b>Increase in Child’s Negative Moods and Behaviors</b></p>	<p><b>Changes in Behaviors:</b> hand flapping, pacing, stimming, perseveration, fidgeting, skin picking, crying, excessive self-talk, boundary pushing, and aggressive behavior (ex. physically attacking parent), sleep (ex. waking up early, going to bed late, or waking multiple time throughout the night), screaming and mania (however, probably attributed to a comorbidity), refusal to participate in activities the child used to normally engage in, mischief (ex. messing with parents grocery list; goofing around which lead to a couple of broken bones)</p>

**Changes in Mood:** irritable, testy, upset, worried, inattentive, sensory-sensitive, unmotivated, sad and withdrawn into their own world

**Language Related Declines:** stuttering, no longer wanting to use a communication device and no longer producing new words

\*Quotes have been altered for grammatical legibility and to hide the identities of participants