



COVID-19 Related Challenges and Advice from Parents of Children with Autism Spectrum Disorder

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Abstract

With the rise of the COVID-19 pandemic and shelter-in-place, families with children with Autism Spectrum Disorder (ASD) face a unique set of challenges related to a diverse set of issues. A qualitative study was conducted in the form of semi-structured interviews from fifteen parents of children and adolescents from a non-public school for children with ASD. Questions covered 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. Quotes and descriptions from the participants were reviewed and grouped into thematic areas. Findings showed that parents of children with ASD are facing a wide range of challenges, including explaining COVID-19 and safety precautions to their child in a comprehensible way, assisting with e-learning, and guiding their child back into social situations and the community. As children with ASD have difficulties with transitions, parents stated the importance of creating structure in the home by creating schedules and boundaries, while allowing for flexibility as to not over enforce the rigidity children with autism often face. Advice on coping with the additional stressors were also shared. Parents recommended finding time for themselves to reset, utilizing support systems, and reflecting on daily pleasures as positive coping mechanisms. This study aimed 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.

Keywords: Autism Spectrum Disorder; Coronavirus; E-learning; Parental Coping; Parenting Stress; Shelter-in-place.

1. COVID-19 Related Challenges and Advice from Parents of Children with Autism Spectrum Disorder

As the coronavirus disease 2019 (COVID-19) pandemic continues to spread, with over 21 million confirmed cases globally as of August 14, 2020, there has been growing concerns regarding the emotional and psychological distress it poses among the general population and those suffering from pre-existing mental health disorders alike [1, 2]. In particular, the effect of the pandemic in exacerbating symptoms of mental health disorders cannot be overlooked [2]. Among these vulnerable populations are individuals with Autism Spectrum Disorder (ASD). Estimated to affect 1 in 68 children, ASD is characterized by impairments in social communication and restricted, repetitive or unusual patterns of interests, behavior or activities [3, 4]. One common feature of ASD is obsession with routine [4]. As such, disruptions in this routine due to COVID-19 may result in substantial emotional and behavioral changes among children with ASD [5], which in turn would present further challenges to their parents and caregivers.

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Changes in routine can lead to challenging behaviors such as noncompliance, aggression, stereotypy and tantrums [6]. Flannery and Horner [7] hypothesized that adolescents with ASD had aversions to transitions because of the lack of predictability. They discovered that when cues were used to signal a transition in both familiar and unfamiliar tasks, problem behaviors, such as losing focus or repetitive behaviors, were reduced. There are teacher trainings and books on how to manage transitions in a classroom successfully, but it is especially challenging for parents to pick these strategies up impromptu while juggling their own schedules during of shelter-in—place [8, 9]. Furthermore, anxiety can provoke problem behaviors in children with ASD [10]. Anxiety and fear are more prevalent in children with ASD versus typically developing children and the stress stemming from COVID-19 can only be expected to exacerbate these anxiety-related problem behaviors [11-13].

Parents play a crucial role in care and management of children with ASD and face numerous additional stressors associated with this task [14]. Indeed, parenting stress is higher in children with ASD compared to stress in parents with typically developing children and children with developmental disabilities [14]. This baseline stress is likely to be 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. As such, it is expected that, from the start of the COVID-19 pandemic and well into the foreseeable future, families with children with ASD face unique sets of challenges.

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. We recognize that 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 that families are currently using to address the unique experiences of supporting a child with ASD amidst a worldwide pandemic.

2. Methods

This qualitative study was approved by the UCSF CHR on April 30, 2020 and had a phenomenological study design. Parents of children and adolescents with ASD from a non-public school were recruited through an email from the school director and interested families were contacted by the study team by convenience sampling (See Figure 1). The study consisted of semi-structured phone interview with the parents. The parent interviews (n=15) were comprised of 17 to 23 questions (see Appendix I), 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. Field notes consisting of paraphrases (for efficiency) and direct quotes were recorded during the interview. Post-data collection, quotes and descriptions given by the participants were reviewed by the study team and grouped into key thematic areas.

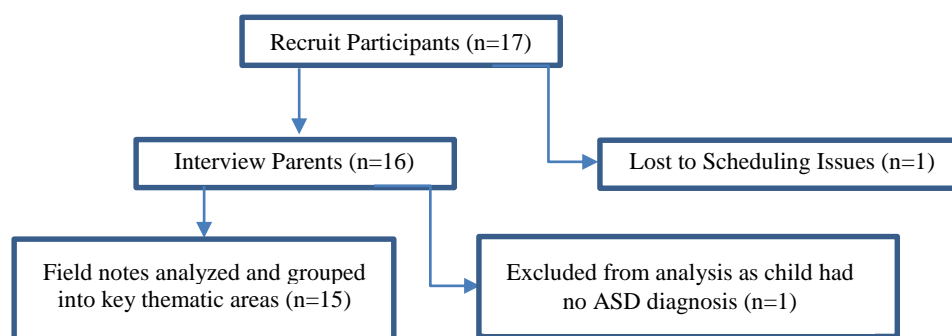


Figure 1. Methods Flow Chart

3. Results and Discussion

Fifteen parents were interviewed for the purpose of this qualitative study. Parent interviews lasted between 27 to 57 minutes and were conducted from May 4 to May 14 (seven to eight weeks into shelter-in-place in their area of residence). The students of the parents who participated ranged in age from 11 to 21. All parents included in analysis had a child with ASD.

In the following sections, interview comments are grouped into thematic areas that illustrate the types of challenges, experiences, advice, or coping strategies experienced by the parents. This is followed by a discussion of

how caregivers and the community might better understand these experiences and provide a more supportive environment.

3.1. Discussions Surrounding COVID-19 and Safety Precautions

The first challenge that arose for 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 [15], 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” [16]. Social stories should be individualized to meet the students’ needs and interest in order to increase engagement and understanding [17]. Families reported using social stories, but the success rates varied. Many accounts echoed the following: “We got three picture frames in and then [my child] lost interest...the pictures were too high level of communication.” Those families who relinquished the social stories found alternatives such as miming symptoms (i.e. coughing) and giving vague statements such as “we can’t go outside for a little while”. Social stories can be useful aids, but do not lend themselves as the solution for all families.

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 [18]. 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. 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.

3.2. Transitions

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 [19]. When transitions normally occur in the lives of children with ASD, priming and warnings are utilized to ease the child into the change [7, 19]. 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. One mother stated that her 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.” 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. [20] 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 communicate the message at a language level that works for the child. Planning in advance may seem difficult in a time of uncertainty, but one parent suggests giving far-out deadlines that the child can look forward to. For example, one mother’s 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 write out “summer camp” in his 2021 calendar.

3.3. Social Skills

With the transition into e-learning, there was less opportunity for children to interact in person with their peers. For example, “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.” The students are missing the opportunity to participate in organized social activities and are also not being immersed in prolonged natural social situations with their peers by

isolating at home. 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 [21]. Without being in a supportive classroom setting surrounded by peers, loneliness especially in a time of stress, may be exacerbated. This can lead to additional stressors for the family. As one mom recounts, "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." 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 where children can engage in peer-centered social activity. 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, parents were still finding creative solutions to foster some social connection.

3.4. E-learning

E-learning helped reinstitute some structure into the children's lives, but parents were asked to assist with the in-home learning, a job normally primarily handled by teachers and aids. With the new shoes to fill, one mom reports on the difficulties that coincide: "There's the 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." There are parents who 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. For example, one mother stated "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." 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.

3.5. Structure

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 were often the most successful for meeting 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 his own checklist for each day. Before starting classes, one child spends 30 minutes writing out his schedule in 30-minute time blocks. This parent also reports that her child has shown more independence: "I haven't had to tell him to come down and do things. The schedule is good... [he's] managing his own time." Alternatively, some students rely on more of an internal clock as routines have been so ingrained that they know that when they wake, they should make a cup of tea, or that 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 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.

3.6. Rigidity

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 [22]. 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 initially that they "were gung-ho with structure and working on

school, but over time [they've] asked him to do less to avoid conflict and stress with him," stopping academics all together as taking on the role of a teacher created an unpleasant parent-child relationship.

Focusing on creating structured environments can make the family feel as if "autism controls their daily lives" [23]. Sometimes focusing too much on the needs of the child with ASD can force the family to overlook the needs of other family members and decrease family participation in activities [23, 24]. For example, a sister of a student "is back from college. She has her own coping skills, she just disappears." Therefore, it's important to strive for a balance of structure that maximizes the family's productivity and happiness as a whole.

3.7. COVID-19 Related Stress

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. As one parent articulates, "[I am] very concerned because from a sensory perspective [my child] 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." Children with ASD are also more likely to violate personal space than typically developing children [25]. Awareness of personal space is necessary when outside of the home to minimize the transmission of germs. Many parents expressed similar concerns as the parents who stated the following: "I can't take him to the grocery store because he'll scare somebody by getting too close to them" and "I feel stressed and concerned because he can't do social distancing so he's under house arrest basically." Furthermore, people with ASD experience sensory sensitivity, and more specifically, in this case, tactile defensiveness [26]. Tactile defensiveness is the inability to tolerate certain tactile materials. Children with ASD may feel discomfort wearing masks when in the community, which may lead to issues for the family when trying to enter establishments that require masks. Failure to comply with the CDC's social distancing rules combined with a lack of understanding from the community about the challenge's 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 admired 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, during Zoom lessons with the students' therapist. Community talks and disseminating information regarding the challenge's children with ASD might face due to the coronavirus is integral to decreasing stigmatization.

Finally, Table 1 provides a more detailed list of parental stressors identified during the interviews.

Table 1. Additional Parent Stressors

<p>Missing Opportunity to Learn/ Aging out of program</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>Problems with E-learning</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>Parents Facilitating/ Supervising E-learning</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>

Social Skills	<p>“You just can replace human interaction with zoom.”</p> <p>“Face to face is much better for socialization.”</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>
Eloping	<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>
Increase in Child’s Negative Moods and Behaviors	<p>Changes in Behaviors: 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> <p>Changes in Mood: irritable, testy, upset, worried, inattentive, sensory-sensitive, unmotivated, sad and withdrawn into their own world</p> <p>Language Related Declines: stuttering, no longer wanting to use a communication device and no longer producing new words</p>

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

3.8. Positive Changes

With the challenges that arise for children with ASD via e-learning, many families decided to focus their efforts towards working on life skills. With more time at home, children are more easily getting into the routine of 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 changes that coincided with the shelter-in-place environment. Many parents reported a decrease in their child’s 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”. Another said her child “might be a little happier. [He’s] much more easy going because he’s not on ‘a treadmill,’ on a strict schedule and tired.” It was also mentioned that the relaxed mood made it easier for some children to get along with other family members. Lastly, even though parents were spending more of their own time aiding their child with schoolwork, parents were satisfied by the new transparency on their child’s progress in school.

3.9. Parent Coping

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 et al. [27] 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 found it difficult to make time for herself said she was “laid out flat from this.” Another parent mentioned that she found herself yelling at her child when stress became overwhelming. To combat this, one mother recommended seeing “a therapist, so for any anxieties, [she doesn’t] take them out on [her] family.” Finding positive ways to decompress can be beneficial for both the parent and child.

3.10. Parent Advice

As one parent nicely stated, “generic advice is tough. What may fit ‘person a’ may not fit ‘person b.’” Consequently, one topic that generated varying parent responses 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). Another family mentioned trying to do more relaxed rewards on the weekends, stating "Friday night, we pick a place to go get takeout... he really enjoys that." 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 community members can make life a little easier for these families by becoming more aware of the difficulties those with ASD face and providing empathy and support. 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."

4. 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.

5. Conclusion

The repercussions of COVID-19 and shelter-in-place have created extra challenges for families with children with ASD. The uncertainty surrounding the virus can pose and exacerbate communication difficulties between parents and children with ASD. The abrupt transition from in-person schooling to e-learning comes with its own set of challenges for the students—from the transition itself, to being unable to engage in ample social skills interactions and unable to sustain attention on a computer screen for adequate time without parental guidance. Parents also must adjust to these changes by becoming stand in teachers aids for their children during hours they would usually have to focus on themselves or their work. As families adjust to the new normal, parents provided some advice on how to create structure in the home while allowing for flexibility and modifying daily schedules and practices based on the child's behavioral and emotional needs. Parents note that it is important to continue education and therapy for their children throughout the COVID-19 pandemic, but also acknowledge how these unprecedented times can affect the safety and well-being of a family. Balancing the family dynamics and individual well-being has proven difficult with the extra stressors of COVID-19, but positive coping mechanisms such as connecting with support systems and reflecting on positive moments can help families to overcome these challenges. We hope that this initial report provides useful suggestions for families and teachers while increasing awareness and support in the community regarding the magnitude of challenges faced by families with children with ASD.

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8. Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

9. Ethical Approval

This study was approved by the UCSF CHR on April 30, 2020. All parents involved in the study signed a consent form giving permission for their deidentified information to be shared as a part of this manuscript.

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Appendix I: Parent Questionnaire

Please answer the following questions since shelter-in-place, which started March 17th. We hope for this to be sort of a therapeutic phone call where you can reflect on your shelter-in-place experiences. Remember you can skip any questions you feel uncomfortable answering!

Introduction

1. How has shelter-in-place affected you and your family?
2. How would you describe your discussions with your child about COVID-19? How did you explain COVID-19/safety precautions to your child? (Optional question—it may or may not be applicable to your child depending on child's communication abilities)
3. What does a typical day look like for you and your family since shelter-in-place?
4. What concerns do you have about the next couple weeks/months regarding your family and child?

Changes in Child

5. Have you observed any declines in your child's behavior? Please consider restricted and repetitive behaviors, social skills, aberrant behaviors (Ex. hyperactivity, irritability, lethargy, inappropriate speech).
 - a. Please describe the worsened behaviors and how you are addressing them.
6. Have you observed any improvements in your child's behavior?
 - a. Please describe the improved behavior(s).
 - b. If your child was previously receiving services such as ABA, are they still able to receive them?
7. Is your child getting along with others in your household? Is it worse or better than usual?
8. Do you know if your child is communicating more/less with classmates and friends? Is it more or less than usual? What modes is your child using to communicate with others (talking via phone, texting, video games; Optional question—it may or may not be applicable to your child depending on child's communication abilities)
9. Have you observed a change in your child's mood?
10. Please describe the changes in mood. What do you think caused those changes and how you are addressing them?
11. Have your child's self-care/ grooming behaviors (shower, cleaning room, brushing teeth) improved/worsened since the beginning of lockdown? How? (Optional)
12. Is your child exercising? (Optional)
13. What does exercise look like for your child during this time? Is it different than usual? (Optional)
14. Have your child's sleeping patterns changed?
15. How has your child's sleep schedule changed? Bedtime/wake time?

Changes in Parent

16. Has your own mood changed? To what do you attribute those changes?
17. Do you have a support system in place/ someone you can turn to to deal with the extra stressors?
18. What does that support system look like? (Optional)
19. As a parent it can be hard to find time to focus on yourself, are there any ways in which you are taking care of your own mental health during this stressful time? (Ex. Meditation)

Advice

20. What are some pros/cons you see with e-learning? Do you think it's better or worse than the instruction the child receives when physically in school?
21. In what ways can the school/UCSF/the community support you and your family during this time?
22. Do you have any advice to other parents of children with autism/NDDs towards dealing with COVID-19 & shelter-in-place?
23. Is there anything else you'd like to share with us?