Intolerance of Uncertainty, Sensory Processing, and Related Correlates in Autistic Children During the COVID-19 Pandemic

Mollie Bradley

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Intolerance of Uncertainty, Sensory Processing, and Related Correlates

in Autistic Children During the COVID-19 Pandemic

Mollie Bradley

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Master of Science

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Mollie Bradley
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Master of Science

The COVID-19 pandemic increased uncertainty and anxiety for most and was especially disruptive to autistic people and their families. Autistic children were particularly vulnerable due to their intolerance for increased uncertainty and disruption to their school and therapy support. This study aimed to investigate the effect that increased uncertainty had on autistic children, specifically their sensory behaviors and stress levels and on the stress levels of their primary caregivers. Parents and guardians of 47 autistic children completed an online survey consisting of questions investigating background and demographic information, their experiences during the first six months of the pandemic, information about the types of support that they were provided, and measures of intolerance of uncertainty (IUS-12) and sensory processing (SSP). Additionally, 10 primary caregivers participated in semi-structured interviews to explore in-depth accounts of their experiences and those of their children during the pandemic.

Eighty nine percent of caregivers reported their children had significant sensory difficulties prior to the pandemic. We found that this majority group showed significant increases in sensory processing and intolerance of uncertainty from pre to during the first six months of the pandemic. Changes from pre to during the first six months of the pandemic were significantly correlated suggesting that as uncertainty increased, sensory processing ability decreased. Disruption to routines was significantly correlated with sensory processing and explained a significant portion of the variance in child, household, and parent stress. The themes found in interview responses including the relationship between sensory processing and uncertainty, living in “survival mode,” and unmasking reflect the quantitative findings, showing that the uncertainty introduced by disrupted routines increased sensory processing difficulty and typically autistic behaviors.

These findings have implications for helping us to understand the relationship between uncertainty, sensory processing, and stress leading to better interventions and supports for this population. Additionally, primary caregivers noted the need for increased education and training for parents during therapy sessions and for a stronger community of primary caregivers to support the unique needs of these individuals and families.

Keywords: autism, sensory processing, intolerance of uncertainty, COVID-19, routine disturbance
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DESCRIPTION OF THESIS STRUCTURE AND CONTENT

This thesis, *Intolerance of Uncertainty, Sensory Processing, and Related Correlates in Autistic Children During the COVID-19 Pandemic*, is written in a hybrid format which combines traditional thesis requirements with journal publication formats and conforms to length and style requirements for submitting research reports to academic journals. The initial pages of the thesis are formatted according to university submission standards while the thesis report is presented in journal article format.

The annotated bibliography is located in Appendix A. Appendix B contains the Institutional Review Board-approved consent form. The semi-structured interview guide, used as an outline for our phase two interviews, is in Appendix C and a comprehensive list of full quotes from the interviews used in the phase two results is in Appendix D. Appendix E contains supplementary data which adds additional information for the results section. Appendix F contains the online participant survey used during phase one data collection.

This thesis format contains two reference lists. The first reference list contains references included in the journal-ready article. The second list includes all citations used in Appendix A entitled “Annotated Bibliography.”
Background

Definition and Prevalence of Autism

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by difficulties in social communication and expression of restricted, repetitive patterns of behavior. These difficulties are often associated with strict adherence to routines, insistence on sameness, and hypo or hypersensitivity to sensory inputs. The presentation of these symptoms varies between individuals in their combination, severity, and impact on daily life (American Psychiatric Association, 2013). Autism occurs in all ethnic and socioeconomic groups and is diagnosed worldwide (Elsabbagh et al., 2012; Maenner et al., 2021). In 2020, the Centers for Disease Control and Prevention (CDC) reported that approximately 1 in 44 children in the United States is diagnosed with ASD according to 2016 data collected on eight-year-old children from 11 communities (Maenner et al., 2021). ASD is reportedly diagnosed more in males than females with a ratio of 3:1, an update based on a meta-analysis by Loomes et al. (2017) from the traditionally held 4:1 ratio.

Observed and Predicted Effects of COVID-19

With the relatively high prevalence of ASD among children in the United States, reports of a high level of disruption to those with ASD during the COVID-19 pandemic are particularly stirring. After the first case of COVID-19 was reported in the United States in January 2020, there were subsequent periods of lockdown and quarantine, followed by the continual need for social distancing and other restrictions (Holshue et al., 2020; Panda et al., 2020). All these requirements caused the need for significant changes to daily life for the majority of those living in the United States and around the world (Aarabi et al., 2021). For autistic individuals who are already sensitive to changes in routine, the rapid and extensive changes to daily activities likely
caused increased psychological distress (e.g., stress and anxiety), due to a high level of intolerance for uncertain circumstances (Colizzi et al., 2020; Hodgson et al., 2017; Patel et al., 2020).

With increased concerns in the home and community came increased feelings of stress and uncertainty concerning family routines and emotional instability. Disrupted routines due to COVID-19 conditions, including the large requirement or need to stay home, led to significant effects on health and well-being of individuals with neurodevelopmental disabilities including, increased screen-time, less physical activity, reduced quality of sleep, and a less healthy diet (Masi et al., 2021).

In a study conducted by Masi et al. (2021), over 300 families with children who have neurodevelopmental disabilities were surveyed to determine the impact of the pandemic on their children’s mental health, socio-emotional well-being, and physical health, impact on the caregivers’ well-being, and the use of supports or services. Of the 300 individuals surveyed, 178 reported that the child in their care had ASD and 58.4% of this group reported that the child’s symptoms had worsened during the pandemic. Overall, 94.6% of participants in this study expressed that COVID-19 significantly disrupted their child’s routines and 73.3% of participants stated that COVID-19 restrictions have been stressful for their child. Additionally, 76.1% of parent and caregiver respondents reported that their well-being had been impacted by the pandemic (Masi et al., 2021). Clauser et al. (2020) found that increased parental stress is highly associated with internalizing and externalizing behaviors in their autistic children. These behaviors include, among others, limited verbal communication, social communication deficits, and possible aggressive behavior (Clauser et al., 2020). This research indicates that increased parental stress could have an impact on the behaviors that their children on the autism spectrum
It is then possible to say that increased parental anxiety due to COVID-19 could be a contributing factor to increased or heightened symptoms of ASD in their children.

Recent literature surrounding the pandemic has implicated COVID-19 conditions in impacting the mental, physical, and emotional health of autistic individuals and their caregiver(s) and, also likely intensifying primary symptoms of ASD including stereotyped behaviors, insistence on routine, and sensory sensitivities (Aarabi et al., 2021; Fuld, 2018; Masi et al., 2021). Increases in these symptoms may have resulted in increased negative outcomes including dysregulation, sleep disturbance, anxiety, and depression for children who already demonstrated difficult behaviors (Ameis et al., 2020). The relationship between an intolerance for uncertain situations, heightened sensory sensitivities, and increased stress may have been implicated in increased distress for individuals, in particular children, during the COVID-19 pandemic. The following paragraphs will outline the relationship between intolerance of uncertainty (IU), anxiety, and sensory sensitivities and will expound on the potential impacts of the pandemic on autistic children and their caregivers as well as the necessity for physical, mental, and behavioral supports for these children and their families during periods of increased uncertainty (Ameis et al., 2020).

Intolerance of Uncertainty and Autism

Autistic individuals tend to show an intolerance for uncertain situations (e.g., where routines may be disrupted), which is shown to increase anxiety for this population (Boulter et al., 2014; South & Rodgers, 2017; Wigham et al., 2015). IU has been implicated in a number of anxiety disorders including obsessive-compulsive disorder (OCD; Holaway et al., 2006; Tolin et al., 2003), social anxiety disorder (Boelen & Reijntjes, 2009; Carleton et al., 2010), and adult separation anxiety (Boelen et al., 2014). It is also suspected to play a key role in fear of receiving
negative feedback, fear associated with injury/illness, and in neurotypical children experiencing worry or social anxiety (Carleton et al., 2014; Payne et al., 2011). Anxiety is prevalent in youth with ASD at a rate of over 40% within the population (van Steensel et al., 2011). Children on the autism spectrum are shown to have higher levels of anxiety than typically developing children, accounted for by a higher level of intolerance of uncertain situations (Boulter et al., 2014). The presence of anxiety symptoms in autistic children is a predictor for development of an anxiety disorder in adulthood which suggests that identifying and mitigating childhood anxiety for this population could lead to improved downstream outcomes. Those who show intolerance for uncertain circumstances find situations with high levels of uncertainty to be stressful, unpleasant, and something to be avoided (Hodgson et al., 2017). In more severe cases, individuals with high levels of IU may find uncertain or novel situations to be threatening and may experience intense somatic stress responses because of facing these situations (Carleton, 2012).

**Reciprocal Relationship Between Intolerance of Uncertainty and Related Correlates**

Connections between core characteristics of autism such as sensory processing abnormalities, restricted and repetitive behaviors (RRBs), anxiety, and IU have been found, such that sensory processing abnormalities increase IU which leads to increased anxiety and the tendency towards RRBs (Wigham et al., 2015). Reciprocal relationships between IU, sensory processing abnormalities, and anxiety have been observed such that the presence of one can determine the presence of one or both of the others (South & Rodgers, 2017). The relationship between these factors results in increased perceived need for routine and normalcy, often manifesting as RRBs (Boulter et al., 2014; Neil et al., 2016). RRBs can be categorized into two types, lower order and higher order. Lower order RRBs include repetitive motor and sensory
behaviors such as repetitive hand movements and insistence on sameness which could lead to rigid routines (Honey et al., 2012). Higher order tendencies to insist on sameness have been shown to be associated with anxiety in individuals on the autism spectrum (Lidstone et al., 2014). Additionally, Wigham et al. (2015) found that there was a direct path from sensory hyposensitivity to both lower order RRBs and insistence on sameness, and from sensory hypersensitivity to insistence on sameness.

The tendency to insist on sameness is viewed as a strategy which individuals on the autism spectrum use to control their environment, manage dysregulation of sensory arousal, and reduce anxiety (Rodgers et al., 2012; Lidstone et al., 2014). Routines are commonly established to help autistic individuals cope with anxiety-inducing, uncertain situations and meet this desire for sameness in their day-to-day lives. Disruption of routines is shown to cause significant distress for youth with general anxiety disorder and is speculated to cause a similar result for youth with ASD (Boulter et al., 2014).

**Predictive Coding Theory of Autism**

Individuals on the autism spectrum also seem to have difficulty with making predictions about sensory information they are receiving from the environment which can lead to increased intolerance for uncertain situations (Pellicano & Burr, 2012; van Boxtel & Lu, 2013; Van de Cruys et al., 2014). Pellicano and Burr (2012) explain that our perception of the world is born from incoming sensory information being compared to prior models of that sensory input. Van de Cruys et al. (2014) calls these prior models, “predictions” and the difference between the incoming sensory input and predictions, “prediction errors.” Previous reports have observed that autistic individuals have difficulty matching their stored predictions to incoming sensory input which indicates to them that all incoming sensory information is novel and requires attention.
In other words, individuals on the autism spectrum are theorized to experience very literal sensory processing in which all sensory input is given the same weight because it does not match the previously stored prediction (Van de Cruys et al., 2014). Presumably, this style of processing could lead to difficulty separating salient stimuli from noise, being easily overwhelmed by multiple inputs, and less ability to see the “big picture”, due to trying to place attention on all details in a given scenario—all traits expressed regularly by autistic individuals.

This predictive coding theory of ASD may account for executive functioning difficulties, difficulty with theory of mind, insistence on sameness behaviors, persisting repetitive behaviors, and intolerance for new or uncertain situations (Van de Cruys et al., 2014). Situations which present a high level of uncertainty or have many new stimuli can seem threatening to an individual for whom the majority of sensory input seems surprising, unexpected, or overwhelming (Pellicano & Burr, 2012). Daily encounters in classrooms, on public transportation, at the grocery store, or other seemingly innocuous settings may seem risky to an individual with ASD who experiences impairments in sensory perception due to the inability to match sensation with their predictions of what will happen (Pellicano & Burr, 2012; Van de Cruys et al., 2014). Over the long-term, such prediction difficulties could lead to an intolerance of uncertainty.

Children around the world have experienced changes during the pandemic to their schooling, home life, ability to interact with others, and to their daily routines (Panda et al., 2020). These changes have most likely increased the amount of uncertainty that these children feel and has caused increased anxiety and other behavioral difficulties (Panda et al., 2020). Prior research has shown that autistic children are particularly vulnerable to uncertainty due to
possible difficulties with matching predictions with incoming sensory information (Pellicano & Burr, 2012; van Boxtel & Lu, 2013; Van de Cruys et al., 2014). These findings prompted the need for further investigation into the effects uncertainty during COVID has had on autistic children, with the possibility of increased anxiety and sensory processing difficulty according to prior research and preliminary findings in the literature surrounding the pandemic (Ameis et al., 2020; Boulter et al., 2014; Masi et al., 2021; Neil et al., 2016; Wigham et al., 2015).

**Relationship Between Intolerance of Uncertainty and Sensory Processing**

Research suggests that IU is not only associated with higher levels of anxiety but is also positively related to sensory sensitivities in those with ASD. Autistic individuals who experience sensory sensitivities are often categorized as being hypersensitive, hyposensitive, sensory seeking, or sensory overloaded (Neil et al., 2016). Hypersensitive refers to individuals who are particularly sensitive to certain sensory inputs such as touch or sound; hypo-sensitive refers to those who respond slowly to or do not recognize sensory stimuli; sensory-seeking refers to those who demonstrate behaviors related to seeking out certain sensory experiences; and sensory overloaded refers to individuals who are completely overwhelmed by incoming sensory stimuli (Neil et al., 2016). These sensitivities have been shown to be related to increased levels of anxiety, often leading to difficulties in social situations (e.g., school, employment, social gatherings, etc.), and increased stress in their home environments. For instance, while Boulter et al. (2014) found that IU was significant in determining anxiety, other researchers have suggested that sensory sensitivities may also be affected by IU.

Wigham et al. (2015) suggested that there was a moderate positive correlation between scores on the *Intolerance of Uncertainty Scale* to sensory over-responsiveness which was measured using the *Short Sensory Profile* in autistic children. Neil et al. (2016) then followed up
on this study to determine if IU was a factor for both typically developing children and those with ASD in determining increased sensory sensitivity. They found that IU explained approximately half of the variance in sensory sensitivity scores on the *Short Sensory Profile* for autistic children and explained only one third of the variance in typically developing children. When anxiety was controlled for, sensory sensitivities and IU remained closely associated for the ASD group. As previously mentioned, individuals in the ASD population often have difficulties relying on previous experiences to predict what will happen in their present circumstances (Van de Cruys et al., 2014). This can lead to increased difficulty when faced with new and ambiguous sensory input resulting in an inability to filter irrelevant stimuli from the environment (Neil et al., 2016). Sensory prediction difficulties experienced over the long-term could eventually lead to greater IU.

**Relationship Between Sensory Processing and Communication**

Additionally, there are indications that sensory sensitivities can intensify difficulties with social and other aspects of communication (Thye et al., 2017; Watson et al., 2011). A study by Watson et al. (2011) sought to understand sensory-responsiveness as a factor in the variability of social-communicative symptom expression and social communication/language development in children on the autism spectrum or other developmental disabilities. They found that there was a positive correlation between hyposensitivity/sensory seeking and social-communicative symptom severity in the ASD group such that an increased number of hyposensitive symptoms was related to greater difficulty with social communication. A negative correlation was found between hyperresponsiveness and social-communicative symptom severity indicating that as hyperresponsiveness increased, social-communication symptom severity decreased (Watson et al., 2011).
Previous research also showed a positive correlation between hyporesponsiveness, sensory seeking, and severity of social and communication symptom severity in children and adults with ASD (Liss et al., 2006). However, contrary to more recent findings, Liss et al. (2006) found a positive correlation between hyperresponsiveness and social communication symptom severity but not language symptom severity. Another previous study of elementary school age children on the autism spectrum found that there was a positive correlation between sensory seeking, hyporesponsiveness, and hypersensitivity with social-communicative symptom severity indicating that an increase in either hyper or hypo sensitivity could increase social communication difficulty (Hilton et al., 2007). Discrepancy between these studies’ findings may be accounted for by differences in methodologies, with the earlier studies relying on parent reports, while others (e.g., Watson et al., 2011) observed the sensory response patterns, social-communicative symptoms of autism, and language, social and communication skills directly.

Watson et al. (2011) found negative correlations between hyporesponsiveness/sensory seeking behaviors and development of language and social adaptive skills suggesting that as hyporesponsive symptoms increase, language development and social adaptive skills are lower. This finding is supported by their hypothesis that recognition of sensory stimuli in the environment during early development is important to learning language, social and communication skills (Watson et al., 2011). The ability to recognize sensory stimuli in the environment is characteristic of typically developing children or for children who experience hypersensitivity (Watson et al., 2011). Thye et al. (2017) additionally found that sensory abnormalities detected in infants who were later diagnosed with ASD can have significant future social and communicative difficulties, including inability to filter out extraneous information, difficulty with selective attention (hypersensitivity to stimuli), delayed visual and auditory
processing, poor sensory integration, lack of appropriate responses to stimuli (hyposensitivity to stimuli). Specific social implications might include inability to attend to social stimuli, difficulty with reading others’ intentions, difficulty with social reciprocity, and difficulty with understanding and maintaining social norms (Thye et al., 2017).

**Uncertainty and Stress During COVID-19**

The first six months of the COVID-19 pandemic brought about situations riddled with uncertainty accompanied by stress for the general population and continues to present unpredictable circumstances (Brooks et al., 2020; Czeisler et al., 2020; Panda et al., 2020). For instance, many faced the cancellation of important life events, inability to visit relatives or friends, transition to virtual formats for work and school, disruption to routine healthcare and possible loss of jobs and benefits. In addition, pandemic conditions caused depression, irritability, mood swings, inattention, and sleep disturbances to be more common among children and their caregivers (Panda et al., 2020). Children were not only concerned about catching the virus or their family catching the virus but were also worried about closure of schools, strict protocols associated with the virus, uncertainty about when the pandemic will end, and inability to visit many public places such as parks or theaters (Colizzi et al., 2020; Duan et al., 2020; Yeasmin et al., 2020).

Caregivers were similarly anxious which exacerbated the behavioral and psychological effects in their children (Yeasmin et al., 2020). Mutluer et al. (2020) reported high rates of anxiety in the ASD primary caregiver population in their study and found that parent anxiety was significantly correlated with the child’s total score on a measure of autistic behaviors during the pandemic. A systematic review of 15 studies, including data from 10 countries and involving a total of 22,996 participants, found that 79.4% of children had behavioral or psychological states
which were negatively affected in some way by pandemic and quarantine conditions (Panda et al., 2020). School closure during the pandemic specifically had an impact on the mental health of children and adolescents. By the end of April of 2020, the United Nations Educational, Scientific and Cultural Organization (UNESCO) reported that schools were closed nationwide in 160 countries (UNESCO, 2020). The disruption of this fixture in most children’s daily routines caused some children to become more anxious due to the uncertainty of being able to return to school, necessity to navigate online learning programs, lack of nutrition normally provided by the school, social isolation, and even possible exposure to domestic violence in their home.

While disruptions to daily routines had a negative impact on children and adolescents at large, the disruption to school services was even more detrimental to youth who required mental health or special education resources (Lee, 2020). Youth who required such resources had many of their in-person therapies and services cancelled and replaced with teletherapy or over-the-phone service which can be difficult for some individuals with these conditions. Many children on the autism spectrum responded negatively to the disruption of their daily routines caused by school closure and protocol related to COVID-19, such as social distancing (Lee, 2020). Other autistic children may have preferred increased social distancing. Asbury et al. (2020) reported finding a minority of autistic children in their study for whom physical distancing, social isolation, and school-closure led to an increase in positive emotion and decreased stress. Hannawi et al. (2022) additionally found that 33% of the autistic children in their sample showed some positive outcomes due to COVID-19 conditions. In some cases, however, social distancing may have led to isolation, which can contribute to a host of negative outcomes including extreme focus on restricted interests, increased time on screens, and negative impacts generally on social, mental, and physical health (Ameis et al., 2020; Leigh-Hunt et al., 2017).
Difficulties for individuals on the autism spectrum and their families have been noted during the pandemic in relation to an increase in stress for both the children and their caregivers. According to a survey conducted by Manning et al. (2020) autistic individuals and their families reported high levels of stress and disruption to family routines due to the pandemic. The results of the survey also showed that parents with younger autistic children or those with children who have a more severe ASD diagnosis had higher stress levels. Caregivers who received a high level of support for their children prior to the pandemic also showed elevated levels of stress (Manning et al., 2020). Furthermore, the most frequent responses of stressors during the pandemic were the infrequency or uncertainty of continued therapeutics services, finances, and the possibility of themselves or their children on the autism spectrum becoming ill. In particular, the fear of becoming ill was a predictor of stress in these families (Manning et al., 2020). More recently, some families have expressed apprehension in receiving the COVID-19 vaccine or in having their children vaccinated due to the vaccine’s rapid development, possible negative side-effects, previous contradictory research surrounding the virus, and the influence of conspiracy theories and vaccine hesitancy attitudes on social media (Bendau et al., 2021). Researchers also indicated that the following were factors which predicted higher vaccine hesitancy, social and economic fears surrounding the virus, lower education attainment, Black race, and not having a recent influenza vaccine (Bendau et al., 2021; Fisher et al., 2020). Bendau et al. (2021) found that an individual’s fear and anxiety about COVID-19 correlated significantly positively with their acceptance of the vaccine. Concerns associated with the vaccination are added to an already extensive list of concerns for parents and caregivers during the pandemic. Given the initial observations from other researchers about the effect of COVID-19 conditions on neurodiverse children, the tendency for autistic individuals to hold on to routines and schedules, and the
connection between IU, sensory processing, and anxiety, it is reasonable to believe that sensory processing difficulties and stress have been exacerbated for this population during the pandemic. However, no study to date has documented such effects.

Statement of the Problem

Although research has shown that the disruption of routines due to the COVID-19 pandemic has caused increased anxiety and an increase in the severity of symptoms for autistic children, little has been discussed about the effect on sensory processing difficulties (Masi et al., 2021). This study seeks to further the existing research about the negative effects on the well-being of autistic children and their families by examining the relationship between intolerance of uncertain situations caused by pandemic conditions, increased anxiety due to aversion to uncertainty, and the possible increase in severity of sensory processing abnormalities.

Statement of the Purpose

The purpose of this study is to examine the relationship between sensory processing, intolerance for uncertain situations, and stress for children on the autism spectrum during the COVID-19 pandemic by investigating the experiences of these children and their caregivers during the pandemic.

Research Hypotheses

1. We hypothesized that there would be an increase in atypical sensory processing and intolerance of uncertainty during-pandemic measures as compared to pre-pandemic measures, and that we would see a positive correlation between atypical sensory processing and intolerance of uncertainty during the pandemic.

2. We also hypothesized that there would be a relationship between relevant demographic factors (e.g., access to resources, community supports, schooling,
employment, etc.) and pre- and during-pandemic atypical sensory processing, intolerance of uncertainty, and child and family stress.

3. In soliciting and analyzing personal interviews with caregivers of autistic children, our goal was to give voice to individuals’ stories and experiences. We expected to observe themes related to sensory processing, uncertainty, and stress and specifically how these factors have interacted during the COVID-19 pandemic. Specifically, we expected that we would observe that increased levels of uncertainty resulted in increased sensory processing difficulties and stress in autistic children. We also projected that we would discover other themes that we had not considered a priori.

**Method**

To observe the interactions between IU, sensory processing, and stress in autistic children and their families during COVID-19, we designed a two-part, mixed-methods study which allowed us to collect both quantitative and qualitative data on these three main factors. Phase one of the study was designed to test the first and second research hypotheses by collecting and analyzing relevant demographic information as well as quantitative measures of IU and sensory processing for the autistic children and stress for the children, caregivers, and household. Phase two of the study allowed us to answer the third research question by allowing caregivers of children on the autism spectrum to share personal experiences in relation to a priori research questions. Due to the qualitative nature of this phase of the study, there were also topics brought up that were not considered a priori.

**Phase One**

Phase one was to investigate the effects of COVID-19 on sensory processing of children and youth with ASD.
Participants

We recruited caregivers of 57 children (mean age 10.82 years; SD = 5.59 years) with diagnosed ASD to complete a battery of surveys examining ways in which the COVID-19 pandemic influenced sensory processing, affected intolerance of uncertainty, altered home life, and impacted stress levels. Participants for phase one were recruited via social media, emails to families who had given prior permission to be contacted about research studies, and through word of mouth (e.g. contacting families through acquaintances of the investigators) all of which were approved by our university’s Institutional Review Board (IRB).

Caregiver participants were mostly mothers (n=44) however there were a few fathers who responded (n=3), one grandparent, and one participant who identified the relationship as other. There were four caregivers who reported having two autistic children and two who reported having three autistic children. Demographic data is only represented once in the case of these caregivers, making the overall count lower than n=57. Only one caregiver reported that the child does not currently live in their home but did not indicate where the child currently lives. Of the participants, 55 reported having two caregivers in the home while two reported having only one. The marital status of the majority of participants was married (n=46) with the others reporting statuses of divorced, separated, and widowed. The majority of participants were Caucasian however there were three participants who responded as being Caucasian along with another race (i.e. American Indian or Alaska Native, Asian, and Native Hawaiian or Pacific Islander). Two participants responded that their ethnicity was Hispanic or Latino. All participants responded that the primary language used in the home was English. The highest levels of education attained by the caregivers were as follows: high school (n=1), some college (n=5), 2-year degree (n=7), 4-year degree (n=19), professional degree (n=3), graduate degree (n=12), doctorate (n=2). The
highest level of education attained by their spouses were as follows: less than high school \((n=1)\), some college \((n=8)\), 2-year degree \((n=5)\), 4-year degree \((n=20)\), graduate degree \((n=7)\), doctorate \((n=3)\), post-doctorate \((n=2)\). The majority of caregivers surveyed were full-time parents/caregivers or worked part time at home while the majority of their spouses were employed full-time outside of the home, at home, or with a hybrid situation. Only one participant reported that their spouse was currently unemployed.

Due to the valid age range (3-15 years) for the Short Sensory Profile (SSP; see below for description), statistical analyses of phase one data were reserved for 47 of the originally recruited participants. All procedures in the current study were approved by the Institutional Review Board of Brigham Young University and carried out in agreement with the Declaration of Helsinki.

**Materials and Data Collection**

Each caregiver was asked to complete an online Qualtrics survey (https://www.qualtrics.com). First, we asked participants to provide consent via an implied consent statement. Then, participants were asked to specify pertinent demographic information including their name, race, and ethnicity (according to The National Institutes of Health (NIH) standards), language spoken in the home, marital status, level of education obtained by caregivers, employment status of parents, health insurance status of caregivers, and current zip code. Participants were also asked to provide some background about their child/children on the autism spectrum including, number of autistic children, number of siblings, age at ASD diagnosis, current age, sex of their child/children, school setting, degree of participation in remote learning during the pandemic, and resources and supports that the family relied on to care for their child/children on the autism spectrum. In addition to demographic and background
information, primary caregivers completed a section of questions dealing with their experiences during the pandemic including rating disruption of daily routines on a Likert scale from 1-10, pre and during-COVID stress levels for themselves, their child with ASD, and their household on a Likert scale from 1-10, changes in ASD symptoms, observed changes in communication, access to technology, level of support given by the school district, resources or support they lacked during COVID, and resources they found that helped.

This information allowed us to evaluate how any change to demographic conditions due to COVID-19 may have increased stress and uncertainty in the home life of parents and their children. Identifying information was immediately replaced with codes to protect confidentiality. Following this short demographic survey, we used the SSP (Dunn, 1999) to evaluate sensory symptoms of autistic children based on caregiver report. This instrument is commonly used with autistic individuals and consists of subtests that assess various sensory modalities. We also used the Intolerance of Uncertainty Scale-Short Form (IUS-12; Carleton et al., 2007) to allow caregivers to report the degree to which their children are averse to unpredictable events. Data collection happened between the spring and summer of 2021, after the pandemic had been in effect for several months. Given this timing, parents were asked to respond to each question twice on the SSP and the IUS-12, first as though they were considering their child’s behavior before the start of the pandemic and then a second time to describe behaviors during the first six months of the pandemic. We evaluated the differences in responses between the pre- and during-pandemic responses to these questions (see statistical analysis in results).

Finally, parents or caregivers were asked to answer a few multiple-choice and open-ended questions regarding changes in their child/children on the autism spectrum during the conditions associated with the COVID-19 pandemic. These questions asked for information
about any changes in sensory processing or anxiety, if any. The questions also asked caregivers to explain what resources have been available to them in caring for their child/children during the pandemic. On average, participants spent 30-45 minutes completing the surveys. The ending of the survey asked parents if they would like to participate in further research, including phase two of the current study, and contact information if they indicated that they were interested.

**Measures**

**Short Sensory Profile (SSP).** The SSP is a shortened version of the *Sensory Profile (SP)* (Dunn, 1999) which consists of 38 questions designed to be answered by caregivers about their child’s sensory processing behaviors. Caregivers rate the frequency of each item on a Likert scale from 1 (*always*) to 5 (*never*). The profile analyzes children’s sensory symptoms and their responses to sensory experiences relating to seven categories including: Tactile sensitivity, Taste/Smell Sensitivity, Movement Sensitivity, Under-responsive/Seeks Sensation, Auditory Filtering, Low Energy/Weak, and Visual/Auditory Sensitivity (Dunn, 1999). The total score on the SSP indicates the level of abnormality in the child’s overall sensory processing, with lower scores indicating greater impairment and more sensory processing abnormalities. The overall score can also be used to classify a child with three types of sensory processing: definite difference, probable difference, and typical.

We chose to use this measure in our study due to its prevalence in autism literature (e.g., Crasta et al., 2020; Neil et al., 2016; Simpson et al., 2019; Wigham et al., 2015). The profile has moderate to strong internal consistency of total and subscale scores (Cronbach’s alpha ranging from 0.70 to 0.90), good convergent validity with physiological measures and discriminant validity of >95% in distinguishing children with and without sensory processing difficulties.
Intolerance of Uncertainty Scale-Short Form (IUS-12). The Intolerance of Uncertainty Scale-Short Form (IUS-12, Carleton et al., 2007) is a 12-item questionnaire adapted from the original 27-item Intolerance of Uncertainty Scale (IUS) developed by Freeston et al. (1994) which measures an individual’s aversion to unpredictable situations. Caregivers were asked to respond as though they were the child with ASD and indicated the extent to which statements were like the child, on a scale from 1 (not at all like them) to 5 (entirely like them). The total score reflected the individual’s level of intolerance to uncertain situations, with higher scores indicating greater levels of intolerance (Neil et al., 2016). The scores are divided into two categories to determine a prospective anxiety score and an inhibitory anxiety score. Good internal consistency of \( \alpha = 0.85 \) is present compared to the internal consistency of the original IUS, \( \alpha = 0.96 \) (Carleton et al., 2007). We chose the IUS-12 for this study due to its ability to show an individual’s behavioral prediction ability, albeit indirectly, in that people with impaired prediction abilities will likely have increased intolerance of uncertainty. The IUS-12 is also relatively quick to administer and has been used repeatedly in autism literature (Boulter et al., 2014; Neil et al., 2016; Wigham et al., 2015).

Data Analysis

Phase one of the study included analysis of the quantitative data obtained through the survey. We conducted a comparative quantitative analysis using repeated measures of analysis of variance (ANOVA) on pre- and during-pandemic SSP and IUS-12 scores. We also investigated partial correlations (controlling for age) between pre-pandemic SSP and IUS-12 and during-pandemic SSP and IUS-12, as well as scores representing the change in sensory processing and
intolerance of uncertainty (i.e., $SSP$-during minus $SSP$-pre and $IUS$-during minus $IUS$-pre). We also computed similar correlations between $SSP$- and $IUS$-during scores and child, parent, and household stress, and increases in autism-related behaviors measured in our survey. In order to estimate the combined impacts of sensory processing and uncertainty on child stress, we calculated a multiple regression with child stress as the dependent variable and $SSP$- and $IUS$-during, and our measure of disruption to routine as the independent variables. In another model, we carried out a mediation analysis with $IUS$-during score as the x-variable, child stress as the y-variable, and $SSP$-during as the mediator.

From our survey questions regarding resources available during the beginning of the pandemic, we created a resource index. That is, each quantitative variable related to resources (i.e., school support, employment status, access to therapy, parent support groups, internet access, etc.) was ordered such that lower numbers indicated “fewer resources” and higher numbers indicated “more resources.” Then, each quantitative variable was standardized by calculating their z-scores (i.e., subtracting its mean and dividing by its standard deviation). Negative z-scores indicate that the observed value is relatively far below the mean for that variable, and vice versa. The “resource index” for each individual is the proportion of z-scores for each participant that were greater than zero. Thus, if the proportion of positive z-scores for each individual is less than 0.5, this suggested that the person had less access to resources relative to others in the dataset. We then examined partial correlations (controlling for age) between the resource index and during-pandemic $IUS$-12. Additionally, we evaluated during-pandemic $SSP$ as a mediator between $IUS$-12 scores and child stress (using the Process macro in SPSS; Hayes, 2022). Multiple choice and short-answer data was not analyzed as part of this study but will be used for future studies.
Phase Two

Phase two was to explore patterns in the experiences of children on the autism spectrum and their families in addressing sensory processing difficulties and their access to resources during the COVID-19 pandemic.

Participants

We used the answers to our phase one survey to recruit 10 participants for phase two of our study—to participate in a virtual semi-structured interview, where caregivers answered questions about their and their child’s/children’s experiences during the pandemic. Interview participants were selected based on a positive response to a question of their interest in participating in the second phase of the study and were narrowed down to 10 participants based on the range their child’s scores fell into for the SSP. We observed in the phase one data that there were three distinct groups for whom sensory processing: 1) got worse 2) stayed the same or 3) got better. We wanted to have caregivers of children from each of these groups represented in the interview data and thus made selections for interview participation based on SSP scores. The majority of participants’ children fell into the group where sensory processing got worse which was consistent with our quantitative finding that sensory processing became more difficult for the majority of our sample, however the other two groups were also represented in equal proportion to each other in the interview data.

Participants for phase two were primarily mothers with one grandmother and one mother and father interviewed. Two of the caregivers had two children on the autism spectrum. All participants were married with two caregivers in the home. Most were employed part or full time with two identifying as full-time parents or caregivers. Their spouses were mostly employed full-time with one identified as a full-time parent or caregiver. All interview participants had attained
a 2-year degree or higher and their spouses had attended at least some college or higher. All
phase two participants identified as white with one also identifying as American Indian or
Alaskan Native and another identifying ethnically as Hispanic or Latino.

Prior to the start of each interview, we explained the details of the study and the process
for giving consent, and then answered any of the caregiver’s questions. If the caregiver was still
interested in taking part in the interview after these explanations, we sent them a consent form to
review and sign prior to their scheduled interview time.

**Materials and Data Collection**

Each interview lasted approximately 60 minutes. Prior to the interview, we adapted our
pre-determined interview guide to fit each caregiver’s situation, based on their survey answers
(see the *Semi-structured Interview Guide*). We centered all questions around our hypotheses and
research questions—i.e., understanding what changes the caregiver observed in their
child/children’s sensory processing behaviors from the beginning of the pandemic until the time
of their interview. No questions included high-risk or sensitive material, though some
participants offered such information spontaneously (e.g., feelings and details about marriage
strain/divorce). While we did not dwell on these matters, we listened and recorded participants’
thoughts. In the end, some of the themes that were of highest importance in the study featured
this type of sensitive information. In light of these inclusions, we have made every attempt to
protect the identities of our participants.

**Data Analysis**

To facilitate qualitative thematic analysis, the Principal Investigator (PI) and graduate
student researcher and author (MB) video recorded each interview. Then, a team of research
assistants orthographically transcribed, and coded all interviews. We stored interview data
(videos and transcripts) on secure password-protected computers in the PI’s research lab, which is always locked when not in use. No one who has access to the research lab has been or will be permitted to remove any identifying information from the lab. However, the research team was permitted to take de-identified written transcripts out of the lab for remote analysis.

Organization of transcripts and codes, and analysis, was facilitated with the ATLAS.ti software package (Version 22.0.2 Mac). The PI, MB, and the research team began the coding process by reading through interview transcripts multiple times each. During these readings, we also took the opportunity to correct any errors present in the transcripts. The main purpose of this stage of the process was to allow all team members to become intimately familiar with the content and quotations of the interviews. The team was encouraged to take notes on their thoughts during this process. Following familiarization, the team held a meeting to discuss the salient themes they observed in the interviews. Along with those specifically related to our hypotheses, the themes and ideas from this meeting were then systematically turned into codes and put into code groups/categories (e.g., codes related to children, parents, sensory processing, uncertainty, maladaptive behaviors, resilience, etc. – see Table 4 for the themes, categories, and codes). The research team then met to discuss each code and come to an understanding of their definitions. During this meeting, the code list was refined (i.e., codes were added, deleted, merged, etc.) to make an initial code book (Braun & Clark, 2006, 2021; Gale et al., 2013; Harmon, 2020). With the code book at their disposal, the team went through one interview individually, selected quotations of interest, and assigned as many codes to these quotations as were pertinent. Following this initial round of coding, the team met again to discuss how the assigned codes aligned and to make any changes that needed to be made to the code book. We determined inter-coder reliability during this meeting by going through the coded passages and
observing how many times codes were the same or similar between team members. We observed that for the majority of coded passages, team members selected the same or similar codes. When there was a discrepancy, the team discussed which code should be kept until we reached consensus on all the codes. This was followed by modifying and adding codes to the code book before proceeding to the next round of coding. Then the coding team carried out another round of coding with each team member coding three or four transcripts. During this round, they followed the same procedure as with the first coded interview then the team met again to modify the code book. After consensus was reached on the code book, the team began another round of coding. During this round, they were asked to review the codes their teammates had added to the transcripts and note any that seemed out of place, incorrect, or should be changed. In our next meeting, we discussed these proposed edits, with the goal of reaching consensus as a group on each of them. This pattern of coding, noting potential changes, meeting, discussing, and reaching consensus on changes was followed two more times. By the final meeting of the team, all agreed that the codes that existed in the transcripts were appropriate and captured the essence of the interviews.

In the next step of the qualitative analysis, the PI and MB met to discuss the final salient themes, along with their sub-themes, codes, and quotations, as an initial step of organizing our thinking and writing about the interviews. Based on this organization, we then completed the writing and reporting of these constructs by summarizing themes and selecting quotations to illustrate and support these notions (Braun & Clark, 2006, 2021; Gale et al., 2013; Harmon, 2020).
Results

Phase One

Sensory Processing, Uncertainty, and Stress

The present study was designed to examine the relationship between sensory processing, IU, and stress, and their relationship to relevant demographic factors within the context of the COVID-19 pandemic for children on the autism spectrum and their families. As such, we calculated total scores on the SSP and IUS-12 for pre-COVID-19 and during the first six months of the pandemic (referred to hereafter with the designation of -pre or -dur, e.g., SSP-pre or SSP-dur; See Table 1 for mean scores and standard deviations). We found that the majority of our sample (n = 42, 89%) had significant sensory processing difficulties prior to COVID (sensory difficulty group) — i.e., they presented with either a “probable” or “definite” difference according to their total scores on the SSP – while (n = 5, 11%) showed typical sensory processing abilities (typical sensory group; see Figure 1). Both the sensory difficulty and typical sensory groups showed similar levels of IU prior to the pandemic.

Repeated measures ANOVA (rm-ANOVA) across the entire sample showed that there was a significant difference \(F = 10.01, p = .003\) between pre- \((M = 118.00, SD = 23.69)\) vs. during-COVID \((M = 112.42, SD = 26.41)\) SSP total scores such that sensory processing became more challenging for the group overall. Similarly, there was a significant difference \(F = 11.34, p = .001\) between pre- \((M = 33.77, SD = 11.29)\) vs. during-COVID \((M = 36.65, SD = 13.18)\) IUS total scores, such that IU also increased for the sample overall (see Table 1). Rm-ANOVA was again used to compare the SSP-pre and IUS-pre scores with scores during the first six months across the sensory difficulty and typical sensory groups and showed a significant difference \(F = 25.83, p < .001\) between SSP-pre versus SSP-dur total scores for the sensory difficulty group,
such that sensory processing became more challenging for the group overall (see Table and Figure 2). Similarly, there was a significant difference ($F = 36.95, p < .001$) between the IUS-pre versus IUS-dur scores, such that intolerance of uncertainty increased for the sensory difficulty group overall during the first six months of the pandemic (see Table 2 and Figure 2). The typical sensory group did not experience a significant decrease in sensory processing ability ($F = 1.83, p = .25$) or a significant increase in IU ($F = 1.40, p = .30$) during the first six months of COVID (see Table 2 and Figure 2). However, the results for the typical sensory group should be interpreted with caution due to the small sample size. Table 3 shows the mean SSP-dur sub scores for the sensory difficulty and typical sensory groups, which indicates that there was greater change in some sensory sub-scores than others. There were no significant differences between males and females on their SSP and IUS scores.

We conducted correlation analyses to determine the relationship between SSP- and IUS-dur total scores, which revealed a weak, but significant relationship ($r = -.29, p = .03$), such that sensory difficulties increased with elevated intolerance of uncertainty scores. There were no significant correlations between any other combination of SSP and IUS pre and during scores. As an exploratory analysis to follow-up this previous correlation, we ran another partial correlation analysis controlling for age looking at the relationship between the change (i.e., difference index) in SSP and IUS from pre to during COVID revealed a significant negative correlation ($r = -.57, p < .001$; see Figure 3). This points to the notion that COVID-related changes in sensory processing and IU were correlated. Figure 4 shows the mean change in SSP scores for the sensory difficulty and typical sensory groups.

With the above in mind, we used a multiple regression analysis to determine how much the IUS- and SSP-dur COVID scores contributed to a measure of child stress during the
pandemic. That is, multiple regression with child stress-dur as the dependent variable and SSP-dur and IUS-dur as independent variables revealed a significant combined effect \((r = .51, p = .03)\) — together these variables accounted for 26% of variance in child stress. This suggests that sensory processing and IU both significantly contributed to child stress during the first six months of the pandemic, but that other factors also played a role. An additional multiple regression analysis revealed that our measure of disruption to routine accounted for a large portion of the variance in child \((r = .79, p < .001)\), parental \((r = .62, p < .001)\), and household \((r = .69, p < .001)\) stress. When sensory processing was added to the model, an additional 4% of the variance in child stress was explained \((r = .82, r^2 = .67, p < .001)\). When we specifically observed the relationship between disruption to routine and sensory processing through correlation analysis, we observed a significant relationship \((r = -.41, p = .005)\), such that as disruption to routine increased, sensory difficulties also intensified. Thus, it appears that, in our sample, disruption to routine and SSP scores pre- and during-COVID were the strongest determinants of child stress, and that uncertainty was closely associated with sensory difficulty increases during the pandemic.

We carried out a mediation analysis to further elucidate the contribution of SSP-dur and IUS-dur on the measure of child stress-dur (see Figure 5). The analysis indicated that SSP-dur mediated the relationship between IUS-dur and child stress-dur across all participants when controlling for age. However, IUS-dur was not found to be a mediator between SSP-dur and child stress-dur. This suggests that sensory processing contributed to the effect that IU had on child stress-dur, but that IU did not seem to contribute to the effect of sensory processing on child stress-dur.
Additionally, we ran correlational analyses between measures of stress for the parent, household, and child in relation to SSP-dur and IUS-dur scores. The analyses revealed a weak significant positive correlation between IUS-dur and child stress-dur ($r = .35, p = .009$). We also found strong significant positive correlations between parental and household stress-dur ($r = .87, p < .001$) and parental and child stress-dur ($r = .63, p < .001$). A strong positive correlation between household and child stress-dur ($r = .76, p < .001$) was also observed. This suggests that IU had a more significant impact on child stress than on parental or household stress. It is also an indication that the stress levels of the child, parent, and household were all strongly connected during pandemic conditions. We also found significant, but weak, negative correlations between SSP-dur scores and parental stress ($r = -.35, p = .008$) and between SSP-dur and household stress-dur ($r = -.40, p = .003$). We noted a stronger significant negative correlation between SSP-dur and child stress-dur ($r = -.46, p < .001$; see Figure 6). These correlations point to sensory processing difficulty having significant associations with child, parental, and household stress during the beginning of the pandemic.

**Access to Resources and Stress**

We found that 78.7% of participants experienced a resource index of 5, or below, suggesting that the majority of our sample did not have access to adequate resources (i.e., adequate school support, access to therapy, continued employment, support from family members, etc.) during the pandemic, according to their own reports. The resource index was significantly positively correlated with parental stress ($r = .40, p = .006$) and, to a lesser degree, household stress ($r = .37, p = .01$) suggesting that as parental and household stress increased, the resource index increased. The resource index was not correlated with SSP ($r = -.16, p = .30$) or IUS scores ($r = .08, p = .62$) during the pandemic. We used regression analysis to determine the
contribution of a lower resource index, among other factors, to increasing parental stress during the pandemic. We discovered that the combination of resources, child stress, and disruption to routine significantly contributed to parental stress (r = .77, p < .001), with the combination of these factors explaining 45% of the variance.

**Intolerance of Uncertainty, Sensory Processing, and Autism-Related Behaviors**

We also used a partial correlation analysis to examine the relationship between SSP-dur, IUS-dur, and increases in severity of behaviors/tendencies associated with ASD. We found that there was a weak significant correlation between safety concerns and IUS-dur scores (r = 0.33, p = .03) such that as uncertainty increased, children demonstrated more behaviors leading to safety concerns. We did not find any significant correlations between SSP-dur scores and increases in any of the symptoms associated with ASD. Despite the lack of significant correlations between these symptom increases and SSP-dur and IUS-dur scores, there were several significant correlations found between increase in one symptom and the increase of another. For instance, there were significant positive correlations between restricted/repetitive interests and self-abusive behaviors (r = .54, p < .001), sleep difficulties and inflexibility/resistance to change (r=0.611; p<0.001, and between sensory sensitivities and restricted/repetitive interests (r = .53, p < .001).

Caregivers reported increases in difficulty with verbal and non-verbal communication were both significantly correlated with each other and with their reported increases in sensory difficulties, feeding difficulty, and changes in diet (See Supplementary Data for a full list of the correlations). Additionally, increase in verbal communication difficulties were also significantly correlated with an increase in RRBs and increase in non-verbal communication difficulties was significantly related to increase in sleep disturbance. Additional changes and disruption to
children’s communication and social skills during COVID will be further discussed with interview results.

**Phase Two**

We organized the qualitative codes used to analyze the interview data into three major themes: 1) sensory processing and uncertainty, 2) living in “survival mode”, and 3) unmasking. The first theme captures the interplay between sensory processing and uncertainty for the autistic children in the families interviewed. The second theme relates to the families’ experiences and challenges within the home to manage parental and child stress while trying to re-establish routines. The third theme refers to instances where parents noted areas of regression, return to comfortable topics or activities, or increased behaviors typically associated with ASD. We noted a fourth theme of resiliency, on the part of both caregivers and children, as an undercurrent to the three major themes detailed above. The quotations included in this section have been modified to facilitate clarity when reading, however the full quotations can be found in the appendix, with the quote number cited in the results.

**Theme 1: Sensory Processing and Uncertainty**

This theme encapsulates the uncertainty that many families faced with disruption to their daily routines and the sensory behaviors and RRBs children demonstrated in conjunction with this disruption, as well as other circumstances surrounding COVID (category a). Statements also reflected families’ and children’s attempts to manage or avoid uncertainty (category b). Coded statements in this theme also included descriptions of positive and negative experiences with transitions within the context of COVID and when the children started to return to school and other typical activities (category c). Several codes are included both as ways to avoid or manage uncertainty and as reactions to uncertainty, suggesting the cyclical nature of the way that
individually on the spectrum process uncertainty—i.e., there were examples in our interviews where sensory difficulties increased due to the uncertainty of the situation, however, the increase in sensory processing difficulty also caused uncertainty or the inability to regulate, resulting in tantrums or "big feelings."

**Category 1.a Reactions to Uncertainty.** Ninety percent (nine out of ten) of the interview participants described disruption to routines for their children and in their homes. Although the majority of participants (70%) reported being able to maintain or eventually re-establish certain routines, only two made statements about how their child’s routine had not really changed from pre to during the pandemic. With the majority of our interviewees and their children experiencing disruption to their daily routines, uncertainty was most likely increased in their lives. In fact, there were 26 co-occurrences of uncertainty and disruption of routines for 70% of participants in the data set. The children and caregivers reacted differently to the increase of uncertainty caused by disruption to routines, but the most common reactions described were increases in sensory behaviors, increases in RRBs, and self-soothing/decompression behaviors.

The code “routine change = increased sensory difficulty” was used 21 times across 50% of the data set. The array of sensory reactions related to uncertainty was varied but the most common were an increase in noise sensitivity, with a co-occurrence of 31 with the code for “uncertainty” and eight with the code “routine change = increased sensory difficulty.” One parent, stated,

But when we went back to in-person church, and she went to...the singing time for the first time...she really struggled when ...they’d say a couple of words and then all the kids and teachers would repeat it...I had to start bringing in her earmuffs to calm that down. And now she’s starting to get comfortable enough that she doesn’t ask for the earmuffs
every week. And so, I think it was the combination of that sort of unexpected loudness of
you know all of these people saying the same words. Like that that was really jarring to
her followed by some of the more like upbeat, active songs. (Interview 020554, Quote 1)

Another parent noted that loud noises were often a sensory trigger for her child which led
to meltdowns and feelings that were difficult for him to explain. She expressed,

C1 gets super overwhelmed. Like loud noises, it just startles him…if he feels
overwhelmed, he’ll kind of just flail out…But for the most part, he gets buried down.
Like he will start crying and he will get really mopey and whiny…And I know it’s
because he’s out of routine and he’s overwhelmed and he is trying to find something
tangible to fixate on to express these emotions that he can’t process... (Interview 150704,
Quote 2)

Touch seeking was associated with routine change or uncertainty 16 times across the data
set. This was another commonly reported sensory reaction to the increased uncertainty in the
child’s life. One mother expressed multiple times during the interview that her daughter’s need
for deep compression increased during the pandemic. She stated that her daughter sought
“Stronger compression than she’s ever had before. It used to be just touch, but now it’s like, ‘I
need it more’ (Interview 225267, Quote 3).

Increases in RRB codes (or codes associated with RRBs) were also frequently observed
throughout the interview data in relation to sensory processing and uncertainty. Although the
codes, “child: restricted interests” and “reverting to typical ASD behaviors” were only associated
with “routine disrupted” and “uncertainty” once respectively, several other codes denoting the
presence of RRBs, such as maladaptive behaviors, rigidity, increased attachment, and hyper
fixation on COVID-19 were observed throughout the data in relation to disruption or change to
routines and uncertainty. One parent described her daughter’s reaction to the disruption of her routines like this, “If a routine is broken up and she doesn’t know why, yes, she does have a strong reaction” (Interview 225267, Quote 4). Another parent described the rigidity her son demonstrated when his school routine was disrupted:

He's very black and white. ‘Well, it’s time that I should be doing homework. Why am I not doing homework? What can I do?’ And I’m like, ‘Well I don’t have anything for you to do right now, so until your teacher gets ahold of me, I don’t know what to tell you.’ (Interview 204143, Quote 5)

We also observed that codes associated with RRBs also frequently co-occurred with sensory codes and the “anxiety/stress” code suggesting an interconnected relationship between sensory processing, RRBs, uncertainty, and stress. One parent described her daughter’s rigid use of electronics and how it fulfilled a sensory need like this:

Because of COVID and because of the lack of having things to do, she was on electronics more…Like she has to have an electronic in her hand all the time now. And it’s not so much that she’s playing with it, but she has her favorite songs, and she just puts it up to her ear and listens to it…and she’s very unhappy if she doesn’t have one. So, um oftentimes she’ll be playing if she’s playing a puzzle or blocks or something she’ll just have it by her side and the music will be going on and she’ll play just fine. So, it’s not like she has to play it, but she just has to have that constant sound. (Interview 225267, Quote 6)

One RRB that we observed throughout the data set was children’s tendency to either self-soothe or seek sensory means of decompression when faced with uncertainty. There were instances where children were either sensory seeking or avoiding sensory triggers to help
themselves self-regulate and decrease chances for uncertainty. There was an interesting
distinction between being able to internally calm themselves (e.g., deep breathing, gross motor,
stimming) versus be calmed by an external source (e.g., a parent, object, lights, sounds, pet,
touch) One mother described how her son would rely on her as an external source of
decompression but that he would utilize self-soothing techniques when she was not available.
She stated:

   It’s this almost like a little cubbyhole. It’s like right by the front door and if I don’t know
   where C1 is, he’s either in there or he’s in his room underneath his blankets in his bed.
   Like if he gets stressed or overwhelmed…It’s like he has to turn off the lights and he has
   to go somewhere else. He has to turn off all the sound. It’s like he has to reset. Or I have
   to talk him through it. So, if I’m not readily available he will go try and get away from all
   the input that he can. (Interview 150704, Quote 7)

**Category 1.b Avoiding/Managing Uncertainty.** In addition to the reactions to
uncertainty that we observed in the interviews, we also discovered that several of the caregivers,
or children themselves used methods to manage the uncertainty brought on by COVID or to
avoid further uncertainty. Avoidance behaviors including avoidance of uncomfortable
environments and outsiders were common. Several parents commented on these avoidance
behaviors with one stating, “He didn’t like anybody getting close him…and he didn’t even touch
anything” (Interview 108725, Quote 8). Another parent commented on her daughter’s avoidance
of neighbors and outsiders expressing, “She just avoided that altogether where my other kids
definitely like…if they saw the kids outside that face our backyard, they were out there too”
(Interview 214156, Quote 9). One parent even mentioned that her son started to avoid family
members, stating, “when we did see family, he seemed to be less…he used to just kind of
gravitate towards them and want to be with them, but he almost was kind of stand backish.” (Interview 151325, Quote 10).

Caregivers attempted to maintain or modify routines to attempt to normalize the situation at home. They seemed to do this both to help their children avoid escalation of behaviors and meltdowns, and as a method of coping with stress and uncertainty themselves. One mother explained the relief that came when she had time to plan and re-establish structure:

Then came summer which gave us a reprieve. I got a reprieve from work…There wasn’t as much pressure to do schoolwork…So that helped me sort of catch up and make a plan and we created structure and I felt confident enough to homeschool them…That summer was a blessing ‘cause it really gave me that time to catch up and see, ‘OK, I kind of know what to expect now with C1’s behaviors. This is what I was seeing. This is how I think I could create structure to minimize those behaviors,’…reflecting back, I think, ‘Wow, that was really hard.’ (Interview 160833, Quote 11)

Caregivers would also use behavior modification techniques to aid children in decreasing uncertainty and managing behaviors associated with the stress uncertainty caused. Even so, children often reacted to the increased uncertainty with increased RRBs. This was both a reaction to uncertainty and a way to decrease the likelihood of further uncertainty. We saw this manifest as children’s desire to understand the future and increased rigidity. One parent stated that instead of giving a guess of a timetable for the pandemic, “We kind of just decided to go with ‘We don’t know.’ ‘Cause no one did know and that was very hard for him…He can usually do pretty well if you give himwhat to expect, but if he doesn’t have that information, it’s a lot harder” (Interview 160932, Quote 12). Another mother spoke of how she and her spouse handled discussing the uncertainty of the pandemic and concurrent world events, stating, “We would have to have
discussions, with not only him but our other children about, ‘It’s ok. It’s not going to affect you personally.’ You know. We had to really calm down the anxiety with those outside things that were happening” (Interview 108725, Quote 13).

**Category 1.c Transitions.** There was a subset of the data in which parents talked about the role of transitions in their children’s experiences. The majority explained how the transition to home-based school and other activities, and onto online platforms, was difficult. Parents also expressed that and that they expected a transition back to school to present additional hardships. One mother commented:

We went and stayed with my family for a week like a couple months ago…it took us probably a week for both C1 and C2 to kind of get back to where they were before that. It was a really rough week of emotional outbursts and transitions were so much harder again… it just seemed like it was hard to get back into the routine. So, I anticipate with C1, when he goes to school…He’s gonna struggle like he did… Definitely I can see his emotional upheaval happening ‘cause it usually does when we get out of routine.

(Interview 150704, Quote 14)

Often sensory triggers, behavioral triggers/escalation, and tantrums/meltdowns were associated with these transitions, especially if the children were not prepared for them. One mother stated that her daughter’s tantrums “were markedly increased near the beginning of COVID…largely just due to the fact that it was just a huge change” (Interview 214156, Quote 15).

In contrast, there were a few instances where children had a positive transition to home or were well prepared for their transitions to another environment. A couple commented that their
daughter did remarkably well with the transition of moving to a new house during COVID due to the preparation that they gave to her and their younger daughter. They stated:

S1: So, we prepped her for a while once we were getting ready to sell our house and she and C2 came with us to look at houses…
S2: We made them a part of the process.
S1: Right we tried very hard to make sure that they understood as best they could that something was coming. That there was going to be a change” (Interview 020554, Quote 16).

Additionally, another mother commented on the benefit to her daughter of continuing with the same therapist from the prior school year. She expressed:

The relationship was maintained. And that actually was helpful in transitioning her back ‘cause her school psych was still the same as last year. So having that relationship be maintained through COVID, I think was still helpful for her to be like, ‘Oh, yeah, I know that A1 is still there for me and will still talk to me. So that was one thing that we could use to reassure her going back to school. (Interview 214156, Quote 17)

**Theme 2: Living in “Survival Mode”**

Due to caregivers and children feeling trapped in their own homes, lack of resources, changes to employment, disruption of routines, increased sensory processing difficulty, and changes in family roles, many families expressed that they were in “survival mode.” Caregivers operating in this mode were not only experiencing the stress of having fewer resources than they needed to care for their families but were also experiencing increased stress due to their children’s increased sensory processing difficulties and increased RRBs. These stressors were compounded by the need to balance the roles of caregiver, teacher, and employee if they were
working from home. In many cases, these increased stressors in the home led to strained relationships between caregivers and autistic children, siblings and autistic children, and marriage partners.

**Category 2.a Lack of Resources.** Less accessibility to resources meant less resources for the family to use when caring for their children which increased parental stress. Lack of support or support that was unhelpful from other areas including family, school, and therapy likely also contributed to overall stress. Several caregivers stated that online school or therapy was not a good fit for their child due to the difficulty of communicating, their child being “distracted” (Interview 214156), difficulty with, “sitting for things” (Interview 160833) or the need, “to be sitting” (Interview 204143) or difficulty building relationships through a screen. One parent noted that online classes were “loud” and a “sensory overload” for their child causing him to, “not want to participate” (Interview 160833, Quote 18). Another parent described the online school experience by saying it, “was awful,” and that the teacher, “was not trained to teach over Zoom” (Interview 225267).

The distribution of resources and support given by school districts was varied, with some families receiving a lot of support and others receiving next to none. Similarly, some families were able to continue ABA or speech therapy either virtually or in their home, while other families struggled to get in with a therapist due to lack of availability or virtual therapy not being a good fit for their child. One parent was disappointed that her son’s therapy time through the school went from, “360 minutes a week to 30 minutes a week” (Interview 151325, Quote 19). Another caregiver, commenting on the availability of therapy stated, “Those services can’t just stop if there’s a pandemic” (Interview 161634). Other caregivers described online therapy as being, “not as effective as being in person,” (Interview 214156); “useless,” due to attempting to
keep a young child’s attention on the screen (Interview 160932); a platform where it, “was very
difficult to build a relationship with the therapist” (Interview 108725). The parent who made this
last comment further stated, “My son would refuse to go or he would sit next to me on the couch
with Zoom open and be under a blanket and refused to speak. I don’t think he spoke for like
three months of weekly visits. It was just me talking to the counselor” (Interview 108725, Quote
20). She continued that her son may have had particular difficulty with therapy online because
when he attended in person, there were “figit toys” and “games.” She also mentioned that he may
have, “felt exposed because I was there,” or that communicating through a screen was,
“unfamiliar or he’s not able to get a relationship with someone that way” (Interview 108725,
Quote 21).

A few families also experienced difficulty obtaining an ASD diagnosis during the
pandemic due to testing being offered by fewer clinicians or not happening at all. Difficulty in
obtaining a diagnosis sooner hindered some families from getting the resources they needed at
the beginning of the pandemic or increased uncertainty about the support they would receive in
the future. Thus, in some cases, different types of challenges compounded each other. One
mother stated:

So, we’ve had a lapse in services...In order for the insurance to provide it [ABA therapy]
you have to have the diagnosis…But in order to get the diagnosis we’d have to come up
with at least three to four thousand dollars depending on the sliding scale. And we just
felt like we could not set aside that money at this time because we’re trying to make sure
we have enough money to get through everything. (Interview 150704, Quote 22)

Additionally, some caregivers experienced changes to their employment or to their
spouse’s employment which made having all their children at home, and life in general, more
difficult. Some of the stressors associated with these changes were lack of adequate internet access, having to fulfill work and caregiver responsibilities simultaneously, not having a quiet or secluded space to work from home, worries about income, health insurance, and other benefits, and having a spouse gone for longer hours of the day. One mother mentioned that her transition to working from home multiplied her roles and made it difficult to resolve conflict, she stated:

At the beginning I was trying to balance now working from home and having the kids home. My husband’s in the tech field, so his job got harder with COVID. So, he was gone more with COVID. I had to balance work and caring for them, so there was a lot of unstructured time where I wasn’t available, you know, to help him immediately regulate or anticipate frustrations and things like that. (Interview 160833, Quote 23)

Many caregivers expressed the desire for community during the pandemic and suggested this as something they would appreciate if they were ever in circumstances like this again. They stated that if they could just have another parent who has autistic kids to talk to, that would have made the situation so much better because they could be validated which might relieve some parental guilt. One mother stated:

Another thing I wish I could have figured out better during the pandemic and I think would have helped me with my kids is figuring out how to reach out to other parents in the same situation…just being able to reach out to another mom or someone else to say, ‘Yeah that’s difficult. That sucks. That’s hard’ (Interview 150704, Quote 24).

Some parents mentioned specifically that parents of neurotypical children, “just do not understand” (Interview 150704) their situation or the children’s behaviors and felt that sometimes these parents would even judge them for expressing concerns that they had for their children and household or they could not appreciate what parents of autistic children see as, “big
accomplishments” (Interview 108725). This increased the desire for support from other parents with kids on the spectrum.

**Category 2.b COVID-19 Precautions/Media.** COVID precautions, reports of cases, and presentation of information about COVID in the news resulted in some children hyper fixating on the pandemic and increased their fear of catching COVID themselves or of family members having COVID. One mother commented, “The constant on the news, he likes to watch YouTube…that constant COVID number, COVID thing, COVID thing. He was constantly asking, ‘My head hurts just a little bit, do you think I have COVID?’…All of my children…were really concerned” (Interview 108725, Quote 25). This increased the overall stress for the child which meant that parents/caregivers had to talk them down from these fears without being able to give them definitive answers about when the pandemic would be over or what was going to happen, which did not to alleviate already abundant uncertainty. A few of the caregivers described their children’s hyperfixation on COVID to be extreme and driven by fear. One parent remarked, “And so of course with a pandemic going on he was extremely anxious about, ‘What if he got sick? What if someone else in the family got sick? What if me and dad like died from the virus? What would happen to him?’ Things that other kids weren’t even really asking…” (Interview 160932, Quote 26). Another parent commented on her daughter’s experience of having COVID and the resulting subsequent fear, she stated:

> In her mind, things get really, really blown up, and she’s kind of had some ongoing things since then, and she has chest pains due to her anxiety, but because she had COVID and because she had multiple complaints of it, her pediatrician had us run an EKG…so she’s kind of just freaked out in general now around COVID, and that was true from the
beginning too, like that was one of the things that increased markedly for her was just like fear of being sick. (Interview 214156, Quote 27)

Some parents additionally commented on their children’s aversion to wearing masks with one stating that wearing a mask was, “too much for him to bear” and, “We can’t get him to obey that rule” (Interview 151325). And another mother stated, “She wouldn’t wear masks so we couldn’t take her shopping” (Interview 225267). On the flip side, a few caregivers commented that their child was hyperfixated on or even enjoyed mask wearing. One stated, “He was putting on masks all the time. He was wondering if we needed to wear them, even though we weren’t going anywhere…He thought maybe we all should wear masks all the time even around each other” (Interview 160932, Quote 28). Interestingly, one parent expressed that her daughter preferred wearing a mask because, “she didn’t have to worry about facial expression, which is something I think she has to take effort to think about” (Interview 214156).

**Category 2.c Strained Relationships.** Increased stress pressure secondary to the aforementioned stressors led to some strain in family relationships. The multiplication of caregiver roles to fit the demands of their children being home, working from home, and maintaining or modifying routines led to increased stress for parents, caregiver exhaustion, and in several cases parental guilt.

Parent-child stress and stress between siblings and autistic child were each reported in 50% of the interviews respectively. This strain between family members was a natural product of being stuck in the house together and in many cases not being able to leave due to lock down procedures or continued COVID-19 precautions. Parents reported that stress with their child was often related to their inability to let their child go where they wanted to go or do what they
wanted to. One parent mentioned specifically that as uncertainty increased, her child began to verbally lash out at her. She stated,

> Anytime that things are really disrupted or she’s not feeling safe for some reason that attachment goes up. So, like when there was something new at the beginning of the pandemic, like when there was that earthquake, that heightened her anxiety and when her anxiety’s high, like when I say co-dependency, like she relies on me to regulate that for her and work through things with her…but she gets very vindictive towards me…And so it's like kind of throwing me under the bus. Like the things that are happening in her life are my fault. (Interview 214156, Quote 29)

Another parent noted, “We’ve noticed his behaviors get worse when we’re stressed. And when we’re calm then his behaviors are better. So, I guess in a way that would be communication that he’s telling us that he can feel the stress and the anxiety or the issues that are happening in our home” (Interview 151325, Quote 30).

Caregivers also noted strain between siblings as in many cases, the autistic child was not used to having all of their siblings home or being in such close quarters for an extended period of time. Siblings were reported on several occasions to be the cause of sensory and behavioral triggers or the child on the spectrum. One mother illustrated this point by saying:

> ‘Cause C3, the sensory seeker, the older brother… he just speaks really fast and he’s just go go go go go and C1 would just be done with it and just start wailing on his brother like, ‘I am done.’ And they’re a really good balance for each other ‘cause they kinda help mellow each other out, but when you’re stuck with that person all day everyday it just gets to the point where he’s like ‘I am done’ and so then I have to calm him down. (Interview 150704, Quote 31)
One caregiver stated that her son began to, “lash out at his siblings and take it out on them if he wasn’t getting to do the thing that he wanted when he wanted to do it” (Interview 160932, Quote 32).

Parental guilt was a theme that ran through several of the interviews as many parents did not feel like they were doing enough to help their child maintain routines, continue working on therapy/educational goals, and improve communication. One parent shared, “because I’m trying to do so many different things, I can’t do all of this. I can’t do it well” (Interview 160833, Quote 33). She continued to say, “It took its toll on me personally. I had to let go of a lot of things. Like I had to let go of speech or PT activities…I tried my best to implement things into our routine, but I know I didn’t do a great job with it, and so that caused a lot of stress within myself” (Interview 160833, Quote 34).

One mother similarly lamented, “I wish that I could say that he got better with his communication ‘cause I worked with him, but I didn’t. Like I thought I would. Like I meant to. Every day I was going to start tomorrow” (Interview 151325, Quote 35). Another parent, speaking of her child’s communication said, “we were trying to survive ourselves and trying to get where we needed and so…we just didn’t encourage her to talk” (Interview 225267, Quote 36). Some parents expressed that they wished they had more training to continue therapy practice at home. Because online school and therapy were not good options for many of the autistic children in our sample, these responsibilities fell to parents to be teachers and therapists, and many felt that they did not have the proper training to do so.

Both positive and negative family interactions were observed in the interviews. For some there were negative experiences due to everyone’s stress levels being high and the feeling of
being trapped. Others had positive family experiences which stemmed from having extra time to be together and having more control over the environment.

**Theme 3: Unmasking**

This theme has to do with the concept of the caregivers and children having a certain threshold for stress and in the case of the children in our sample, difficult sensory processing. The uncertainty and increased burdens during COVID likely pushed stress levels up to this threshold for everyone but especially for autistic individuals. Throughout our interviews, there were experiences described in which the children were more likely to demonstrate big feelings and tantrums quicker or more frequently than they would have before. There were also accounts of how maladaptive behaviors increased, suggesting that the children were less able to self-regulate than before the pandemic. To cope with dysregulation, there was an observable return to comfort or unmasking of autistic behaviors/tendencies. There were positive and negative ways that individuals demonstrated this return to comfort. Some demonstrated increased attachment to family members and channeled their desire for stability into their interests. Others demonstrated maladaptive behaviors, including self-harm and increased aggression.

**Category 3.a Dysregulation.** Several parents and caregivers noted that their children were experiencing more escalation of behaviors and were quicker to meltdown due to sensory or behavioral triggers. One parent noted the effect of auditory input on her son during the pandemic by stating:

He has to wear noise dampening headphones that we put on his ears and if a fly ever gets in the house we immediately go and put them on him until we can get it and kill it because if not, he has the worst the worst tantrums he has ever had. And he’ll throw himself on the floor or he’ll run upstairs screaming. He gets really upset. He just hates it
when they fly near his ears. So that was a really big, new disruption that we haven’t experienced before. (Interview 160833, Quote 37)

Another parent noted that her son:

was getting very anxious…was just on edge more and so things upset him more. So a fight with a sibling that normally he would just be mad…it became something where he was on the floor screaming, crying. He started hitting himself again, which he hadn’t done for a couple years…other things were setting him off that would not normally set him off and it was escalated. Just seeing that increase in his meltdowns and the increase in the physical, like punching his arm sort of thing when he was upset. (Interview 160932, Quote 38)

**Category 3.b Return to Comfort.** Return to comfort looked different for each individual but for many of the children on the spectrum, it looked like an increase in behaviors typically associated with ASD. This included increases in engaging in restricted interests or increased RRBs. For some, this return to comfort looked like an increased attachment to a parent, sibling, pet, or object. One parent noted that their daughter, “always wanted the cat with her. And she will flip out if she cannot find him find him…like won’t sleep. Won’t do schoolwork…Like she’d wanna hold him a lot” (Interview 214156, Quote 39). Another parent noted that their daughter, “started being a little bit more needy…she was on my lap and she would just sit and get compression” (Interview 225267, Quote 40). For others, this was a return to simpler communication or engaging less in social communication in general, including less eye contact and mouth words. One mother noted that her son returned to using “hand over hand” and there was “reduction in eye contact.” She shared, “He had gotten so good with the eye contact and whenever he wanted something he would make eye contact and then make the request, as
opposed to just taking my hand and asking for something” (Interview 160833). Some children demonstrated more sensory seeking behaviors for comfort while others were more averse to sensory input. One mother noted that her son started, “climbing on furniture,” and “leaping off of things” (Interview 160932). Another parent noted that her daughter experienced, “restriction in diet,” and “mostly wanted junk food and was refusing to try a lot of new foods” (Interview 214156). Some children became more protective over their spaces (bedroom, their side of the bedroom, a quiet or secluded place in the house, a particular room in the house where they liked to be) and needed more alone time. One parent noted that her son’s behavior and willingness to comply changed. She said:

> When we were highly stressed, he just didn’t want to comply. He would just, we call it flopping…and I can’t make him move. So, he would flop or just sit in a chair and refuse to get up ‘cause I can’t do anything about it. We saw a lot of that or just not wanting to follow instructions. Just pushing us away or shaking his head no, and just wanting to stay in his room, and play his iPad. (Interview 151325, Quote 41)

Another mother noted that she felt her daughter was more comfortable with reduced socialization and that she seemed to like to be able to, “go into my cocoon at home and not have to interact outside of the home” (Interview 214156, Quote 42). This may be linked to her other observation about her daughter’s masking behaviors. She stated, “I see more autistic tendencies at home than they do at school…She’ll hide them at school. And actually, even since being diagnosed, I feel like she’s gotten even more comfortable about letting them show at home” (Interview 214156, Quote 43).
**Theme 4: Resiliency**

A theme that ran as a contrasting/complimentary undercurrent to the others listed above was that of resiliency, adaptability, and thriving. Despite all the challenges that each of these families faced, many showed remarkable resiliency in maintaining or re-establishing routines. A few of the parents even mentioned how their child’s situation was better during the pandemic because they were able to do things their own way and provide more support for their child at home. Some parents also mentioned increased family bonding and a time to reset what their priorities and what they were doing at home.

**Category 4.a Flexibility.** A few parents mentioned the benefits of flexibility of jobs, church, and school that was introduced during the pandemic that made it easier for their child or their family to participate in these different areas. They hoped that this flexibility could continue beyond the pandemic because it increased their accessibility to full and comfortable participation. One parent wanted to emphasize the message that, “people are different and it’s valuable to help these people who are who are different” (Interview 108725). She elaborated on how technology during COVID provided flexibility for her family which improved their lives in several ways indicating that:

> It just actually helped us a lot to get ease stress to have online church or to not have to go places and not be required to go places…offering these new things that people are getting more used to technology-wise, and because of COVID, I think if we if we learn from it we’ll be able to make a better place for a lot of a lot more people… just being able when you’re sick, or away from home, or you’re having a need a mental health day, to still be able to participate in [church] meetings ... It it helps build that connection with those people (Interview 108725, Quote 44).
She also stated that it was positive for her daughter with severe depression because she could, “do things in her way and not having to sit at school and be dealing with some of her mental health issues,” and that, “individualization of education really is a wonderful thing” (Interview 108725, Quote 44).

**Category 4.b Thriving at Home.** Several parents mentioned factors that made transitions easier or lauded the benefits of keeping their child on routine because they said this helped them to not tantrum or be dysregulated. Some parents were able to have time to educate their children and help them find ways to be successful during this time. One parent mentioned that a benefit of having her children home was, “The bond that we created” (Interview 160833). She additionally spoke of the positives of homeschooling her children during COVID and expressed:

> The biggest positive was feeling empowered to really take full control of my children’s education and be able to do it…We had to learn how to be together and how to understand or or anticipate people’s needs for space and playing together. Like my kids came up with so many neat new ways to play together because they were around each other all the time We also grew to understand what they were doing in school…When we send our kids off to school, we really are cutoff from their day-to-day routines and so we grew as a family and I’m grateful for that. (Interview 160833, Quote 45)

Another parent spoke of how her daughter had more time during COVID to learn how to use her AAC device for communication. She stated, “You should see her talk on her little machine now!... she’s doing so good, I think I’m holding her back because she’s just picking up things so fast…” (Interview 225267, Quote 46). Additionally one mother spoke of the increased time that she had to teach her son how to communicate his feelings. She expressed:
With him it was almost like a trial by fire with the emotional regulation… Doing so much work during the pandemic I think really helped him come through it and so now he is able to go out with other people, he can come home and be like, ‘Mom, I am just sad today,’ … he can identify that a little bit better (Interview 150704, Quote 47).

Discussion

Because the COVID-19 pandemic disrupted both individual and societal routines, introducing widespread and increased uncertainty, the present study aimed to explore the effects of these conditions on autistic children and their families, with particular interest in the relationship between sensory processing, intolerance of uncertainty, and stress within the context of the COVID-19 pandemic. Although studies have been conducted that have observed the relationship between these factors in autistic children (Boulter et al., 2014; Hodgson et al., 2017; Neil et al., 2016; South & Rodgers, 2017; Van de Cruys et al., 2014; Wigham et al., 2015), we are the first to report them within the context of COVID-19—a natural experiment of increased uncertainty and its correlates. Throughout the quantitative and qualitative data, we found evidence of a reciprocal relationship between sensory processing, RRBs, uncertainty, and stress. The increase of these factors led to most participants living in “survival mode” during the pandemic in addition to lack of adequate resources and disruption to normal routines. Some parents and autistic children responded to living in “survival mode” by returning to comfortable behaviors, environments, people, and interests. Many caregivers and autistic children showed remarkable resiliency during the pandemic, adapting to circumstances and re-establishing routines under difficult circumstances. The findings suggest that families would have a greater chance of thriving during future times of uncertainty with increased access to resources and training as well as establishing a community that understands their unique challenges and needs.
Additionally, greater awareness about the relationship between uncertainty and sensory difficulties has the potential to enhance our knowledge of the underlying mechanisms of the same and influence clinical supports for people on the autism spectrum.

**Findings**

**Relationship Between Sensory Processing, Restricted and Repetitive Behaviors, and Uncertainty**

We found that the majority of our sample had sensory processing difficulties before the pandemic and that these difficulties generally got worse during the pandemic. Both sensory processing and intolerance of uncertainty increased for our entire sample. Interestingly, there was also a significant correlation between change in sensory processing and intolerance of uncertainty for the sensory difficulty group indicating that as uncertainty increased from pre to during COVID, sensory processing ability decreased. This finding was supported by the study conducted by Ameis et al. (2020) who predicted that uncertainty caused by changing living situations due to COVID-19 would increase sensory processing difficulties. Additionally, Colizzi et al. (2020) observed a significant relationship between pre-pandemic behavior problems and negative behavior outcomes during the pandemic. Although the type of behavior problems were not specified, it seems reasonable that some of these behaviors might have been sensory in nature, consistent with our findings with the sensory difficulty group. The reciprocal nature of these two factors is also supported by Wigham et al. (2015) whose results strongly indicated that sensory processing difficulties lead to increased anxiety and uncertainty which then leads to repetitive motor behaviors and insistence on sameness behaviors. Neil et al. (2016) adds additional insight into this relationship with the finding that IU explained approximately half the variance in autistic children’s sensory sensitivity scores, with the relationship partially mediated
by anxiety. South and Rodgers (2017) also indicate reciprocal relationships between sensory processing abnormalities, intolerance of uncertainty, and anxiety such that the presence of one can determine the presence of another. We found a weak significant relationship between SSP and IUS-dur scores overall but no other significant relationships between any other combo of SSP and IUS pre and during scores was found in the sample. This contradicts the findings of Neil et al. (2016) who demonstrated strong negative correlations between SSP and IUS scores. The lack of significant correlation in this study in comparison to other similar studies of the same factors (sensory processing and IU) may be attributed to the time that passed between the first six months of the pandemic and the window of interest when questionnaires were filled out (approximately one year). Another possibility is that children on the spectrum and their families may have had different responses to COVID-imposed lockdowns (i.e., some experienced negative effects of the restriction, some enjoyed the time at home, and for others there was no significant change).

Parents and caregivers reported in their interviews of increased sensory processing difficulty, RRBs, and self-soothing/decompression behaviors in their children due to the “big change” that COVID presented to their daily routines as predicted by Ameis et al. (2020). Increases in sensitivity to noise were particularly prevalent in both our quantitative and qualitative data with a few parents reporting that their children had to wear earmuffs or headphones more often and others reporting that their children would turn off the source of noise or remove themselves from the situation entirely. Additionally, increases in touch-seeking were noted by several caregivers across the data set. In both our quantitative and qualitative data, more hyperresponsivity and sensory seeking behaviors were noted than hyporesponsivity, as defined by Neil et al. 2016, however these behaviors may still have been present or part of children’s
sensory responses but were overlooked due to more obvious or overt sensory difficulties. Our findings add to the current literature addressing the relationship between sensory processing, intolerance of uncertainty, and anxiety (Boulter et al., 2014; Hodgson et al., 2017; Neil et al., 2016; Van de Cruys et al., 2014; Wigham et al., 2015) as it indicates that sensory processing difficulty, although unique to individuals, may be more concentrated around certain sensory modalities when individuals are presented with increased uncertainty and stress. This understanding may have implications for improving caregiver and professionally provided intervention in future uncertain environments and circumstances.

Increases in RRBs such as biting nails, head-banging, and stimming were noted by caregivers in addition to increased attachment to people, pets, and objects, increased rigidity, and hyper-fixation on COVID during the pandemic. These behaviors were frequently coded in tandem with disruption to routines, uncertainty, sensory codes, and anxiety/stress. These findings are partially supported by Hannawi et al. (2022) who found that self-injurious behaviors increased from 43% pre- to 52% during the pandemic in their sample of autistic children. However, they did not observe any increases in hyperactivity, anxiety, aggressive behavior, or frequency of stereotypies/repetitive behaviors, all of which we observed in our study. The findings in the present study are also supported by Masi et al. (2021)’s findings that 58.4% of caregivers reported their child’s symptoms had worsened during the pandemic. This percentage is less than the percentage in our study that experienced increased sensory difficulties during the pandemic and since Masi et al. (2021) did not specifically account for sensory processing difficulties, it is likely this percentage would be higher with sensory difficulties taken into account. Our findings add to this finding by Masi et al. (2021) in that we found that when sensory difficulties are considered, more childrens’ autism-related symptoms worsened. Our
findings surrounding the intersection of sensory processing, RRBs, uncertainty, and stress further the work of Wigham et al. (2015) who discovered direct paths from sensory over-responsiveness to insistence on sameness behaviors and the role of IU and anxiety leading to repetitive motor behaviors. The findings of Boulter et al. (2014) and Neil et al. (2016) also indicate that the relationship between increased uncertainty, sensory difficulties, and anxiety can result in perceived need for routine and normalcy, which often results in the person using RRBs to add some control over themselves and their environment which we observed to be the case in the present study.

Strategies used by caregivers to increase certainty and tolerance of uncertainty as identified by Hodgson et al. (2017) were reflected in the present study’s participants’ attempts to manage uncertainty. We observed avoidance behaviors, children trying to stick rigidly to routines, and caregivers’ attempts to re-establish routines to decrease the possibility for uncertainty in the home. The avoidant behaviors reported in the present study build on findings by Masi et al. (2021) of neurodivergent children having significantly more difficulty maintaining relationships during COVID. Caregivers also demonstrated trying to increase their children’s tolerance for uncertainty by preparing their child ahead of time for changes and made them, “…a part of the process” (Interview 020554, Quote 16) and ensuring, when possible, that relationships inside and outside the home were maintained.

One sub-theme that came to light in the qualitative data that was not present in the quantitative was parents’ apprehension of their children going back to school due to anticipation of their negative reactions to another big transition. Preparing the child ahead of time, as mentioned above and continuing relationships with therapists and teachers/aids where possible were proposed as ways to help with the transition. The children in the present study who thrived
the most with transitions were able to do so because of continuity of routines and relationships. This finding was similar to that of Amorim et al. (2020) who noted that within their ASD group, those that maintained their prior routines during the pandemic had lower levels of anxiety than those that did not maintain routines. Our findings add to the current literature surrounding autistic individuals and transitions (Marsh et al., 2017; Sterling-Turner & Jordan, 2007; Stoner et al., 2007) and could play a role in improving school and therapy experiences.

**Effects of Living in “Survival Mode”**

Disruption to routines accounted for a large portion of the variance in child, parental, and household stress and led many families to live in “survival mode.” This finding was a follow-up to the survey given by Manning et al. (2020) which also included families’ reports of high levels of stress and disruption to routines during COVID-19. Parental and child stress were also found to be significantly correlated which is supported by Clauser et al. (2020) who noted that child stress increases in relation to parental stress leading to difficult behaviors. Caregivers in this study specifically expressed that their children’s behaviors got worse when they were stressed. The present study added to the findings of Clauser et al. (2020) by showing that parental stress also increased when child stress increased. In addition to parental and child stress being strong determinants of each other, disruption to routines and SSP scores were the strongest determinants of child stress, with a weak significant correlation between IUS-dur and child stress. This finding confirms the suppositions of Colizzi et al. (2020), Hodgson et al. (2017), and Patel et al. (2020) who predicted that the extensive changes to daily activities likely caused increased psychological distress, due to high level of intolerance for uncertain circumstances. Additionally, we found that SSP-dur mediated the relationship between IUS-dur and child stress-dur when controlling for age, but IUS-dur was not a mediator between SSP-dur and child stress-dur. These mediation
models add to findings presented in Neil et al. (2016) and Wigham et al. (2015) in that we used sensory processing as a mediator between IU and stress which was not presented in the mediation models of these studies. Neil et al. (2016) found that IU mediated the relationship between autism diagnosis and anxiety and, to a lesser degree, between autism diagnosis and sensory sensitivities. Although we did not use a standardized measure of anxiety, we added to the findings of this study by showing how sensory processing and IU acted as mediators. We did not, however use stress as a mediator to confirm the findings of Neil et al. (2016) as we were not using a standardized measure of anxiety/stress. Future research of these factors within the context of the COVID-19 pandemic would benefit from determining if stress mediated the relationship between sensory processing and uncertainty.

Caregivers reported on the survey and in the interviews that fear of themselves or a family member catching COVID-19 was a prevalent fear, causing hyper-fixation on the pandemic for some of the children. COVID-19 precautions including isolating, social distancing, mask wearing, working from home, and staying home from school were all mentioned in interviews and contributed to disruption of normal routines. Mask wearing presented as a sensory challenge for a few of the participants’ children and as a rule to be followed rigidly by others. In one case it was viewed as an equalizer because no one could see facial expressions, which were difficult for that child to discern. These findings continue the work of Ameis et al. (2020), Manning et al. (2020), Masi et al. (2021), and Panda et al. (2020) who all observed or made predications about the effects of COVID-19 precautions and circumstances on adolescents and in the case of all but Panda et al. (2020), specifically adolescents with ASD. There were no reports of vaccine apprehension in our study, as was noted to be the case for some families by Bendau et al. (2021). We did not include any questions about the COVID-19 vaccine in our survey as we
were asking caregivers to reflect on the first six months of the pandemic, prior to the vaccine being available. We also did not specifically ask about the vaccine during semi-structured interviews, but one parent brought up that her son receiving the vaccine helped to assuage his fears of catching the virus.

In addition to their children’s stress and the added stressors introduced during COVID-19 which caused disruption to routines, lack of resources also significantly contributed to parental stress. We found that the majority of our participants did not have access to the resources they needed to adequately care for and promote the success of their autistic children. We found that the resource index score was significantly positively correlated with parental stress, such that as the resource index score went up, stress went up. We would expect this to be the opposite considering lack of resources explained part of the variance of parental stress, however, this may be the case due to families with more severely affected children seeking out more resources. There were also families included in the study who have more than one child on the spectrum, which may have necessitated their seeking out more resources, because they had greater need. Manning et al. (2020) also noted in their survey results that caregivers who received a high level of support for their children prior to the pandemic showed elevated levels of stress during the pandemic. It is possible that for some of these families, they retained their previous resources but still required more to function with the added pressures of the pandemic. School support and employment status were also included in the resource index which were both variable depending on the school district where the family lived and the type of job the parent had, which may have impacted their overall number of resources.

Several parents and caregivers noted in the present study’s interviews that online school and therapy were not a good option for their children due to their inability to focus, sensory
triggers, and difficulty building or maintaining relationships over screens. Masi et al. (2021) noted parents’ initial dissatisfaction with remote therapies and Hannawi et al. (2022) stated that parents in their study reported that their children were unable to sit and focus during online classes, both of which were confirmed in the present study. Lack of testing availability and the cost of being tested were barriers for obtaining an autism diagnosis during the pandemic, additionally for families who had received diagnoses right before the pandemic, intervention services were limited. These observations confirm the predictions of Ameis et al. (2020) who speculated that reduced access to ASD services during the pandemic would place barriers to formal diagnosis of ASD, leading to delays in intervention. The stress caused by lack of support outside of the home during the pandemic was initially noted by Manning et al. (2020) and with the increased physical and mental health challenges for neurodiverse children and parental dissatisfaction with remote therapies observed by Masi et al. (2021), changes need to be made to include caregivers more in the therapy process and to ensure that adequate services continue to be provided for autistic children during future times of uncertainty.

**Returning to Comfort**

Many or most demonstrated a return to comfort in some way during the pandemic (e.g., wearing more comfortable clothes, going out less, watching more TV, returning to a favorite hobby or learning a new one, and putting less effort into our physical appearances). For the children in the present study, returning to comfort behaviors were manifestations of coping with uncertainty. They included physical behaviors such as stimming and nail biting, emotionally driven behaviors such as showing greater attachment to a parent and increased tantrums, increased rigidity in following routines and engaging in interests, and decreasing uncomfortable communication practices such as making eye contact and engaging in social communication with
outsiders. The quantitative data also indicated that autistic behaviors/tendencies increased during the pandemic although these were not significantly correlated with SSP-dur scores and only one behavior (safety concerns) was weakly significantly correlated with IUS-dur scores. Although we did not see direct correlations with these measures, the behaviors were significantly correlated with each other, such that if one increased, another was more likely to increase as well, indicating that children were less able to self-regulate. These findings follow previous evidence in the COVID-19 and ASD literature in which pandemic conditions were shown to intensify primary symptoms of ASD including stereotyped behaviors, insistence on sameness, and sensory sensitivities, all of which were speculated to result in dysregulation, sleep disturbance, anxiety, and depression (Aarabi et al., 2021; Ameis et al., 2020; Masi et al., 2021). Most caregivers in the present study described the behaviors they observed as regressions, ruining the progress their child had made socially and in over-coming autistic behaviors/tendencies. However, we posit that instead of these behaviors being regressions, they were part of an unmasking process. Masking and camouflaging have been cited repeatedly in the autism literature, particularly in relation to females on the spectrum. When these individuals are in more comfortable environments, they feel they can “unmask” and demonstrate behaviors that are not readily acceptable in society (Allely, 2018; Cook et al., 2018; Miller et al., 2021; Milner et al., 2019; Pearson & Rose, 2021). COVID-19 raised most people’s stress to meet the threshold, making any added stressors or inconveniences uncomfortable or even impossible to manage, affecting the mental health around the globe as noted by Brooks et al. (2020), Czeisler et al. (2020), and Panda et al. (2020). With additional behavioral, physical, and emotional repercussions for neurodivergent children, as described by Colizzi et al. (2020) and Masi et al. (2021), autistic children were also reaching or surpassing their thresholds which meant they had less energy or
motivation to mask autistic behaviors or conform to neurotypical communication expectations. We did not find any significant correlations between sensory difficulties and communication as noted by Liss et al. (2006) and Watson et al. (2011), however we did find that increased sensory difficulty explained part of the variation in child stress which may have led to more withdrawn or avoidant behaviors. The observed return to or increase in autistic behaviors/tendencies during the pandemic follows the observations of Colizzi et al. (2020) of increased behavioral concerns at the beginning of the pandemic and Masi et al. (2021) who predicted increased emotional arousal, aggression, impulsivity, and anxiety for this population. Mutluer et al. (2020) reported similar increases in physical and behavioral disruptions including 55% of parents in their study reporting increased aggression, 29% reporting their child’s communication deteriorated, 26% reporting increased tics, and 44% and 33% reporting sleep and appetite changes respectively.

Resilience in Facing Uncertainty

Despite their extremely difficult circumstances, caregivers and autistic children demonstrated resilience in re-establishing routines and discovering ways to make transitions a more positive experience. This theme was not readily apparent in the qualitative data, but it shone through in the statements of parents and caregivers in the interviews. Some things that parents identified that helped them to thrive during uncertainty, such as the increased flexibility of having meetings or school online, having continued therapy in the home, receiving education on therapy, and allowing children accommodations to learn in the best way for them while meeting sensory needs may be instructive in how we can change practices in schools, therapies, and additional autism support systems to better meet the needs of autistic children and their families. These findings support those reported by Siracusano et al. (2021) who found that adaptive skills (i.e. communication, use of environment, health and safety, play, preschool
competences, self-care, self-control, social abilities, and motility) increased in preschool-age autistic children during the pandemic who were receiving online intervention. The parents of these children were also receiving online support/education which helped them better teach these adaptive skills. Their research showed the benefits to the children of having their parents home and available to teach them these skills, reinforcing the idea of thriving at home with parental support and routines.

Limitations

There were limitations in the present study due to having a relatively small sample size which was characterized by primarily white, middle-class caregivers living in Utah. Greater variety in race, socioeconomic status, and geographical area would have allowed us to capture a richer narrative of the experiences of families with autistic children with stressors not fully considered in this present study such as racial inequity and lack of access to resources due to financial burden. Another limitation of the study was that we used formal measures of sensory processing and intolerance of uncertainty but did not formally evaluate stress/anxiety. Having a formal measure of anxiety would have allowed us to get a better sense of how anxiety mediated other factors. The data collected in the quantitative and qualitative portions of the present study were based on parent report and may have been affected by their answering questions about a period of time that occurred several months prior to data collection. In creating codes and coding the interview data, there may also have been inherent bias by the researchers, however we attempted to mediate this through multiple rounds of coding and coming to agreement on which codes should apply to sections of data.
Implications for Future Research

Based on the results in this study, future research could focus on factors that lead to positive and negative transitions for children on the autism spectrum. Additional research is also needed to understand why some sensory areas may be more affected in the wake of uncertainty than others. The finding that sensory processing is a mediator between intolerance of uncertainty and stress opens a whole new door for understanding why uncertain situations or disruption of routines may be so distressing for people on the spectrum and could be studied in contexts other than the COVID-19 pandemic. Further research into the concept of unmasking and returning to comfort when faced with uncertainty would also be beneficial to better understand why people on the spectrum may be communicating in a certain way or demonstrating certain behaviors. Another area of interest for future research would be observing the cycle of uncertainty causing sensory difficulties, which causes more uncertainty, anxiety, and RRBs or possibly meltdowns in other contexts such as school, new therapy appointments, or other novel environments or situations.

Clinical Implications

The clinical implications of this study are numerous due to the disruption to many therapies and school support during COVID-19 and the continued need for this support for inside and outside the home. The discovery that some sensory areas, most predominantly noise sensitivity, increased more than others when faced with uncertainty allows therapists to not only try and decrease the uncertainty of therapy appointments but also to be sensitive to the sensory needs of their clients. Service providers in many fields currently do not evaluate or directly address sensory difficulties in their practice. However, atypical sensory processing has the potential to affect virtually every aspect of life and, as is shown here, can be associated with
heightened stress. Both sensory differences and increased stress/anxiety could have negative impacts on therapeutic, educational, and other gains. Thus, considering an individual’s sensory challenges and needs, and adapting support activities accordingly, could result in positivity for all involved. Similarly, making the most of the sensory abilities and talents of a client, patient, or student could also lead to improvements.

An additional implication is that several parents and caregivers noted that they wished they could have more training associated with their children’s therapies, that they could feel empowered to do more at home and then talk about what they observe in therapy sessions. Clinicians should provide more education to family members and involve them more in the therapy process so they can feel empowered to help their children, even if services are not readily available. The children who thrived the most during the pandemic were those whose therapies continued in-person or in their home, with the same service providers, indicating that the continuity of the environment and relationship was important to their continued progress. The desire for connection with other parents of autistic children was also prevalent in the present studies data and could be encouraged by service providers as a way to discuss common experiences and have support in future times of uncertainty.

Conclusion

The COVID-19 pandemic increased uncertainty for everyone, causing increases in stress and fear. These concerns were especially prevalent for autistic people, due to their common intolerance for uncertain situations and disruption to the routines that often help them to self-regulate. We found that the majority of families who participated in our study felt they did not have the resources they needed to adequately care for the needs of both caregivers and autistic children. Increased uncertainty during the pandemic was strongly related to increases in sensory
processing difficulties and RRBs which, in some cases, pushed children past their self-regulation threshold and resulted in increased dysregulation and meltdowns. Parents and caregivers attempted to mitigate uncertainty by re-establishing routines and preparing their children for future changes while autistic children sought comfortable environments, people, interests, behaviors. These families showed resiliency during the pandemic but were existing largely in “survival mode.” There is more that can be done on the part of local governments, school districts, and private service providers to ensure that autistic people and their families receive the support they need during future times of uncertainty such as anything that can be done to decrease unpredictability, increased involvement of caregivers in therapy, facilitation of contact between parents of autistic children to increase community, continuance of therapy mandated by IEPs, and increased flexibility in work, school, church, and social formats to better accommodate neurodiverse people.
References


https://doi.org/10.3389/fnint.2020.00022


https://doi.org/10.15585/mmwr.mm6932a1


https://doi.org/10.1016/j.jad.2020.06.029


https://doi.org/10.1177%2F1362361306062021

https://doi.org/10.1016/j.jaac.2017.03.013

https://doi.org/10.15585/mmwr.ss7011a1


### Tables

**Table 1**

*Demographic Characteristics and Comparison of Pre- and During-COVID SSP/IUS Scores for the Entire Study Sample*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>47</td>
<td>8.97</td>
<td>3.76</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>SSP</strong> pre</td>
<td>47</td>
<td>116.47</td>
<td>23.77</td>
</tr>
<tr>
<td><strong>SSP</strong> dur</td>
<td>47</td>
<td>111.74*</td>
<td>27.18</td>
</tr>
<tr>
<td><strong>IUS</strong> pre</td>
<td>47</td>
<td>33.68</td>
<td>10.91</td>
</tr>
<tr>
<td><strong>IUS</strong> dur</td>
<td>47</td>
<td>36.53*</td>
<td>12.99</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01  ***p < .001.*
Table 2

Repeated Measures ANOVA Comparison of Pre- and During-COVID SSP and IUS Scores for Sensory Difficulty and Typical Sensory Groups

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>During</th>
<th>F; p</th>
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</thead>
<tbody>
<tr>
<td>Sensory Difficulty Group</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>(n=42)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP</td>
<td>111.81 (18.27)</td>
<td>104.79 (18.64)</td>
<td>25.83; &lt;0.001**</td>
</tr>
<tr>
<td>IUS-12</td>
<td>33.43 (10.70)</td>
<td>37.52 (12.64)</td>
<td>36.95; &lt;0.001**</td>
</tr>
<tr>
<td>Typical Sensory Group (n=5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSP</td>
<td>155.60 (30.57)</td>
<td>170.20 (12.50)</td>
<td>1.83; 0.248</td>
</tr>
<tr>
<td>IUS-12</td>
<td>35.80 (13.74)</td>
<td>28.20 (14.38)</td>
<td>1.40; 0.30</td>
</tr>
</tbody>
</table>

*p < .05  **p < .01  p < .001.
Table 3

*Mean SSP Sub Scores for Sensory Difficulty and Typical Sensory Groups*

<table>
<thead>
<tr>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory Difficulty Group</td>
<td>-1.50</td>
<td>3.05</td>
<td>-1.00</td>
<td>2.15</td>
<td>-0.29</td>
<td>0.64</td>
<td>-1.24</td>
<td>2.63</td>
<td>-1.55</td>
<td>2.23</td>
<td>-0.43</td>
<td>1.31</td>
<td>-1.02</td>
<td>1.81</td>
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<tr>
<td>Typical Sensory Group</td>
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<td>5.22</td>
<td>2.20</td>
<td>4.38</td>
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<td>0.89</td>
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<td>4.20</td>
<td>7.36</td>
<td>1.00</td>
<td>2.24</td>
<td>2.40</td>
<td>3.58</td>
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Table 4

**Major Qualitative Themes, Categories, and Codes**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sensory Processing and Uncertainty</th>
<th>Living in “Survival Mode”</th>
<th>Unmasking</th>
<th>Resilience</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categories</td>
<td>Reactions to uncertainty, Avoiding/managing uncertainty, Transitions</td>
<td>Lack of resources, COVID-19 precautions/media, Strained relationships</td>
<td>Dysregulation, Return to comfort</td>
<td>Flexibility, Thriving at home</td>
</tr>
</tbody>
</table>
negative, IEP-positive, school support: negative, school, support: positive, school: online, school: homeschool, difficulty obtaining diagnosis, antecedent manipulation, parent: wanting stability, lack of resources, child: suicidal, ideation, clinical anxiety, decrease in self-esteem, depression, parent/child stress relationship, COVID: hyperfixation, child: exhaustion, child: feeling trapped, child: masking, child: screen time, child: withdrawn, communication: negative, emotion: child negative, emotion: child positive, communication: social communication difficulty, communication: symbols/AAC, social awareness, social negative, social positive, emotion: caregiver negative, emotion: caregiver positive, avoid uncomfortable environment, child: elopement, communication: scripted/quoting, avoiding family, avoiding outsiders, isolation, need for parental attention, parent: return to comfort, child: attachment to sibling, reverting to typical autism-related behaviors, cooperation, adaptability, thriving at home, advocacy for child, advocacy for parents, transition positive, self-soothing, child: big feelings/happy/excited, routine change: positive, routine maintained, routine modification, thriving with routine, communication: enjoyment of social interaction
| Big feelings/happy/excited, child: big feelings/tantrums/meltdowns, sensory: difficulty with closeness of others, sensory: triggers, change in environment, perception of time, loss of control | Wearing, physical activity: decrease, sibling/child stress relationship, communication: stuttering, social awareness, COVID: cases, COVID: fear, COVID: precautions, emotion: caregiver negative, emotion: caregiver positive, avoiding leaving house, employment change: negative, SES impact, lack of community, Desire for community, parents of neurotypical children don't understand, isolation, parent involvement in therapy: negative, parent involvement in, therapy: positive, marriage strain, communication: hand over hand, communication: decrease in, social communication, communication: gestures, protection of space | Comfortable environment, communication through a screen, communication: decrease in, attachment to parent, increased attachment, attachment to pet, attachment to object, communication: hand over hand, communication: decrease in, social communication, communication: gestures, protection of space |
Figures

Figure 1

SSP Total Scores During COVID-19
Figure 2

Sensory Processing and Intolerance of Uncertainty From Pre- to During-COVID-19 Conditions
for Sensory Difficulty and Typical Sensory Groups
Figure 3

Scatter Plot of the Correlation Between Change in Sensory Processing and Intolerance of Uncertainty Regression Model

$r = -0.599$
$p < 0.001$
Figure 4

*Mean Change in SSP for the Sensory Difficulty and Typical Sensory Groups*

![Graph showing mean change in SSP for sensory difficulty and typical sensory groups.]

Figure 5

*Sensory Processing, Intolerance of Uncertainty, and Stress Mediation Model*

![Diagram illustrating the relationship between IUS-dur, SSP-dur, and Child Stress with their corresponding coefficients and model statistics.]
Figure 6

Scatter Plot of the Correlation Between Sensory Processing and Child Stress During COVID-19

$r = -0.46$

$p < 0.001$
APPENDIX A

Annotated Bibliography


**Background:** The researchers in this article provided commentary on the impact of changes to the environment, changes to routines, school closure, transition to online platforms for school and therapy, physical distancing and changes to services in relation to COVID-19 on autistic individuals. They additionally included information about potentially helpful coping strategies during disruptive situations such as COVID-19. The researchers also note the potential for the circumstances surrounding COVID-19 to encourage resilience in the ASD community in the wake of uncertain circumstances and the benefits that could be applied to future care of Autistic individuals, including improvements to virtual therapy and learning. The background information for the commentary includes the points that early analysis has shown that individuals with intellectual and developmental disabilities often have physical comorbidities which could lead to worse outcomes if they were to contract COVID-19. They also included that social distancing measures have impacted the mental health of Autistic individuals and their families.

**Aim:** The purpose of this article was to increase public understanding of the impact of circumstances surrounding COVID-19 on autistic individuals and to offer positive perspectives on what service delivery providers, caregivers, and autistic
individuals can learn from these circumstances. This article reviewed studies which were conducted about the impact of COVID-19 on the mental health and well-being of autistic individuals and their caretakers.

**Results:** The researchers’ key points about the impact included the fact that changes to daily routine and access to regular services could disrupt physical and mental health as well as family relationships. They noted that circumstances during COVID-19 may have necessitated changes to living situations for autistic individuals which would likely cause sensory processing difficulties due to unfamiliar sensory inputs which accompany a new environment. They also commented that more time spent at home could lead to unhealthy fixation on certain activities or tasks. Additionally, they hypothesized that behaviors such as sleep dysregulation, anxiety, depression, and attention deficits would increase in severity for these individuals. In relation to school closure and limitations to therapy, the researchers noted that school closure would reduce adolescents' access to needed social supports which could increase mental health challenges. They made the point that reduced access to ASD services would place barriers to formal diagnosis of ASD which could lead to delays in needed early intervention and other services. The researchers additionally make suggestions of coping mechanisms during the pandemic and note that COVID-19 provides an opportunity to improve service delivery and explore more virtual options. They state that access to technology and time available to devote to virtual care need to be taken into account when developing these service delivery models to prevent inequality.

**Implications for the Current Study:** This article provides useful background information about autistic individuals and the potential impacts that COVID-19 has had
on them. The information included in this article provides ideas for areas of concern for autistic individuals and their families during uncertain circumstances such as the pandemic. It is also beneficial as a starting place for improving service delivery for people with ASD during difficult and disruptive circumstances.


**Background:** Boulter et al. (2014) were interested in investigating the correlation between intolerance of uncertainty (IU) and anxiety in children with autism spectrum disorders (ASDs). They presented evidence that anxiety is commonly diagnosed in autistic children but noted that there was a shortage of models or theories explaining the cognitive processes underlying this comorbidity. They postulated that intolerance of uncertainty (IU) may be able to explain the prevalence of anxiety in this population, as it has been shown to explain anxiety in neurotypical children.

**Aim:** The objectives of the study, designed to test the hypothesis above, were as follows: to replicate previous findings that anxiety is present to a higher degree in autistic children than those without, to replicate the finding that IU is correlated with anxiety in typically developing (TD) children and see if this relationship exists for autistic children too, and finally to compare the relationship of IU and anxiety in the ASD and TD populations.

**Methods:** The researchers tested the hypothesis by using parent and child self-report measures and comparing the results of the ASD and a typically developing
comparison group. Results from the *Intolerance of Uncertainty Scale: Child and Parent Versions (IUS-C and IUS-P)*, *Spence Children’s Anxiety Scale Child and Parent Versions (SCAS-C and SCAS-P)*, and the *Social Responsiveness Scale (SRS)* were collected for a total of 224 participants including 114 children and adolescents with high-functioning ASD and 110 TD children. The researchers calculated Cronbach’s Alpha coefficients for the parent and child versions of the measures. The calculations were made separately for the ASD and TD groups. A three-way between-subjects analysis of variance (ANOVA) was used to find the differences between the ASD and TD groups in levels of anxiety, difference in research location (USA vs. UK) and gender. The same type of analysis was carried out for the parent-report data and researchers found that parents of autistic children reported higher levels of anxiety in their children.

Boulter et al. (2014) found that autistic children had higher levels of anxiety and IU than their TD counterparts. A causal mediation model also indicated that when IU was entered into the model, the amount of variance in levels between the groups was reduced to no difference. The ANOVA analysis of the child and parent reports also showed that increased levels of anxiety in the ASD group was best accounted for by IU.

**Results:** The results of this study indicate that children on the autism spectrum have higher levels of anxiety than their TD peers. Not only do they have higher levels of anxiety, but they have higher levels of IU which the evidence strongly suggests is the reason for the increased level of anxiety. When IU was taken into account, there was no difference between the ASD and TD groups’ levels of anxiety. These findings indicate a need for assessment of IU in children on the autism spectrum to aid in understanding the full range of their difficulties when being assessed and treated for anxiety.
Implications for the Current Study: The present study is looking at the effects of the uncertain conditions surrounding COVID-19 on the well-being of autistic children and their families. The researchers posit that the increased uncertainty during COVID-19 has likely increased anxiety and possibly severity of sensory processing abnormalities for these children. The results of this study strongly indicate that an increase in IU can lead to increased anxiety in autistic children which supports the current hypothesis.


Background: Colizzi et al. (2020) investigated the effect of COVID-19 conditions on individuals on the autism spectrum and whether pre-pandemic demographic or clinical factors were predictive of negative outcomes during the pandemic. They noted that pandemic conditions would likely increase psychological distress for the general population and would potentially have negative outcomes for people with pre-existing conditions. With the massive amount of change and potential psychological distress, the researchers hypothesized that the pandemic would likely increase stress, anxiety, and confusion among other characteristics for autistic children. They were also curious about the needs of families required during the pandemic to help care for their child or children on the autism spectrum.

Methods: The researchers collected data for 527 participants in Italy who filled out a 40-question online survey which contained questions about demographic information, clinical characteristics of the children, impact of the pandemic on
individuals on the autism spectrum and needs of families during the emergency.

Statistical analysis was used on the multiple-choice questions to determine baseline
information about the autistic children and the predictive power of pre-pandemic
demographic or clinical characteristics affecting the frequency and intensity of behavior
problems during the pandemic. The authors categorized the responses to the short answer
questions into categories including healthcare, social, financial needs, etc.

**Results:** The results of the study showed that 51.5% of the children had
behavioral problems present prior to the pandemic. A logistic regression model revealed
that the relationship between pre pandemic behavior problems and negative outcomes
during the pandemic was statistically significant (p<0.001) and that these children were
2.16 times more likely to exhibit intensified behavior issues. Behavior problems for the
whole group were reported to be more intense (35.5%) and more frequent (41.5%). The
parents reported experiencing difficulties in overseeing their child’s meals (23%),
autonomies (31%), free time (78.1%), and structured play (75.7%). The parents also
reported receiving support from healthcare services (27.7%), the school (direct-70.1%,
indirect 84%), and private therapists (73.3%). The most commonly reported need on the
free-response questions was for in-home healthcare support (29.9%).

**Implications for the Current Study:** This study was conducted relatively early
in the pandemic, with survey results collected in April 2020. The study gives a
preliminary look at the effect of COVID-19 conditions on the behaviors of autistic
children. It also provided some information about the experience of family members
during the pandemic and what they struggled with as well as their needs during pandemic
conditions.

**Background:** Hodgson et al. (2017) wanted to investigate the relationship between intolerance of uncertainty (IU) and anxiety by learning directly from the experiences of parents who have autistic children. The results of this study extended findings by Boulter et al. (2014) and Wigham et al. (2015) that IU is present in individuals on the autism spectrum and plays a role in determining the presence of anxiety in these individuals. They included the following definition of IU in their background information, “IU is the belief that uncertainty is upsetting, and not knowing what is going to happen is negative.” The researchers also noted in their introduction that anxiety is common in individuals on the autism spectrum and can negatively affect their life participation. Additionally, they include information from other studies about the relationship between anxiety and RRBs and anxiety and sensory sensitivities in their background information.

**Aim:** The main purpose of this study was to investigate the relationship between IU and anxiety in autistic children by examining the experiences of parents with Autistic children shared in a focus group setting. The researchers chose to investigate this relationship by having parents share their experiences rather than by using formal questionnaires to find out more about the experiences of the parents and children with IU and to determine what types of strategies parents are already using to mitigate the effects of IU.
Methods: Hodgson et al. (2017) invited parents of eight years and older with diagnoses of ASD but no comorbid intellectual disabilities to participate. The nine participants were divided into two focus groups and were facilitated by two of the authors. The focus groups were audio-recorded and focused on activities which would aid in development of an intervention technique. The main objectives of the group were to check for acceptability of activities and language that would be used in the intervention, check to see if parents could distinguish IU from fear and need for sameness, collect examples of IU in autistic children, understand more about the strategies parents were using to manage IU.

Results: Based on the examples provided by the parents, the researchers found that IU was present for autistic children in both novel and familiar situations. They also found that IU could take place during both expected and unexpected events. They also found that the strategies that parents used to manage IU fell into two categories, strategies to increase certainty and strategies to increase tolerance of uncertainty.

Implications for the Current Study: The research presented in this study is helpful to the current study in that it gives a clear explanation of what IU is and how it manifests in autistic children. The examples provided by the parents in the focus group illuminate the situations and stimuli that may be difficult for autistic children to handle without a negative reaction. The changes brought about by COVID-19 are likely to yield examples from parents of IU in their children as well. This study also provided a look at a qualitative study involving parents of Autistic children which comprises half of the current study’s design.

**Background:** The researchers were interested in examining the effects of COVID-19 on the stress levels and sources of stress for individuals and families of autistic children in the United States. At the time this study was published, there was no data for the experience of caregivers of children on the autism spectrum in the U.S. during the pandemic.

**Aim:** The main aims of the study were to identify causes of stress during the pandemic for these families and individuals and to discover if there was a relationship between parents’ working status, the individual’s level of ASD severity, and prior levels of support with distress levels during the pandemic. They also sought to understand the support needed by families of children or individuals on the autism spectrum.

**Methods:** An online Qualtrics survey was created and disseminated by the Autism Alliance of Michigan (AAoM) to determine the sources of stress and needed support for the aforementioned population. The respondents’ demographic information was reported using mean for numerical data and frequency for categorical. The four outcome measures included in the study were the levels of disruption and stress reported for both the individual with ASD and their caregiver. Linear models were used to assess these four measures’ relationship with possible predictors (e.g., age of person with ASD, severity score of diagnosis, use of services, etc.). The researchers used thematic analysis to categorize the free responses into sub-themes.
**Results:** Researchers collected responses from 471 individuals in Michigan. The survey participants reported high levels of stress and disruption in relation to pandemic conditions including a stay-at-home declaration. The most frequent stressors reported were worrying about the person with ASD being home all the time (54.5%), being concerned about themselves or the person with ASD becoming ill (52.1%), stress over finances (30.7%), worrying about lack of care for the person with ASD outside of the primary caregiver (22.2%), and the stress of being separated from the individual with ASD (5%). They found that the higher ASD severity scores corresponded to higher disruption levels for both the caregiver and individual with ASD. Higher levels of caregiver stress were also reported for children with higher ASD severity. They also found that caregivers with younger children diagnosed with ASD had higher stress levels however as the age of the child increased, the child’s stress level went up. Children on the autism spectrum who attended school regularly were reported to have a higher disruption level than children who did not attend school pre-pandemic. They also found a significant relationship between ASD severity and interest of the caregiver in respite care.

**Implications for the Current Study:** This study provides evidence of the circumstances surrounding COVID-19 causing increased stress and disturbance to autistic individuals and to their families. The findings are helpful in pinpointing the most frequent stressors and support needed for these families during the first six months of the pandemic in the United States.

Background: Masi et al. (2021) were interested in determining the impact of COVID-19 on the well-being of children with neurodevelopmental disabilities (NDD), including ASD, and their families. They noted in their review of the literature that the stressors associated with COVID-19 have already caused increased psychological and physical impacts on the general population and that children with NDDs are more susceptible to these stressors due to changes in routine. They noted that the impact of these changes may cause children with NDDs to experience emotional arousal, impulsivity, anxiety, mood swings, aggression, and sleep difficulties. They also cite recent evidence which suggests negative effects on parental and caregiver well-being resulting in increased mental health challenges, domestic violence, and child abuse.

Aim: The main purposes for this study were to observe the impact of the COVID-19 pandemic on mental health, social-emotional state, and physical well-being for children with NDDs and their parents or caregivers. The researchers also wished to determine the types of services these individuals were using and their satisfaction with service delivery.

Methods: To determine the impact on this population, the researchers created and distributed an anonymous cross-sectional self-report survey with fixed-response questions. The survey was distributed by contacting parents on disability service and support group email lists and by posting the survey link on social media. The survey was open for a period of six weeks.
**Results:** The following results were determined from the responses of 302 caregivers of children with NDDs. Concerning the impact on children’s well-being, the results showed that 76.9% of caregivers reported that their children’s overall health and well-being was impacted by COVID-19. Additionally, 73.3% of respondents reported that COVID-19 restrictions were stressful for their child. In addition to the reports on overall well-being and stress levels, 81.6% of respondents reported their children’s screen time increased, 68% reported reduction in exercise, 43.6% reported worse sleep quality for their children, 32.4% reported that their children had a poorer diet, 62.8% reported that their child was more irritable and 66% stated that their child had a more difficult time maintaining relationships.

Results for the impact on parental/caregiver well-being was as follows, 76.1% of participants reported that COVID-19 impacted their well-being, 73.6% reported difficulty with balancing work and family responsibilities, 43.4% reported exacerbation of pre-existing mental health conditions, 46.9% expressed worry about making it through future isolation periods, 27.1% expressed worry about their living situation stability and 39.5% expressed worry about finances. Additionally, this study found that caregivers generally rated the effectiveness of and satisfaction with telehealth services as being low.

**Implications for the Current Study:** This study was very instructive on the creation and dissemination of a survey to parents and caregivers of children with NDDs. The way that the survey questions are crafted could be helpful in editing the survey for this study. The results of this study also justify the hypothesis that children with NDDs are more susceptible to the stressors associated with COVID-19 which can result in negative outcomes for them and their families.

**Background:** Neil et al. (2016) investigated the relationship between intolerance of uncertainty (IU), anxiety, and parental reports of sensory sensitivities. The researchers identified the need for understanding this relationship due to recent understanding that autistic children process uncertainty differently than typically developing (TD) children. They also cite the increase in focus on sensory sensitivities in the recent literature surrounding ASD, including the impact of these sensitivities on the individual, social relationships, and families. They note that sensory sensitivities are common but manifest differently in individuals in two broad categories, hyposensitivity and hyper-sensitivity to sensory inputs. The researchers include in their review of the literature recent theories about sensory processing abnormalities arising due to autistic individuals relying more on bottom-up processing of sensory information which can lead to sensory overload or a mismatch between what is expected and perception of experienced events. They also include background information from studies which identify a relationship between sensory sensitivities and increased anxiety.

**Aim:** The purpose of this study was to investigate the relationship between IU, anxiety, and sensory sensitivities in children with and without ASD. This study is a follow up to the Wigham et al. (2015) study which indicated the role of IU in mediating the relationship between sensory sensitivities, anxiety, and restricted and repetitive behaviors (RRBs). To determine the relationship between the three aforementioned
variables, the researchers sought to examine the between-group and within-group differences on the variables, test the relationship between IU, sensory sensitivities, and anxiety by examining the role of anxiety as a mediator between IU and sensory sensitivities, and investigate differences in these potential relationships in the ASD and TD groups.

**Methods:** The participants included the primary caregivers of 64 autistic children and 85 TD children. The caregivers completed the *Social Communication Questionnaire (SCQ)* and then researchers administered the *Autism Diagnostic Observation Schedule (ADOS-G)* to the children with autism to confirm their diagnosis. All of the children in the study obtained an IQ score of at least 70 measured by the WASI-II. All of the parents who participated in the study also completed three measures on behalf of their children including the, *Intolerance of Uncertainty Scale: Parent Version (IUS-P)*, *Short Sensory Profile (SSP)*, and the *Spence Children’s Anxiety Scale: Parent Version (SCAS-P)*. Various analyses of the data from the questionnaires were completed to examine between-group and within-group differences, the relationship between the scores on the questionnaires and gender, age, and ability, correlations between the three main variables, IU and anxiety as potential predictors of children’s sensory sensitivities, and IU as a potential mediator between ASD and anxiety and ASD and sensory sensitivities.

**Results:** In the analysis of between-group differences, researchers found that parents of children on the autism spectrum reported greater levels of IU, sensory sensitivities, and anxiety. Significant correlations were found between the *SCQ, IUS, SSP*, and *SCAS-P* scores for autistic children. Children with more autistic symptoms/behaviors showed increased levels of IU, sensory sensitivities, and anxiety.
Analysis of the correlation between IU, sensory sensitivities, and anxiety revealed that there was a large negative association between ASD children’s scores on the IUS and scores on the SSP. A similar negative association was found between scores on the SCAS-P and the SSP. Analysis of the measures also revealed that increased levels of IU and anxiety was associated with increased sensory sensitivities. A strong positive association was shown between scores on the IUS and the SCAS-P for both the typical and ASD groups. Researchers reported further evidence for IU and anxiety as predictors of sensory sensitivities through a mediation analysis which showed that the relationship between IUS scores and SSP scores was affected by the SCAS-P scores. Researchers showed that IU explained approximately half of the variance in autistic children’s sensory sensitivity scores and this relationship was partially mediated by anxiety. Conversely, they found that IU explained approximately one third of the variance for typically developing children.

**Implications for the Current Study:** These research findings extend the research conducted by Wigham et al. (2015) and solidify the relationship between IU, sensory sensitivities, and anxiety. The findings from this study add to the literature that these three variables are found more commonly in children on the autism spectrum and that greater levels of IU and anxiety can increase the presence of sensory sensitivities in these children. These findings support this study’s hypothesis that the increased amount of uncertainty surrounding COVID-19 could have an effect on autistic children’s sensory processing.


https://doi.org/10.1093/tropej/fmaa122

**Background:** Panda et al. (2020) conducted a systematic review of research articles pertaining to the psychological and behavioral problems of children resulting from COVID-19 conditions such as lockdown, quarantine, school closure, and other unexpected situations. Prior to this review, there were no other systematic reviews of the literature concerning these problems in children.

**Aim:** The researchers decided to conduct a systematic review to inform public health officials and the general public of the full impact of the pandemic on the psychological well-being of children and the effect on their behaviors. They sought to collect high-quality publications which detailed the effects on both typically developing children and on children with existing behavioral abnormalities caused by ASD, ADHD, and other conditions. The researchers also wanted to determine an estimate of the psychological problems experienced by caregivers.

**Methods:** Researchers started by conducting a literature search on various databases, followed by the use of MeSH terms, and then by manually searching the publications. Articles which were prospective/cross-sectional studies without controls were accepted. The children in the study had to be 18 years or younger and the sample size had to be at least 50. After quality checks and analysis for eligibility in the study, 15 studies were included in the review which included a total of 22,996 participants. The outcome measures for this study were the proportion of children and adolescents who had depression, anxiety, irritability, fear and other psychological or behavioral problems due
to COVID-19. The researchers were also looking for the proportion of children with existing behavioral abnormalities due to ASD, ADHD, and other conditions whose behavior worsened during the pandemic. Finally, the researchers investigated the proportion of caregivers who developed psychological problems as a result of COVID-19 conditions and confinement with children.

**Results:** This systematic review summarized the findings from the included studies and provided an overall look at the percentages of psychological and behavioral problems in children and their caregivers. From the studies, the researchers determined that overall, 79.4% of children were found to have psychological and behavioral states negatively affected by the pandemic with 34.5%, 41.7%, 42.3% and 30.8% of children presenting with anxiety, depression, irritability, and inattention respectively. Additionally, 22.5% of children feared the virus, 35.2% were experiencing boredom, and 21.3% experienced sleep disturbance. The summarization of the studies also showed that 52.3% of caregivers developed anxiety and 27.4% developed depression while in social isolation with their children. The researchers also observed there was a high probability of worsening behavioral problems during the pandemic in children who had pre-existing behavioral difficulties due to ASD, ADHD, and other conditions.

**Implications for the Current Study:** This systematic review is useful to the current study because it gives a wide-angle view of the impact of COVID-19 conditions on typically developing and neurodiverse children. The overall percentages from these studies give a good indication that children all over the world have been negatively affected by pandemic conditions as evidenced by the proportion of children with
psychological and behavioral difficulties. This review also shows that caregivers
developed psychological difficulties as a result of isolation and other pandemic factors.

Van de Cruys, S., Evers, K., Van der Hallen, R., Van Eylen, L., Boets, B., de-Wit, L. &
American Psychological Association, 121(4), 649-675. https://doi.org/10.1037/a0037665

**Background:** Van de Cruys et al. (2014) explained their theory that people with autism
are less likely to be able to match their brains predictions to incoming prediction errors.
They also hypothesize that people with autism are unable to correctly filter prediction
errors which causes too much importance to be given to all incoming stimuli. Equal
weight being given to all incoming stimuli could mean that there is too much to process
at once which can lead to shutting down, meltdowns, or resorting to compensatory
behaviors such as stimming. These hypotheses are based on the predictive coding theory
related to ASD. They explain in their background information that the way that humans
process incoming stimuli is to make and test predictions about the stimuli. This means
that incoming information, referred to in this article as prediction errors, is compared to
existing predictions in the brain. The degree to which the prediction error and prediction
match determines if a new model of that stimulus or of the environment needs to be
created.

**Aim:** The purpose for Van de Cruys et al. (2014) proposing these ideas is that
impairments in prediction could be instrumental in explaining the presence of many
symptoms of Autism. These symptoms include deficits in executive functioning, theory
of mind, restricted and repetitive behaviors (RRBs), insistence on sameness, and
meltdowns. The article relates the predictive coding theory to several symptoms and
clinical observations related to ASD. The researchers also cite various research articles explaining the neural underpinnings of this theory. Currently, the anterior cingulate cortex (ACC) and the insula are thought to play a role in autistic individuals having difficulty with prediction.

Implications for the Current Study: This research article contains extremely detailed and helpful information to understand how prediction in the brain helps us to process the world and how this function may be impaired in people with ASD. This impairment would help to explain many symptoms of ASD and, in relation to this study, could provide the background for understanding the presence of IU. If people with ASD have a difficult time predicting, then a circumstance that would seem normal to a typically developing person may be scary to an individual with ASD because of the number of things that do not match their predictions. It is as if everything in the environment is novel and deserves the same amount of attention. This would, of course, be exacerbated if the uncertainty in the situation increased which is likely the case during COVID-19 due to changes in routines.


Background: Wigham et al. (2015) were interested in determining if intolerance of uncertainty (IU) mediates the relationship between sensory processing abnormalities, anxiety, and restricted and repetitive behaviors (RRBs). These are frequent, co-occurring behaviors in autistic individuals, but little was known about the connection between
them. Their review of the literature revealed that relationships exist between sensory processing abnormalities and anxiety, between sensory processing abnormalities and RRBs, and that IU may be useful in explaining the connections between these constructs.

**Aim:** The purpose of the study was to find the connections between sensory abnormalities and RRBs and the role that anxiety and IU may have in these connections for children and young people with ASD. Their aim was to study these connections as part of several constructs including the conditions of sensory over and under responsiveness, repetitive motor RRBs, and insistence on sameness RRBs. They proposed that increased understanding of these phenomena, and the connections between them, could lead to improvements in intervention techniques, possibly by addressing IU.

**Methods:** This study recruited parents of 53 children with clinical diagnoses of ASD from the UK (23) and the USA (30). The parents were recruited in the UK through the Database of Children with Autism Spectrum Disorder Living in the North East and in the USA through the Brigham Young University Autism Research Database. There were 47 boys and six girls between the ages of 8-16 years included in the study with a mean age of 12.49 years. The researchers screened the child participants for ASD characteristics using the parent version of the *Social Responsiveness Scale (SRS)* and for Full Scale IQ using the *Wechsler Abbreviated Scale of Intelligence (WASI)*. The researchers then collected caregiver report data using the *Short Sensory Profile (SSP)*, *Spence Children’s Anxiety Scale (SCAS)*, *Intolerance of Uncertainty Scale-Parent Version (IUS-P)*, and the *Repetitive Behavior Questionnaire (RBQ)*. The researchers analyzed the data using Pearson’s two tailed correlations to consider the relationships between the covariates and between the covariates and the demographic information.
Independent sample t-tests were used to compare the UK and US samples. A computerized serial mediation model was used to show the relationship between sensory over/under responsiveness, RRBs, IU, and anxiety.

**Results:** The researchers found that there were direct paths from sensory under responsiveness to both repetitive motor behaviors and insistence on sameness. They also found a direct path from sensory over responsiveness to insistence on sameness behaviors. The researchers found an indirect path involving IU and anxiety in both cases of sensory over and under responsiveness with a sequential path from both of these sensory conditions through IU and anxiety to insistence on sameness. The researchers found that there was a greater than anticipated role of IU and anxiety leading to repetitive motor behaviors. The results of their study strongly indicate that sensory processing difficulties lead to increased anxiety and uncertainty which in turn leads to repetitive motor behaviors, in the case of sensory under responsiveness, and insistence on sameness for both sensory over and under responsiveness.

The finding that IU plays a role in mediating the relationship between sensory processing abnormalities and RRBs could have implications for autism research and treatments for anxiety. If interventions contained a component to address IU and taught children how to face the uncertainty with more flexible behaviors or strategies, they may be able to stem symptoms associated with anxiety. Reduction of rigid reaction to uncertainty could have implications for reducing RRBs and insistence on sameness which could improve life circumstances for the child and their family.

**Implications for the Current Study:** The findings from Wigham et al. (2015) add to the current understanding of the presence and intensity of ASD behaviors. These
results improve understanding of the role of IU in increasing the use of RRBs to add stability to a situation which has been distorted by sensory processing abnormalities. An event like COVID-19, which has increased uncertainty for the general population (citation), may play a role in increasing the presence of RRBs in children on the autism spectrum due to the children’s need for stability and sameness in their environment. If COVID-19 has also increased the likelihood of sensory processing abnormalities in children on the autism spectrum, the results of this study indicate that repetitive motor behaviors and insistence on sameness may have increased for these children.
APPENDIX B

Institutional Review Board Consent Letter

Memorandum

To: Garrett Cardon
Department: BYU - EDUC - Communications Disorders
From: Sandee Aina, MPA, HRPP Associate Director
Wayne Larsen, MAcc, IRB Administrator
Bob Ridge, Ph.D., IRB Chair

Date: April 12, 2021
IRB#: IRB2021-081
Title: Sensory processing and intolerance of uncertainty in autistic individuals during the COVID-19 pandemic: A mixed methods approach

Brigham Young University's IRB has approved the research study referenced in the subject heading as expedited level, categories 6 and 7. This study does not require an annual continuing review. Each year near the anniversary of the approval date, you will receive an email reminding you of your obligations as a researcher. The email will also request the status of the study. You will receive this email each year until you close the study.

The IRB may re-evaluate its continuing review decision for this decision depending on the type of change(s) proposed in an amendment (e.g., protocol change increases subject risk), or as an outcome of the IRB’s review of adverse events or problems.

The study is approved as of 04/12/2021. Please reference your assigned IRB identification number in any correspondence with the IRB.

Continued approval is conditional upon your compliance with the following requirements:

1. A copy of the approved informed consent statement and associated recruiting documents (if applicable) can be accessed in iRIS. No other consent statement should be used. Each research subject must be provided with a copy or a way to access the consent statement.
2. Any modifications to the approved protocol must be submitted, reviewed, and approved by the IRB before modifications are incorporated in the study.
3. All recruiting tools must be submitted and approved by the IRB prior to use.
4. In addition, serious adverse events must be reported to the IRB immediately, with a written report by the PI within 24 hours of the PI's becoming aware of the event. Serious adverse events are (1) death of a research participant; or (2) serious injury to a research participant.
5. All other non-serious unanticipated problems should be reported to the IRB within 2 weeks of the first awareness of the problem by the PI. Prompt reporting is important, as unanticipated problems often require some modification of study procedures, protocols, and/or informed consent processes. Such modifications require the review and approval of the IRB.

Instructions to access approved documents, submit modifications, report complaints, and adverse events can be found on the IRB website under iRIS guidance: https://orca.byu.edu/IRB/Articulate/Study_Management/story.html
APPENDIX C

Semi-Structured Interview Guide

Introduction:

As stated above, the purpose of the following semi-structured interview guide is to prompt discussion with the caregivers of children on the autism spectrum about their child/children’s experiences with sensory processing abnormalities and behavioral change during the COVID-19 pandemic. We expect to see some congruent answers between interviewees that may help us gain further insight into the challenges that prolonged periods of uncertainty bring to families who have one or more children on the autism spectrum, and what resources may be available—or should be made available—to help them. We will encourage participants to be open and truthful when sharing their experiences and the experiences of those in their care. However, should the interviewer ask a question the participant doesn’t want to answer, they are under no obligation to do so. This will be made clear to the interviewee prior to the start of the interview, along with ensuring we have obtained their proper consent to participate in and record the interview.

1. What have been your family’s greatest concerns or challenges during the COVID-19 pandemic?
   a. If further prompting is required:
      i. How has your home life changed since the beginning of the pandemic?

2. How has quarantining/staying home for extended periods of time affected your child/children on the autism spectrum?
   a. If further prompting is required:
      i. Did you notice if these conditions affected your child/children’s responses to sensory input such as light sensitivity, aversion to certain textures, need for increased stimulation, or sensitivity to loud sounds?

1. Share set of concrete examples that may trigger families to think about sensory issues if needed:
a. For example, many people on the spectrum are hyper-sensitive to bright lights or certain light wavelengths (e.g., from fluorescent lights). Many find certain sounds, smells and tastes overwhelming. Certain types of touch (light or deep) can feel extremely uncomfortable. This can include having a low sensitivity to pain. Another possible symptom is under-responsiveness to the body signals that help control balance and physical coordination. This can result in clumsiness, which has been associated with autism.

2. Have you had to provide more of any of the following? (Provide relevant prompts/examples from list below)
   a. Sensitivity to light:
      i. Dimmed lights
      ii. Incandescent versus fluorescent lighting
      iii. Sunglasses or visor to block overhead fluorescent lighting
   b. Sensitivity to sound or sights:
      i. Ear plugs or headphones in noisy environments
      ii. Closed door or high-walled work areas to block distracting sights and sounds
      iii. Visual supports for those who have difficulty processing spoken information
   c. Sensitivity to smell:
      i. Avoidance of strongly scented products (perfumes, air fresheners, soaps, etc.)
   d. Sensitivity to taste or texture of food:
      i. Food options that avoid personal aversions (e.g., intensely spicy, textured, cold, hot, etc.)
   e. Sensitivity to touch/texture:
      i. Clothing that accommodates personal sensitivities (e.g., to tight waistbands and/or scratchy fabric, seams and tags)
      ii. Request for permission before touching
      iii. Firm touch (according to preference)
      iv. Weighted blankets
   f. Need for sensory stimulation:
i. Sensory-stimulating toys (e.g., safe chewies and fidgets)
ii. Opportunities for rocking, swinging and other sensory stimulating activities
iii. Strong tasting and/or textured foods, cold beverages, etc.
iv. Fun opportunities to practice physical skills (catching, dancing, jumping, running, etc.)
g. Furniture arrangements that reduce chances of bumping into sharp or hard surfaces

ii. What does/do your child/children like/not like to do while they are home and how does this compare to before the pandemic?
   1. How does your child feel about social isolation?
iii. Has your child/children’s screen-time increased since the beginning of the pandemic? Please explain.
   1. If so, was this the result of schooling needs or your child/children’s preferences?

3. How has your child/children’s daily routine changed since before the pandemic? Do you think there have been any changes in the behavior of your child due to these changes in routine?
   a. If further prompting is required:
      i. Have you noted any increased anxiety or development of specific and repeated behaviors as a result of changes to daily routine?
         1. Do they seem more “touchy;” have you noticed an increase in meltdowns; do they become overwhelmed more easily; have they been more interested in being alone?
         2. Have they seemed to be acting with more frantic energy?
         3. Have they become more rigid?
      
   ii. Have your child’s sleep or eating patterns been affected? How?

4. What kind of support or help do you typically receive to help care for your child/children with autism (school, family, church, support groups, advocacy groups etc.) and have these supports continued through pandemic circumstances?
   a. If further prompting is needed:
      
      i. How have changes in supports affected you and/or your child/children?

      ii. Are there any resources or sources of support that you wish you had during the pandemic that would make it easier to care for your child/children?
5. Are there any other changes that you have noticed in your child since the beginning of the pandemic that we have not yet discussed?
   a. If further prompting is needed:
      i. Are there any other changes associated with sleep or eating that we have not yet discussed?
      ii. Are there any restricted interests that have changed/increased during the pandemic?
      iii. Have you noticed any changes in your child’s/children’s communication?

6. Are there any other changes in the way that your family functions as a result of pandemic conditions (including parents, siblings, extended family, etc.)?

7. In addition to the information, you have provided so far about your child’s experience, have there been any changes you have noted with sensory sensitivities for your child since the beginning of the pandemic? If yes, please explain.
APPENDIX D

Quotation Index

1) S1: But when we went back to in-person church and she went to primary and the singing time for the first time> And I only know this because I'm> I play the piano for primary and so um she really struggled when they like they do the article of faith and they'd say a couple of words and then all the kids and teachers would repeat it. That was too much for her.
PI: OK.
S1: And um I had to start bringing in her earmuffs to to calm that down. And now she's starting to get comfortable enough that she doesn't ask for the earmuffs every week. And so I think it was the combination of that sort of unexpected loudness of you know all of these people saying the same words. Like that that was really jarring to her followed by some of the more like upbeat, active songs. (Interview 020554)

2) S1: Yeah, so C1 is kind of on the opposite side of C2 where C2's like a huge sensory seeker and he just goes at it, where C1 gets super overwhelmed. Like loud noises, it just startles him. He> And then, instead of like> He will sometimes hit. Like he'll get so frustrated that he'll just punch or like if he feels overwhelmed he’ll kind of just like flail out and ‘I gotta get out of this situation.’ But for the most part, he gets buried down. Like he will start crying and he will get really mopey and whiny and h*> And we've been really working on feelings that he can't quite identify, but I'll say, ‘Hey bud, are you sad?’ and he'll say, ‘I don't know’ and he's crying, and then we have to work through what is it that's triggering him because it it can be something completely random. Like something that he has remembered from three days ago when he stubbed his toe and he is still fixated on that because the world is so chaotic around him or it’s so uncertain around him that he gets so fixated on these little things that we’re manifesting this blowout four to five days later or like he had like a zit on his leg. Just like one of those like little tiny ones that kids get sometimes and my husband made the mistake of popping it without asking him. Without preparing him and we heard about that for two weeks. Every time we would change his clothes it would be*> And we were trying to potty train him during this time too 'cause he really struggled with that. And so any time it’s like, ‘Let's go into the bathroom.’ ‘Mom don't pop my zit. Mom you can't’> You know, like it was just like he would be so fixated on it and then if anytime someone will get frustrated with him he would just get down and depressed. Like just this mopey like, ‘Oh everybody’s so mean to me.’ And I know it's because he's out of routine and he's overwhelmed and he is trying to find something tangible to fixate on to express these emotions that he can't process and so we had to spend a lot of time> (Interview 150704)

3) S1: Stronger compression than she's than she's ever had before. It used to be just touch, but now it's like “I I need it more.” (Interview 225267)

4) S1: Um well um ;02 Well, do you know what? If a routine is broken up and she doesn't know why, yes, she does have a strong reaction. (Interview 225267)

5) S1: And so, in his head he’s like, “well, I should be doing”> He's very bla* black and white. “Well it's time that I should be doing homework. Why am I not doing homework? What can I
do?” And I'm like, “well I don't have anything for you to do right now, so until your teacher gets
ahold of me, I don't know what to tell you.” (Interview 204143)

6) S1: The other thing is is um, she would> She> Because of COVID and because the lack of
having things to do, she was on electronics more.
MB: Yeah.
S1: And so electronics have have played a really big um> Like she has to have electronic in her
hand all the time now. And it's not so much that she's playing with it, but she has> She p*> Has
her favorite songs and she just puts it up to her ear and listens to it. So, if she’s jumping on the
trampoline or if she's playing a game the the music has to be there for her. I don't know what it
is. I don't know if it's hiding if it's masking another sound that she's hearing.
MB: Yeah.
S1: You know, I I don't know, but that's something that she just has to have and she's very
unhappy if she doesn't have have one. So, um oftentimes she’ll be playing if she’s playing a
puzzle or blocks or something she she'll just have it by her side and the music will be going on
and she'll play just fine. So, it's not like she has to play it, but she just has to have that constant
sound. (Interview 225267)

7) S1: Absolutely. It's like he just wants to go off on his own. Like I will find him sometimes>
We have a fireplace. Like it's kind of hard to describe. but it's just like you walk in and then you
turn a corner. He will go behind that. It's this almost like a little cubbyhole. It's like right by the
front door and if I don't know where C1 is, he's either in there or he's in his room underneath his
blankets in his bed. Like if he gets stressed or overwhelmed or> It's like he has to turn off the
lights and he has to go somewhere else. He has to turn off all the sound. It's like he has to reset.
Or I have to like talk him through it. So, if he> if I> if I'm not readily available he will go try and
get away from all the input that he can. (Interview 150704)

8) S1: But he didn't like anybody getting close to <him>
MB: <Yeah>
S1: and he didn't even touch anything, and but once we he was vaccinated then he went to a
youth overnight youth activity with our ward was fine.

9) S1: Um she just avoided that altogether where my other kids definitely like, if they saw
someone outside, um the way our backyards are like we don’t have a fencing on most sides of
our yard and so like if they saw the kids outside that face our backyard, they were out there too.
(Interview 214156)

10) S1: When we did see family he seemed to be less, this this probably isn’t the right question
this is a different question, but um, he used to just kind of gravitate towards them and want to be
with them, but he almost was kind of stand backish. I don't think he quite knew what to do with
different people (Interview 151325).

11) S1: Then came summer which gave us a reprieve. I got a reprieve from work. I felt like I
could breathe a little bit more, you know. There wasn't as much pressure to do schoolwork and
then in> So that helped me sort of catch up and make a plan and we created structure and I felt
confident enough to homeschool them, you know. And that went> I could talk about that for
another hour <{laughs}>... That summer was a blessing 'cause it really gave me that time to catch up and see, ‘OK, I kind of know what to expect now with C1’s behaviors. This is what I was seeing. This is how I think I could create structure to minimize those behaviors ;02 um, but yeah. It was quite the journey. And like I said, talking about it now, reflecting back, I think ‘wow, that was really hard’ {laughs} you know (Interview 160833).

12) S1: And so, we kind of just decided to go with the ‘we don't> You know, we don't know.’ 'Cause no one did know and that was very hard for him because he likes a very definite> He can usually do pretty well if you give him, you know, what to expect um, but if he doesn't have that information it's a lot harder, you know, for him (Interview 160932).

13) S1: And we would have to have discussions, with not only him but our other children, about ‘it's ok. It's not going to affect you personally, you know. We've been through> This country's been through’> You know. We had really had to really, really calm down the anxiety with those outside things that were happening (Interview 108725).

14) S1: Yes. Just because like we went and stayed with my family for a week like a couple months ago an getting back to that, like when we're back home, it was like it took us probably a week for both C1 and C2 to kind of get back to where they were before that. It was a really rough week of emotional like outbursts and just transitions were so much harder again, and they didn't want to sit at the table because we were at grandma and grandpa's house, and they only had a really small two-person table so we ate most of our meals in the front room as a family and so then it just seemed like it was hard to get back into the routine. So, I anticipate with C1, when he goes to school, he’s gonna be emotionally> He's gonna struggle like he did, but the benefit of that is C3 is going to be in first grade so he's there all day and C2, we're getting him into his routine now. So, when C1 starts his we're going to be able to kind of work through that with him a little bit easier just 'cause he only does a half day. Well, he might do full day. I don't know. They they're doing their kindergarten testing this week, but I anticipate a half day because he is so intelligent. Like he doesn't have an IEP even though he has an autism diagnosis because it doesn't affect his education is what they told me. That he doesn't need an IEP right now because he knows all his numbers and letters and colors and some kids don't even know how to say their name and so, or spell their name and he does. So, I'm anticipating him only being a half day. So, I'll have that afternoon to kinda work through that with him, but yeah. Definitely I can see his emotional upheaval happening 'cause it usually does when we get out of routine (Interview 150704).

15) S1: Um. Some tantrums. Or meltdowns. Whatever you want to call them. They will increase um and they were markedly increased near the beginning of Covid. Um. I think, like I said, largely just do to the fact that it was just a huge change (Interview 214156).

16) S1: So we prepped her for, you know, a while once we once we were getting ready to sell our house and she and C2 came with us to look at houses um, so it's like> I I think that may have been a factor just that we^ S2: We made them a part of the process. MB: Sure.
S1: Right we tried very hard to make sure that they understood as best they could that something was coming. That there was going to be a change (Interview 020554).

17) S1: Yeah, and the relationship was maintained. And that actually was helpful in transitioning her back ‘cause her school psych was still the same school psych as last year. So having that relationship be maintained through COVID, I think was still helpful for her to be like, ‘Oh, yeah, like I know that A1 is still there for me and will still like, talk to me. So that was one thing that we could use to reassure her going back to school (Interview 214156).

18) S1: He didn't want to participate. I mean the crates were awesome because I was able to sit down with him, you know, and do things, but online he didn't want to participate. And it was loud, too, you know. You you get 6 kiddos on the spectrum in in a zoom room and all have their mics on at the same time {laughs} it's so it was quite the sensory overload, you know^ (Interview 160833).

19) S1: Um, and he I think> A1, she got creative and made it fun for him and I I think it was fairly good, but to go from an IEP that has, you know, 360 minutes a week to 30 minutes a week that's^ (Interview 151325).

20) S1: He's wonderful, but my son would refuse to go or he would sit next to me on the couch with zoom the zoom thing open and be under a blanket and refused to speak. I don't think he spoke for like three months of weekly visits. It was just me talking to the counselor and trying ta’> You know, It was very difficult for him to build a relationship with that therapist (Interview 108725).

21) S1: Yeah. Well, he wasn't really willing> He didn't really want to do therapy {laughs} But at the therapist office they have little fidget toys and they have> I don't know. Where we go where his psychiatrist is, as well, they have games that he can play while he's there and he can do things like that. And, well we're just sitting on the couch. I I think he felt exposed because I was there and he was having, you know, to talk about things with me there.

S1: And I would even leave the room, but it's he would just sit there. And one time he just walked away from the computer and and didn't> You know. I think that he doesn't> He's also hypersensitive to criticism. Really, really, really, so you have to to have to do that and he felt that being in therapy was meant there was something wrong with him instead of trying to build some skills so that he can be more comfortable in his life. And I think he just felt exposed for some reason. He loves YouTube and watching YouTube things, but maybe the two way thing with it was unfamiliar or he's not able to get a relationship with somebody that way. I don't know. (Interview 108725)

22) S1: He's gonna go to the district preschool, but until he actually gets into that environment, they can't really test for behavior, social skills, stuff like that 'cause he just wouldn't do the tests...So, we've had a lapse in services and I tried to get him> Oh what is it called? ABA therapy? But because we have don't have a diagnosis for him there was a couple routes to go, but it was like trying to get around the system, if that makes sense, like because you have to <have>...In order for the insurance to provide it you have to have the diagnosis…But in order to
get the diagnosis we'd have to come up with at least three to four thousand dollars depending on the sliding scale. And we just felt like we could not set aside that money at this time because we're trying to make sure we have enough money to get through everything (Interview 150704).

23) S1: But then, at the beginning I was trying to balance now working from home and having the kids home. My husband's in the tech field, so his job got harder with COVID. So, he was gone more with COVID. I had to balance work and caring for them, so there was a lot of unstructured time where I wasn't available, you know, to help him immediately regulate or anticipate frustrations and things like that. You know, when I'm present, I can anticipate those things and sort of intervene. There wasn't as many opportunities to do that (Interview 160833).

24) S1: Like it's a totally different experience and I think that is another thing I wish I could have figured out better during the pandemic and I think would have helped me with my kids is figuring out how to reach out to other parents in the same situation without, you know, like, ‘Oh, we're going to have a weekly support meeting’ ’cause that would have put me over the edge. Like that's just one more thing that I have to do. But just being able to reach out to one mom or someone else to say, ‘Yeah, that's difficult. That sucks. That's hard.’ Instead of being like ‘we're all we're all struggling’ and I'm like, ‘Yeah, you know, you are, but you don't understand.’ And not <like> (Interview 150704).

25) S1: Yeah, so I have a little list over here. But, first of all, he's kind of a germaphobe in an ironic> Only with certain things. Anyway, but the constant on the news, he likes to watch YouTube or whatever, that constant COVID number, COVID thing, COVID thing. He was constantly asking “my head hurts just a little bit, do you think I have COVID?” He um> All of my children were constantly asking me, “my nose is running. Do you think I have COVID?” You> They were really <concerned> (Interview 108725)

26) S1: And so of course with a pandemic going on he was extremely anxious about, you know, what if he got sick? What if someone else in the family got sick? What if, you know, me and dad like died from the virus? Like what would happen to him? Things that other kids weren't even really asking, but my other kids didn't even> They were like ‘oh, there's a pandemic. OK, we'll stay home.’ (Interview 160932)

27) S1: So, um, and she wasn’t like crazy ill, but, there’s, I mean > in her mind, things get really, really blown up, and she's kind of had some ongoing things since then, and like she has chest pains due to her anxiety, but because she had Covid and because she had multiple complaints of it, her pediatrician had us run an EKG <XXX>, and so they’re running an EKG on her, so she’s kind of just freaked out in general now around Covid, and that was true from the beginning too, like that was one of the things that increased, like, markedly for her was just like fear of being sick. (Interview 214156)

28) S1: He was putting on masks all the time. He was wondering if we needed to wear them at> Even though we weren't going anywhere. Literally we went nowhere. We had groceries delivered. We went nowhere. He thought maybe we all should wear masks all the time um even around each other um. (Interview 160932)
29) S1: Yeah {questioning tone}. I mean she’s always been this way and its gone up and down through her life, but I would say anytime that like things are really disrupted or she's not feeling safe for some reason um that attachment goes up. So like when there was something new at the beginning of the pandemic, like when there was that earthquake, that heightened her anxiety and when her anxiety’s high, like when I say co-dependency, like she relies on me to regulate that for her and work through things with her and so> Like that’s one of the things that we’re working on in therapy is like having her take breaks and get away and then communicate more effectively with me cause she'll get> I> I> She gets really like> She’s very verbal. Um. Which I know isn’t always true for Autism, but um but she gets very like vindictive towards me.

S1: And so it's like kind of throwing me under the bus. Like the things that are happening in her life are my fault.

S1: Um. So this gets into like really personal territory but that's where I’m assuming identify is removed around all of this. But uh> Just not respectful and> And I don't think she intends to but I think it's like how she copes with her anxiety is like, ‘You should be here all the time for me.’ Like, ‘You should never leave. You shouldn't work. You shouldn't be doing these things. You shouldn’t be going to the grocery store without me.’ Like> I mean, its extreme. <Um> (Interview 214156).

30) S1: We've noticed his behaviors get worse when we're stressed. And when we’re calm then his behaviors are better. So I guess in a way that would be communication that he's telling us that he can feel the stress and the anxiety or the issues that are happening in our home (Interview 151325).

31) S1: And it would it was crazy ’cause he's never really been that way and then other times where he would just randomly just start beating on his brother…’Cause C3, the sensory seeker, the older brother… he just speaks really fast and he’s just go go go go go and C1 would just be done with it and just start wailing on his brother like, ‘I am done.’ And they're a really good balance for each other ’cause they kinda help mellow each other out, but when you're stuck with that person all day everyday it just gets to the point where he's like ‘I am done’ and so then I have to calm him down (Interview 150704).

32) S1: ...he would kind of lash out at his siblings and take it out on them if he wasn't getting to do the thing that he wanted when he wanted to do it (Interview 160932).

33) S1: Well, because I'm trying to do so many different things, I can't do all of this. I can't do it well (Interview 160833).

34) S1: It took its toll on me personally. I had to let go of a lot of things. Like I had to let go of speech, you know, or PT like activities ’cause his his physical therapist was sending me things to do with him and it was like, you know, I'm spent {laughs} at the end of the day. I could> You know, I tried my best to implement things into our routine, but I know I didn't do a great job with it, you know, and so so that caused a lot of stress, right, within myself (Interview 160833).
35) S1: Um, and I wish that I could say that he got better with his communication 'cause I worked with him, but I didn't. Like I thought I would. Like I meant to every other> Every day I was going to start tomorrow (Interview 151325).

36) S1: I hate I hate to say this, but we were the bad situation because we were trying to survive ourselves and trying to get where we needed and so C1’s so sweet that we just didn’t encourage her to talk (Interview 225267).

37) S1: And this is a recent thing. Like he has to wear> Um, we have these little, right, noise dampening headphones that we put on his ears and if a fly ever gets in the house we immediately go and put them on him until we can get it and kill it because if not, he has ;03 really just the worst the worst tantrums he has ever had. And he’ll throw himself on the floor or he’ll run upstairs screaming. He gets really upset. Um he just hates it when they fly near his ears. So that was a really big, new disruption that we hadn’t experienced before (Interview 160833).

38) S1: <But> once this started up um and he was getting very anxious he was just on edge more and so things would upset him more. So, a fight with a sibling that normally he would just be mad <um>
MB: <Mmm-hmm>
S1: It became something where he was on the floor um screaming, crying. Um he started hurt* hitting himself again, which he hadn't done for a couple years. Um and that was just the stress, you know. It's like h* how he kind of gets it out. So, like little thing> He was really worried about the pandemic and all that stuff and he was> But his emotions being on edge, other things were like setting him off that would not normally set him off and it was just escalated, you know. Um just seeing that increase in his meltdowns and the increase in the physical> You know, just like um punching his arm sort of thing when he was upset (Interview 160932).

39) S1: Well, she always wanted the cat with her. Um. And she will flip out if she cannot find him find him. Sorry, that’s not a great technical term. Um. But like won’t sleep. Won’t like> Won’t do school work. Those kinds of things. And it's a cat so like he doesn’t really want, necessarily, to be held twenty four hours a day.
MB: Yeah. {laughs}
S1: Um. So yeah. Like she’d wanna hold him a lot um and he definitely would like show displeasure at that (Interview 214156).

40) S1: And so she started being a little bit more um a little bit more needy. Like um I I also had to start working at from home and so when I would work at home she was on my lap and she would just sit and get compression as she sat in my lap (Interview 225267).

41) S1: Um, generally we can, we can talk him through things and make a picture schedule or> And explain that we need to do A, B, and C, D and then we get to do E um with him. Or just talk him through the the situation, ‘we need to do this and this but, during those times when, when we were high, highly stressed, he just> He wouldn’t> He didn't want to comply. He didn't want to to> He would just> We call it flopping where he just> I mean he's, he's 240 pounds and he's 6 foot tall and I, I can't make him move. So, he would flop or, or just sit in a chair and refuse to get up
‘cause I can't do anything about it. Um, we saw a lot of that or um just not wanting to follow instructions. Just pushing us away or shaking his head no, and just wanting to stay in his room, and play his iPad. Um. Yeah. So, the> that's the the main thing I just just noncompliance where generally we can work through things, but he just wasn't compliant. Just ;02 refused to do what we asked him to do (Interview 151325).

42) S1: I think for her in a lot of ways, like it was like, ‘Oh this is comfortable, I’m gonna kind of go in my cocoon at home and not have to interact outside of the home,’ (Interview 214156).

43) S1: I see more autistic tendencies at home than they do at school. I think she hides them quite a bit like some of her mannerisms and stuff. She'll hide them at school. And actually, even since being diagnosed, I feel like she's gotten even more comfortable about letting them show even at home (Interview 214156).

44) S1: It just actually helped us a lot to get ease stress to have online church or to not have to go places and not be required to go places. Getting back into it is being difficult for me, too. I'm having a hard time 'cause I think I've forgotten all my social skills and {laughs} trying to go back and <being with people>

PI: <You’re you’re> I don't think I don't think you're alone at all.

MB: Yeah.

PI: I mean, yeah. I I think a lot of people are experiencing these same things.

S1: Yeah. It> That's been a thing. I I hope that that a lot of the stuff sticks. A lot of the changes the the technology is there that we can do so much more more efficiently and not require so much time away from families.

MB: Yeah.

S1: Or families can> Our daughter, who was a senior in high school last year, she> It was so nice that she could just do the classes in the order that she wanted to. That flexibility was wonderful for us and for her because she was really struggling to graduate and just having that> Being able to do things in her way and not having to sit at school and be dealing with some of her mental health issues but be able to do it at home at late at night when she's more awake, 'cause she's more of a night owl. Just those kind of things that indivi* individualization of of education really, I think, is a wonderful thing. And the option, you know. We didn't have those kind of options when our older daughter was in school. We didn't have an online school option, or we would have done it.

MB: Yeah.

S1: Because public school was just not the best thing for her. We just had to kind of grin and bear it and, you know, work with the teachers a lot. But offering these new things that people are
getting more used to technology-wise, and because of COVID, I I think if we if we learn from it we'll be able to make a better place for a lot of a lot more people.

PI: Yeah, I mean, your your comments about the church have caused me to think, ‘Man, maybe we should not end this,’ you know, and have at least the option for people to join in to sacrament meeting and other things, you know, virtually.

MB: Right.

S1: Yeah, that's that's kind of how I feel. I mean, just being able when you're sick, or away from home, or you're having a need a mental health day, to still be able to participate in sacrament meeting even if you don't have the sacrament. It it helps build that connection with those people and, if you're not there, I I think it would be a wonderful thing. I don't know if if it's a possibility, but> (Interview 108725).

45) S1: So, the biggest positive was feeling empowered to really take full control of my children's education and be able to do it. My daughter> Well, both of them and C1, actually, took end of level exams at the end and they were on track. So that was a huge like ‘Wow.’ Like ‘we really did this.’ You know, ‘I didn't fail them.’ Like ‘we were able to do this.’ Um, the other things we we had to learn> Um, we had to learn how to be together. Which sounds funny because we're family. We're always together, right, but school really does take up so much of the day an* and by the time you come home right it's it's kind of fun stuff. Like it's it's togetherness play time, right, and then bedtime routines, and then they’re off to bed, right. Um, we had to learn. We had to learn how to be together and how to understand or or anticipate people's needs for space and, you know ;02 playing together. Like my kids came up with so many neat new ways to play together because they were around, you know, each other for for so much> All the time, right. So, yeah. I think we grew as a family. We grew to understand uh what each person needs. We also grew to understand what they were doing in school. That was the biggest gift is I learned exactly what my daughter was doing and where she needed help. Um, and where she rocked it. Like she was> She's awesome with like science. Like that's something I never really knew. I saw it on the report card, right, like you see a good grade in the specific subject, but no. She's got a talent for it. Yeah, and being able to, you know, reinforce that and and buy her things that are science related and seeing her be excited about science. Like that was so neat to just see a whole new area of their life that we’re sort of cutoff from. When we send our kids off to school, we really are cutoff from their day-to-day> Right. Like little routines and so we grew as a family and I'm grateful for that (Interview 160833).

46) S1: Oh, very very good! You should you should see her talk on her little machine now! It’s so cute!

MB: <How has that> been going?

S1: So good! She's doing so good I I think I'm holding her back because she's just picking up things so fast.
47) S1: The older he gets, the better and working so much with him, like it was almost like a trial by fire with the emotional regulation. Doing so much work during the pandemic I think is really helped him come through it and so now that he is able to go out with other people, he can come home and be like, ‘Mom, I am just sad today because blah blah blah blah blah.’ Like he can identify that a little bit better (Interview 150704).
APPENDIX E

Supplementary Data

Correlations Between Autistic Behaviors/Tendencies During COVID-19

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<th>Inflexibility</th>
<th>RRBs</th>
<th>Sensory Difficulties</th>
<th>Feeding</th>
<th>Sleep Issues</th>
<th>Diet Issues</th>
<th>Safety Issues</th>
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