

2021 Gatlinburg Conference Symposium Submission

Symposium Title: Masks, Mandates, and Mourning: Individuals with Neurodevelopmental and Genetic Disorders and Their Families During the Time of the COVID-19 Global Pandemic

Chair: Jessica Goldblum¹

Discussant: Brian Boyd⁴

Overview: The COVID-19 pandemic has brought about unprecedented challenges for individuals with neurodevelopmental (NDD) and genetic (GD) disorders and their families. However, through months of stay-at-home orders, upended routines, and extreme uncertainty, little is known about how individuals with NDDs and GDs and their families are coping. This graduate student symposium features three presentations that examine the psychological, social, and economic impacts of COVID-19 on families and their children with disabilities. The first presentation examines how child mental and behavioral characteristics in autism and financial strain from the pandemic are impacting parental distress. The second presentation presents results from the national CARING through COVID survey, a large-scale survey that examined access to telehealth and tele-education services for children with NDDs, particularly those with more severe NDDs. Finally, the third presentation examined the social outlets and mental health risks of individuals with Autism Spectrum Disorder during the pandemic, including internalizing symptoms and loneliness. Collectively, this symposium will share findings from three unique, multidisciplinary research studies that seek to understand how best to support families and their children with NDDs/GDs during current and future times of crises.

Paper 1 of 4

Paper Title: The Hardest of Times: Child Mental and Behavioral Characteristics in Autism, Parent Distress, and Financial Strain in the Time of COVID-19

Authors: Jessica Goldblum¹, Aaron Dallman², Cathy Perry¹, Luc Lecavalier³, Brian Boyd⁴, Clare Harrop¹

Introduction: The COVID-19 pandemic is a time of quarantine, upended routines, social isolation, and financial burden. Due to the unprecedented nature of the pandemic, individuals with Autism Spectrum Disorder (ASD) may have a particularly difficult time coping due to the nature of their disorder, characterized by behavioral inflexibility (BI), high risk for anxiety, and generally poorer self-regulation. Autistic individuals are more likely to experience elevated risk for clinical anxiety disorders (Scahill et al., 2019) and may be experiencing exceptional anxiety during this time of uncertainty. Coupled with deficits in self-regulation (Ting & Weiss, 2017), managing anxiety during a global crisis is surely more difficult. BI, or the inability to exhibit flexibility and openness to new situations, is thought to underlie the repetitive nature of ASD (Boyd et al., 2020) and may make the pandemic changes more difficult for children and their parents. The pandemic has caused most US families undue financial stress, leading to cut costs and changes to routines, such as meals and access to childcare and services (NFE/The Harris Poll, 2020). Outside of the pandemic, parents of children with ASD are more likely to report higher distress levels compared to parents of typically developing children (TD) (Alnazly & Abojedi, 2019), but research is needed to examine how financial strain is affecting these families during this exceptionally difficult time. Moreover, examining how BI and child anxiety might compound the effects of financial strain on parent distress will allow us to understand how best to improve the quality of life of ASD families during times of crises. This study had three aims. First, we sought to examine COVID-19 financial strain, particularly in families with ASD children, and if it is contributing to overall parent distress. Second, we aimed to understand how children's BI, parent ratings of their child's self-regulation, and child anxiety affected the relationship between COVID-19 levels of financial strain and overall

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parent distress. Third, we sought to understand whether parent distress for families with ASD significantly predicted parent-child dysfunctional interactions during the COVID 19.

Methods: Participants were a sub-sample of children recruited from the UNC and OSU sites of Project BIDD (Behavioral Inflexibility in Developmental Disorders). Participants were 59 autistic or TD children (40 ASD, 19 TD) aged 3-19 and their primary caregivers. Parents of participants completed an online Qualtrics survey that included the Parenting Stress Index (Abidin & Abidin, 1990), demographic measures, the Parent Rated Anxiety Scale for ASD (Scahill et al., 2019), the Behavioral Inflexibility Scale (Boyd et al., 2020), and a measure of financial strain during the time of COVID. Descriptive statistics were used to examine financial strain. Due to the small size of the TD group, we did not test for differences in study variables between ASD and TD groups. Lastly, for ASD families, stepwise regression was used to examine the relative contributions of financial strain, child BI scores, child anxiety scores, and parent perceptions of children's self-regulation scores on parent distress and simple linear regression was used to examine the relationship between parent distress and parent-child dysfunctional interaction. All study analyses were conducted in R and standardized estimates are reported for beta coefficients.

Results: Of the 59 participants, most had families who were affected financially by the pandemic. One third (N = 20) had parents who took a cut in salary (ASD=11, TD=9) and 9 had parents who were laid off or furloughed during the pandemic (ASD = 4, TD =5). 22 families had to postpone medical or dental care to save money (ASD =10, TD=12) and 23 families had reduced or eliminated medical insurance due to financial reasons (ASD=12, TD=11). TD and ASD groups did not significantly differ in financial stress levels. However, ASD children had higher levels of BI ($F=32.88, p<0.000$) and average child anxiety ($F=22.97, p<0.000$), and were more likely to be identified by their primary caregiver as having poorer self-regulatory abilities ($F=5.0, p=0.03$). We ran 5 stepwise regression analyses using Bonferroni adjusted alpha levels of 0.01 per test (0.05/5). First, having a child with an ASD diagnosis alone did not significantly predict parent distress during the pandemic. Subsequently, we dropped TD cases from regression analyses due to small sample size. Next, financial strain was regressed upon parent distress scores, which was an insignificant predictor. Upon adding BI to the model, financial strain and BI did not predict parent distress scores. Next, parent perceptions of their children's self-regulation scores were added to our model. Financial strain became a strong, significant predictor of parent distress ($\beta=0.54, p<0.001$), while self-regulation scores were shown to be another robust predictor of parent distress ($\beta=1.01, p<0.000, R^2= 0.63$). Finally, we added child anxiety to our model, which did not significantly predict parent distress, while financial strain and parent perceptions of their child's self-regulation continued to be significant predictors (FS, $\beta=0.44, p<0.01$; Self-reg, $\beta=0.99, p<0.000, R^2= 0.62$). Lastly, using simple linear regression, when examining families with ASD children, parent distress was a strong predictor of parent-child dysfunctional interactions during COVID-19 ($\beta=0.50, p<0.000, R^2= 0.32$).

Discussion: Overall, many study families were hit hard by the pandemic. Not surprisingly, financial stress was a significant predictor of parent distress. However, coupled with financial stress, parent scores of child self-regulation was the most significant predictor of parent distress, suggesting that parents – most of whom exhibited some level of financial stress – who rated their child as having poorer self-regulation had significantly more distress, and subsequently, more dysfunctional parent-child interactions during the COVID-19 pandemic. This suggests that for children with ASD, interventions that target self-regulation are critical in helping to alleviate parent stress from financial strain during the pandemic.

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Paper 2 of 4

Paper Title: Impact of COVID-19 restrictions on individuals with intellectual and developmental disorders: The CARING through COVID survey

Authors: Carly Hyde⁵, Shafali Jeste⁵

Introduction: COVID-19 restrictions have greatly impacted both individuals with intellectual and developmental disorders (IDD) and their caregivers. Within the heterogeneous spectrum of IDD, children with a comorbid diagnosis of autism spectrum disorder (ASD) and their families may experience unique challenges and benefits; for example, while some may thrive in the relative absence of overstimulation, some may struggle due to loss of familiar routine, in-person social support services, and 1:1 aid. CARING through COVID was a large-scale national survey of individuals with IDD which examined, (1) access to telehealth and tele-education services following early stay-at-home restrictions, (2) resources that could mitigate the burden placed on families, and (3) personal experiences of caregivers and children during COVID-19. The first two topics were published earlier this year (Jeste et al, 2020) and here we describe results from the third area of focus, namely caregiver report about the perceived personal impact of COVID-19 restrictions.

Methods: CARING through COVID was an online survey for caregivers of children with IDDs about their experiences during early stay-at-home restrictions. The survey was disseminated through Qualtrics between April 15 and May 1, 2020. Participation criteria included having a (1) genetic diagnosis and (2) neurodevelopmental or neurological diagnosis (developmental delay (DD), intellectual disability (ID), autism spectrum disorder (ASD), epilepsy). The survey assessed: (1) demographics, (2) impact of restrictions on healthcare services, (3) impact of restrictions on educational services, (4) resources that caregivers found most helpful and suggestions for further resource allocation, and (5) the financial, emotional and practical impact of COVID-19 restrictions on caregivers and their children. Analyses presented here examine the subset of participants who were above 3 years old and also identified by their parents as having either intellectual disability or developmental delay (n=536). First, we compared parent-reported symptoms and resource access for children with (n=232) and without (n=304) ASD. Second, we calculated composite scores for positive and negative emotional responses endorsed by caregivers and compared those who expressed net positive and net negative emotional responses within the ASD and no ASD subgroups.

Results: Individuals with ASD were perceived by their parents to have increased anxiety (p=.044), regression (p=.018), and restricted/repetitive behaviors (p<.001) compared to those without ASD. Individuals with ASD lost access to a greater number of services during early COVID-19 restrictions than those without ASD (p=.002) and continued to receive fewer number of services through tele-education (p=.047), though more of the services they did receive were conducted in-person (p<.001). There were no significant differences in the number or type of emotional experiences endorsed by parents of individuals with or without ASD, nor in the financial impact experienced by the family or medical services accessed. Overall, most caregivers reported experiencing negative emotions, such as frustration and anxiety, although almost half endorsed experiencing a sense of closeness with their family. Parents of individuals with ASD who experienced net positive emotional responses lost access to fewer therapeutic services (p=.040) and endorsed higher satisfaction with their tele-education services (p=.021) compared to those with net negative emotional responses. Parents of individuals with ASD who endorsed a net positive emotional response maintained ABA (but no other therapeutic services) at a higher rate (p=.013), and endorsed lower rates of aggression (p=.003), anxiety (p=.001), refusal to participate (p=.006), and mood disturbances (p=.006) in their child compared to parents with a net negative emotional response. Neither group significantly varied based on financial impact or access to medical services. Within

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the no-ASD group, only lower rates of mood disturbance differentiated those who reported net positive or negative emotional impact ($p=.037$), but not the number or type of therapeutic or medical resources accessed nor the families' financial impact.

Discussion: To our knowledge, this is the largest survey of parents and caregivers with neurodevelopmental disorders associated with genetic syndromes. COVID-19 restrictions greatly impacted both caregivers and their children, though parents of children with ASD may have experienced unique challenges related to the loss of ABA services and social interaction. With stay-at-home restrictions likely to continue, it is critical to provide individualized support to children and caregivers, and consider the variation of needs and challenges across the IDD spectrum (Constantino 2020).

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Paper 3 of 4

Paper Title: Social Interaction and Psychosocial Wellbeing in Youth with and without ASD During Mandated Quarantine.

Authors: Alan Gerber⁶, Jennifer Keluskar⁶, & Matthew Lerner⁶

Introduction: Mandated quarantine, while an essential step in mitigation of the spread of COVID-19, can lead to considerable negative psychological effects (Brooks et al., 2020). Indeed, social isolation and the ensuing loneliness already represent significant public health concerns (Holt-Lunstad, Smith, Baker, Harris, & Stephenson, 2015). Youth with autism spectrum disorder (ASD) are already at considerable risk for experiencing elevated levels of social isolation and loneliness (Kasari & Sterling, 2014), making them uniquely vulnerable to the impacts of mandated social isolation. Furthermore, parents of youth with ASD already experience high levels of parenting stress (Hayes & Watson, 2013) and are likely to be at heightened stress levels during compulsory isolation. Indeed, early research demonstrates high parental stress, increased behavioral challenges, and disruption of services for youth with ASD during COVID-19 (Ameis, Lai, Mulsant, & Szatmari, 2020; Colizzi et al., 2020). However, despite heightened vulnerability, there is little published data concerning how mandated quarantine impacts the psychosocial wellbeing of youth with ASD and their families.

Methods: Participants were 76 youth (51 ASD) ages 7-17 with IQ>70 (per KBIT-2; Kaufman & Kaufman, 2004). ASD diagnosis was confirmed via the ADOS-2 (Lord et al., 2012). Parents completed measures of their child's current ASD symptoms (SRS-2; Constantino & Gruber, 2012) and parenting stress (QRS-F; Friedrich, Greenberg, & Crnic, 1983) during mandated quarantine. Youth completed a measure of loneliness (UCLA LS-R; Russell, 1996). In addition, youth and their parents completed a measure of the child's internalizing symptoms (RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000) and a retrospective and current measure of youth quantity and quality of social interactions, including "virtual" social interactions (e.g. phone, video chat, messaging, interactive video games). First, we examined bivariate correlations between ASD symptom severity and other variables. Next, we ran two-way RM-ANOVAs comparing changes in social activity between youth with and without ASD. Significance is reported as $p < .05$, while marginal significance is reported as $p < .10$.

Results: ASD symptom severity (during quarantine) was associated with greater youth symptoms of anxiety ($r = .33$) and depression ($r = .31$) according to parent-report, and depression symptoms according to self-report ($r = .23$); it was marginally associated with greater child-report of loneliness ($r = .22$). Further, current ASD severity was related to less parent-reported time

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spent playing interactive video games ($r = .23$), talking on the phone with friends ($r = .36$), and video-chatting with friends ($r = .36$), while alone as well as less time spent on the phone with friends while around others ($r = .29$). Finally, ASD symptoms were related to higher parenting stress ($r = .47$) and pessimistic attitudes ($r = .67$) in parents. Results from the RM-ANOVAs revealed significant a main effect of ASD group, $F(1, 74) = 6.07$, and time (pre- to during-pandemic), $F(1, 74) = 8.20$, on playing interactive video games. In addition, there was a significant main effect of ASD group, $F(1, 73) = 8.11$, and time, $F(1, 73) = 11.79$, on talking on the phone with friends. There was a marginally significant interaction between group and time, $F(1, 73) = 2.81$, such that youth without ASD increased more than those with ASD over time. Further, there was a significant main effect of ASD group, $F(1, 74) = 17.28$, and time, $F(1, 74) = 5.56$, on video chatting with friends. Finally, there was no main effect of ASD group, $F(1, 74) = 2.68$, however, there was a significant main effect of time, $F(1, 74) = 7.25$, on messaging with friends. For all significant effects, youth without ASD demonstrated more time spent in social interactions, while both groups increased in “virtual” social interactions over time.

Discussion: Our findings demonstrate that both youth with and without ASD increased their time spent interacting with friends through key social outlets during mandated quarantine (e.g. interactive video games, phone and video chatting). Nonetheless, youth with ASD still lag behind their peers considerably, with the gap widening in one key social outlet (talking on the phone with friends). Underscoring the importance of these social difficulties, youth currently experiencing higher symptoms of ASD were also at greater risk for internalizing symptoms and loneliness and their parents reported higher parenting stress and pessimistic attitudes towards parenting, consistent with other studies linking internalizing symptoms and parenting stress in this population (Rodriguez, Hartley, & Bolt, 2019). These results highlight the enduring impact of ASD symptoms on mental health during mandated quarantine and reveal lags in adaptive distanced social behaviour in those with ASD during this critical period.

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