Brief Report

Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities

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Abstract

Background The COVID-19 pandemic introduced challenges to families with young children with developmental delays. Beyond the widespread concerns surrounding illness, loss of employment and social isolation, caregivers are responsible for overseeing their children's educational and therapeutic programmes at home often without the much needed support of professionals.

Method The present study sought to examine the impact of COVID-19 in 77 ethnically, linguistically and socioeconomically diverse families with young children with intellectual and developmental disabilities (IDDs) in California and Oregon, who were participating in larger intervention studies. Parents responded to five interview questions about the impact of the pandemic, services for their child, silver linings or positive aspects, coping and their concerns about the long-term impact of the pandemic.

Results Parents reported that their biggest challenge was being at home caring for their children with the loss of many essential services. Parents reported some positive aspects of the pandemic, especially being together as a family. Although there were positive aspects of the situation, many parents expressed concern about long-term impacts of the pandemic on their children's development, given the loss of services, education and social engagement opportunities.

Conclusion Results suggest that parents of young children with IDD report significant challenges at home during the pandemic. Professional support, especially during the reopening phases, will be critical to support family well-being and child developmental outcomes.

Keywords autism spectrum disorder, coronavirus, COVID-19, developmental delay, Hispanic/Latinx ethnicity

Background

The COVID-19 global pandemic has introduced many challenges to daily life including quarantine and other social distancing measures to prevent the rapid spread of infection and serious illness or death.
Schools, daycares and after-school programmes have closed, placing additional burden on parents to serve as their child’s teacher, while juggling the demands of employment, household tasks and other caregiving responsibilities. Working parents have reported incredible strain on their time, resources and ability to manage the day-to-day needs of parenting and homeschooling (Fontanesi et al. 2020).

The negative effects of the COVID-19 quarantine on mental health have been documented (e.g. Mazza et al. 2020). According to a recent review, the psychological effects of quarantine in the general population include post-traumatic stress symptoms, confusion, anger, frustration, boredom, financial loss and stigma (Brooks et al. 2020). The psychological impacts of COVID-19 on children and youth are still unfolding; however, evidence from a study conducted on a sample of 1143 Spanish and Italian parents of children between 3 and 18 years old suggest negative effects of quarantine on youth (Orgilés et al. 2020). Nearly all (85.7%) parents reported changes in their child’s emotional state during school closures and lockdown, with the most common symptoms reported being difficulty concentrating, boredom, irritability, restlessness and nervousness. In turn, parenting stress was positively associated with increased reporting of child emotional symptoms (Orgilés et al. 2020). These findings are consistent with evidence suggesting transactional parent–child effects and interdependence in parent and child adjustment following major negative world events (e.g. natural disasters, Juth et al. 2015).

Less is known about the impact of COVID-19 on American families, but studies from Europe suggest that the COVID-19 pandemic has impacted families caring for children with intellectual and development disabilities (IDDs) even more than the pandemic has impacted the general population. For example, Fontanesi et al. (2020) conducted a study of 1126 families in Italy to understand the impact of COVID-19 on parents and children. Fontanesi et al.’s (2020) data suggest that parents of children with mental or physical disabilities reported higher levels of parental burnout and perceived less social support than did parents of children without disabilities. Further, parents of children with mental and physical disabilities were more likely to report changes in their child’s behaviour, such as distractibility, inability to concentrate, irritability and general discomfort. Fontanesi et al. (2020) conclude that the pandemic and quarantine place increased stress on parents, especially those parenting children with special needs.

The marked uncertainty of the pandemic and associated disruptions in routine may be particularly deleterious for children with IDD, who often benefit from heightened structure, clear expectations and an array of services, and may have difficulty understanding changes necessitated by COVID-19; increased child difficulties may in turn exacerbate parent stress. For parents raising children with IDD, including autism spectrum disorder (ASD), quarantine means not only serving as their child’s teacher, but also serving as their child’s special educator, social skills coach, speech–language pathologist or behavioural/mental health therapist, sometimes with little support from professional helpers (Eshraghi et al. 2020). Children with IDD often require more intensive services and supports than children with typical development, which may intensify parental strain during the pandemic. Examples of these intensive services and supports include specialised instruction in the form of special education, behavioural programming based on applied behaviour analysis, speech therapy, occupational and physical therapy and social skills instruction, to name a few (National Research Council 2001).

Even without considering the effects of the global pandemic, the literature unequivocally suggests that parents of children with IDD experience heightened parenting stress in relation to parents of children with typical development (Woodman et al. 2015). Further, parents of children with ASD often report more parenting stress than parents of children with other IDs (Barroso et al. 2018). Parenting stress is heightened in the presence of child challenging behaviour (e.g. Baker et al. 2003), with this association bidirectional in nature (Neece et al. 2012). That is, child challenging behaviour impacts parents’ adjustment and parents’ adjustment affects child behaviour.

Ethnically and linguistically diverse families, such as Hispanic (sometimes referred to as Latinx) families in the USA, may experience additional challenges accessing care, resources and support for their children with IDD. The Pew Research Center (2020) estimates that the US Hispanic population makes up...
nearly 61 million of the US population, approximately 18% of the overall American population. Recent prevalence estimates suggest that Hispanics represent the fastest growing population in ASD (Maenner et al. 2020). Unfortunately, several studies document that US service systems may not meet the needs of Hispanic/Latinx children with IDD and report disparities in identification, diagnosis and treatment (Liptak et al. 2008; Nguyen et al. 2016; Zuckerman et al. 2017), in part due to language proficiency (Stahmer et al. 2019; Zuckerman et al. 2017), socioeconomic status (Escarce and Kapur 2006) and other factors such as mental health literacy, stigma and discrimination (e.g. DeFreitas et al. 2018). The caregiving burden and experiences of Hispanic/Latinx caregivers may be compounded by these contextual variables, which may contribute to increased support needs (Blanche et al. 2015).

In light of contextual risks that families of children with IDD may experience, especially those from ethnically and linguistically diverse backgrounds, coupled with the extraordinary financial, physical health and mental health effects of the COVID-19 pandemic, the purpose of the present study was to investigate parental perspectives on the impact of COVID-19 in a sample of predominantly Hispanic/Latinx, Spanish-speaking families of young children with developmental delay or ASD living in the USA.

**Method**

**Procedure**

Seventy-seven parents of children with preschool-aged children (3–5 years old) with developmental delay or ASD participated in the study. These parent participants were currently involved in larger randomised controlled trials in California and Oregon investigating the effects of parent-focused interventions to promote parent and child well-being (McIntyre and Neece 2018; Neece and Fenning 2018). All current participants were invited to participate in the COVID-19 interview (N = 107), and 77 (72.0%) chose to participate. The only notable difference between the families that chose to participate and those who did not is that the families who chose not to participate were more likely to have dropped out of the trials.

Primary caregivers who were participating in the clinical trials were invited to participate in a short five-question telephone interview to discuss the impact of COVID-19 on their families. Interviews were conducted in the parent’s preferred language (54% Spanish; 46% English) between 31 March 2020 to 5 May 2020. Parents provided their consent to participate in this interview, and the interview was not a requirement to participate in the larger ongoing studies.

Parents were asked the following questions. (1) Please tell me how have you been doing during this time, that is since the current 'lockdown' situation due to COVID-19? What has been most difficult? (2) Have your child’s services changed during this time? (3) Have there been any benefits or surprising silver linings for your child or your family during this pandemic? (4) What coping strategies are you using to help you and your family during this time? (5) How do you see the coronavirus pandemic impacting your family in the long term? These questions were asked in an open-ended format and follow-up prompts were not given.

Interviews were approximately 25 min in length and were audio recorded for later coding. Interviewers also took notes on parents’ responses to each question. The lead author and a research assistant reviewed the interviewer notes for each participant and analysed all responses using standard qualitative data analysis procedures: briefly, all notes were coded and organised into categories with subcodes. This allowed systematic review of themes in the responses (Berg 2009) for summary (Corbin and Strauss 2008). The lead author and research assistant then independently coded participants’ responses to each question. The reliability between the two independent coders was good (intraclass correlation coefficients ranged from .78 to .95), and, where there was disagreement in the ratings, the coders discussed and reached a consensus rating. Data from these responses are reported descriptively and are based on the consensus codes.

**Sample**

Table 1 depicts the demographics of the current sample. Of the 77 parent participants, the majority were married and identified as Latinx and monolingual Spanish speaking. The sample was...
economically diverse, with a significant portion of our sample receiving some sort of government financial assistance. The majority were male children. All children had a developmental delay or intellectual disability diagnosis, and 62.34% had a comorbid diagnosis of ASD.

Results

Biggest challenges

Parents were asked to identify what had been most difficult for them. Table 2 details the challenges raised by parents in the sample. The most frequent challenge centred around difficulties being home during the pandemic. Among those who reported difficulty being at home, the majority (47.8%) said that being stuck at home and unable to leave the house was most challenging, followed by balancing work, caring for young children and lack of childcare (17.4%). Other challenges include changes in routine (15.2%), emotionally supporting family (10.9%) and finding activities and preventing boredom for children (8.7%). Parents reported financial concerns as well, most commonly due to one or both parents losing jobs as a result of the stay-at-home order. Parents also expressed dealing with significant challenges related to their children’s developmental services decreasing or stopping and feeling like they could not meet their child’s educational and developmental needs at home. A subset of parents said that their biggest concern was their family’s health and not getting COVID-19. Lastly, a group of parents stated that their child’s behaviour problems had been the biggest challenge since the stay-at-home order had gone into effect.

Even though parents were asked to report their primary challenge, several parents (36.4%) spontaneously reported a second significant challenge. The most common secondary challenge parents reported was having a lack of services and unmet educational and developmental needs.

Changes in services

Parents were also asked to report on how their child’s services had changed since the stay-at-home order had gone into effect. The vast majority of parents said that their child’s services had decreased (77.9%), while 18.2% said that the amount and intensity of their services had stayed the same but that they were now delivered online. Two participants (2.6%) said that changes in services had been mixed (some services increased and some decreased), and one parent (1.3%) said that their child’s services had increased during the pandemic.

Benefits or silver linings

Parents reported on whether their family had experienced any benefits or surprising silver linings during the pandemic (Table 3). A subset of families reported that there had been no benefits (13.8%);
however, the majority of the families reported some benefits, most commonly having more time together as a family (49.2%). Some parents also said that their child continued to make developmental gains, mainly in language, since being home despite experiencing a reduction in services. A subset of parents mentioned enjoying a slower pace of life, with some saying that they were able to sleep more, go outside more and meditate and reflect. A handful of parents said that they were happy to see communities coming together to support each other during the pandemic, and some noted that they were surprised how well their child had adjusted to being at home. A small number of parents also said that they were thankful they had been able to get more government financial assistance, that they had not contracted COVID-19 and that they had learned to be more patient.

### Coping

Parents described the coping skills they were using to get through this challenging time (Table 4). Parents reported a range of coping skills, the most common being implementing behavioural strategies (e.g. reinforcement systems) and routines as well as engaging in enjoyable activities with the family (e.g. family games, walks outside). Parents also reported practicing meditation, exercising and eating healthy, providing space for family members to decompress and taking breaks from each other and connecting.
with other people, usually by phone or computer, to be helpful during the stay-at-home order. A subset of families (7.6%) did not report using any specific coping skills to manage current circumstances related to the pandemic.

Long-term impact

Lastly, parents indicated how they thought the pandemic and stay-at-home order would impact their family in the long term (Table 5). At the time of these interviews, families most commonly reported economic concerns about the pandemic (28.6%), but several other families did not think the pandemic would have a significant impact on their family or were unsure of the impact; however, most of these families reported that if restrictions continued for an extended period of time (e.g. an additional 30–60 days, into the summer), the pandemic would have a range of negative impacts on the family. Specifically, parents expressed that if the pandemic continued for several months and into summer 2020, they had concerns about the long-term impact of the pandemic on their employment and finances, as well as on their own and their children’s emotional health. Families also expressed a variety of other long-term concerns including lack of educational and developmental
progress in the child if school and services did not resume, worries about long-term social changes (e.g. wearing masks, not seeing people for a long time) and emotional concerns for themselves and their child (e.g. fear of what the future will look like, feeling constant panic, getting very bored).

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Parents in this sample reported a range of experiences associated with the COVID-19 pandemic and stay-at-home orders. Importantly, the main concerns expressed by these caregivers focused on their children’s needs and the challenges of being at home, losing services and anxiety about the future. That being said, many parents reported unexpected ‘silver linings’ or positive aspects of

| Long-term impact                                      | n  | %     | Illustrative quote                                                                 | Translation of quote if applicable                                                                 |
|-------------------------------------------------------|----|-------|-------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|
| Economic challenges                                    | 18 | 28.6  | ‘Lo único que me preocupa es los pagos que se tiene que hacer: la renta, los carros, la comida. Me preocupa que no haya mucho ingreso.’ | ‘The only thing that worries me is the payments that have to be made: rent, the cars, food. I am concerned that there will not be much income.’ |
| No impact                                              | 11 | 17.5  | ‘Honestamente, no creo que nos afecta mucho.’                                       | ‘Honestly, I do not think it will affect us much.’                                                 |
| Lack of child educational and developmental progress   | 10 | 15.9  | ‘Creo que en la escuela, porque como no se mucho de internet, y las maestras no me contestan, no puedo acesar las clases de su escuela… y me preocupa a largo plazo sus estudios y en el desarrollo porque es mucho tiempo de estar sin clases.’ | ‘I think that in school, because I do not know much about the internet, and the teachers do not answer me, I cannot access his classes… and I’m concerned long term about his studies and development because it’s a long time to be without classes.’ |
| Social changes (e.g. wearing masks, not seeing people) | 8  | 12.7  | ‘En la cuestion de socializar, eso es lo que está afectando todo nosotros. Nos afecta no poder salir a las compras, llevar a los niños a la escuela o al parque. Esas son las cosas que nos están afectando.’ | ‘In the issue of socialising, that is what is affecting all of us. It affects us not being able to go shopping, take the children to school or to the park. Those are the things that are affecting us.’ |
| Positive impact                                        | 6  | 9.5   | ‘You know what it’s an eye opener for sure … being at home you appreciate what you normally do not. We do a lot more family activities, you know, boards games, things like that, then we did before.’ | ‘It will affect everything, because I am no longer calm. Because they say so many things on the news. One day they say one thing, another day they say another. Like now they are saying that the pandemic can come back the same in winter, and I am already thinking of winter, that the same thing happens again. And I think that things are not going to be the same. For me, it changed everything, everything, everything.’ |
| Emotional impact (e.g. anxiety, fear, boredom)         | 5  | 7.9   | ‘Va a afectar demasiado, porque yo ya no estoy tranquila. Porque dicen tantas cosas en las noticias. Un día dicen una cosa, otro día dicen otra. Como ahora están diciendo que la pandemia puede venir igual en invierno, y ya estoy pensando en invierno, que pasa otra vez lo mismo. Y pienso que ya las cosas no van a ser igual. Para mí, cambió todo todo todo.’ | ‘Oh my god. I think I do not know, really. I hope not. If not, it will hurt us a lot.’ |
| Unsure                                                 | 5  | 7.9   | ‘Ay dios mio. Creo que no lo sé, de verdad. Espero que no. Si no, nos daña mucho de esto.’ |                                                                                                                                 |

*N = 63.*
staying at home including spending more time with family and improved family relationships. Almost all families reported positive coping strategies, such as establishing routines at home, using behavioural strategies to support their children’s development or engaging in exercise, meditation or social support. Although our findings are similar to other recent reports on the impact of COVID-19 on families, there is consistent evidence that the burden on parents who have children with disabilities, or educational or social vulnerabilities, is greater than in the general population (Coyne et al. 2020; Fontanesi et al. 2020; Masters et al. 2020). Because we do not have a comparison sample of ethnically, linguistically and socioeconomically diverse families of young children without IDD/ASD in the USA, it is difficult to say with certainty that our families parenting young children with developmental disabilities are experiencing the pandemic differently. However, there is ample pre-pandemic evidence supporting heightened parenting stress, increased caregiving burden and heightened challenges with child behaviour in families of children with IDD/ASD in comparison with counterparts with typical development (e.g. Hayes and Watson 2013). Given the transactional relationship between parenting stress and child challenging behaviour (e.g. Neece et al. 2012; Woodman et al. 2015), increases in child difficulties during the pandemic (Fontanesi et al. 2020) are likely to adversely affect parents’ stress and ability to cope. Further, decreases in services for young children with IDD/ASD as a result of COVID-19 are likely to have detrimental short-term and long-term consequences given that the early childhood years represent a critical window for intervention due to brain plasticity and the potential for rapid developmental gains (National Institute of Child Health and Human Development 2017; National Research Council 2001; Reichow and Wolery 2009).

The current sample was ethnically, linguistically and socioeconomically diverse, with the majority of participating parents identifying as Hispanic/Latinx and almost half as monolingual Spanish speaking. This diversity is unusual for studies of families with IDD in the USA (Safer-Lichtenstein et al. 2019). Past studies suggest that the Latino cultural value of ‘familismo’ is associated with improved well-being and adjustment, especially under difficult circumstances (Ayón et al. 2010). These strong family ties may be associated with improved coping (Perez and Cruess 2014) and may be partially responsible for parents’ reports of improved family relationships and more family time as unexpected positive aspects of the pandemic. Resilient perspectives are particularly notable given the health and socioeconomic disparities disproportionately affecting individuals from racial and ethnic minority backgrounds during the COVID-19 crisis in the USA (Webb Hooper et al. 2020). Although the overrepresentation of ethnically, linguistically and socioeconomically diverse families in this sample is a notable strength, caution must be taken in interpreting findings as the experiences reported by this group of participants may not generalise to other populations. Although findings from this study represent just a snapshot of challenges faced by families with children with IDD during the spring of 2020, the long-term impacts of the pandemic have yet to be fully identified by both families and professionals. During the lockdown in spring of 2020 and associated school closings, parents reported significant challenges associated with being at home with their child with an IDD and providing full-time care and services without the same level of support from professionals. At best, services moved to telehealth and remote platforms, and at worst, services were simply eliminated. More research needs to be done on the short-term and long-term impacts of COVID-19 on children with IDD and their families. Additional investigation of the utility of novel telehealth and remote platforms for clinical care to support both children with IDD and their families is also required, with particular attention to those from ethnically, linguistically and socioeconomically diverse backgrounds.

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Conflict of Interest

The Authors declare that there is no conflict of interest.

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