IMPACT OF COVID-19 PANDEMIC ON FAMILIES OF YOUNG EXCEPTIONAL CHILDREN: PARENTAL STRESS AND SERVICE DELIVERY

by

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ABSTRACT

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IMPACT OF COVID-19 PANDEMIC ON FAMILIES OF YOUNG EXCEPTIONAL CHILDREN: STRESS AND SERVICE DELIVERY (Under the direction of Dr. Ann Mickelson)

Families of young exceptional children (young children with identified delays or disabilities) have different life experiences, characteristics, and stressors than families of typically developing children. This makes the study of these families, and especially their responses to disaster, unique. This study used an online survey to investigate parents perceptions of stress and service delivery, as well as related characteristics. Across 6 participants, 100% reported increased parental stress, mostly attributed to disruptions or inconsistencies in services, impacting daily routines, schedules, and activities of families. Other results are mixed, indicating the diversity of family experiences across demographics, as well as the need for further research to inform recovery efforts. Finally, the author contends that there must be planning, by systems, schools, and teachers, for the next such disaster.

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My wholehearted thanks to Dr. Ann Mickelson, who kept faith in me and shared encouraging feedback through the ups and downs of this process; even when I was losing motivation, you helped me to understand and push through to the finish line!

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And finally, to my husband (who I married during the throes of this study)—I promise I will take a break now! Thank you for your endless support and understanding.

DEDICATION

This paper is dedicated to the children and families I worked with during the COVID-19 pandemic in the 2020-2021 school year. Your resilience, compassion, and joy through the trauma surrounding all of us during this time will fuel my passion for teaching young exceptional children for years for years to come.

CJ, CB, LW, ML, JG, CB, GY, A&AB, and ZB

TABLE OF CONTENTS

LIST OF TABLES AND FIGURES

LIST OF ABBREVIATIONS AND TERMS

ABA: Applied Behavioral Analysis, a treatment program for individuals with Autism or other disabilities. Usually classified as a “private” service, not affiliated with a school district.

ASD: Autism Spectrum Disorder

DD: Developmental Delays

Disability-Related Services: Therapy, special education services, or other programs that a child receives or participates in specifically related to their disability or developmental delays.

ECSE: Early Childhood Special Education, usually referring to 3 and 4 year old preschool programs for children who have identified delays or disability, and receive services from the school district.

Private/Public Therapy: Speech and Language Therapy, Occupational Therapy, or Physical Therapy services either provided by a school district (public) or through a for-profit program/clinic (private.)

Zoom: A video meeting platform widely used during the COVID-19 pandemic by schools, individuals, and therapists for virtual service delivery.

CHAPTER 1: INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic and public health responses have impacted the lives of children and their families all over the world. The virus was first detected in the U.S. in late January 2020. By April 21st, 793,699 confirmed cases had been identified in communities across the country (Schuchat, 2020). In response to the rapid spread and transmission, 42 states and territories issued mandatory stay at home orders (Moreland et al., 2020). According to Education Week data (2020), resulting school closures affected at least 55.1 million children and their families. Schools provide necessary childcare for working families, regular nutrition for low-income children, safe spaces for children to learn and play, and services to meet the needs of exceptional children. It would be no stretch to infer that school closures drastically changed the daily lives of families in the United States. Stay-at-home orders across states limited families' access to in-person social activities, health and education services, childcare, and regular family outings. The pandemic and stay-at home orders also drastically impacted daily lives of parents. As businesses temporarily or indefinitely closed, this meant loss of income or employment for many parents and caregivers.

Given these factors, the COVID-19 pandemic can be classified as a "disaster" according to (Bonanno et al., 2010). "Disasters are most commonly conceptualized as natural or human-made events that cause sweeping damage, hardship, or loss of life across one or more strata of society" (Bonanno et al., 2010, p. 2). This classification allows for a comparison of the COVID-19 pandemic to disasters impacting American families such as school shootings, Hurricane Katrina, terrorist attacks on 9/11, and others. Research on these events may give light to the toll that the current disaster may have on families and communities, now and in future years. Post-traumatic stress disorder (PTSD), anxiety, and depression are all noted in research as a result of disaster (Betty, 2020; Bonanno et al., 2010; Elliott & Pais, 2006; Hoffman & Kruczek, 2011). However, disasters often have a broader negative impact on families, communities, and larger segments of society than an increase in mental health diagnoses. Bonanno et al (2010) notes the results of disaster can impact nature and structure of families, tax community institutions, and ripple through larger segments of the society.

1.2 Statement of the Problem

Each family in the U.S. experiences and copes with disaster differently. The diversity of each family structure is unique and lends itself to unique experiences. Bonanno (2010) contends that response to a disaster depends on individual risk and resilience factors, including the "predisaster context". Predisaster context includes typical demographic information like age, race, gender and socioeconomic status. It also includes personal characteristics such as strength of social supports, personality, and preparation and prior exposure. This combination can also be conceptualized using the broader terms "resilience" and "protective factors," which are commonly used in the study of families and children across disciplines. The combination of these predisaster characteristics influence a family or individual's response to the disaster, and how profound of an impact it may sustain. One family characteristic of particular interest for this study is those that include a young exceptional child.

An exceptional child can be defined as a child with an identified delay or disability. This study will focus on children aged 3-5 years old who are receiving services for their identified delay or disability through private or public services. These services include: special education services, speech therapy, physical therapy, occupational therapy, and/or applied behavioral analysis therapy. Families who include a young exceptional child have a different predisaster context than other families of young children. Researchers have concluded that these families experience more instability and dysfunction than “typical” families, and therefore more stress. In a meta-analysis, Hayes and Watson found that parents of children with Autism Spectrum Disorder experience the most stress, followed by families that include a child with another delay or disability (2013). Stressors affecting families that include a family with a young exceptional child can be generalized as the following: issues related to the disability and diagnosis, learning about and accessing the service system, managing their child’s behavioral challenges, and school transitions (Minnes et al.., 2015). The aforementioned stressors have only been multiplied and amplified as a result of the COVID-19 pandemic.

Of particular interest for this study is the stressor regarding accessing the service system. According to the U.S. Department of Education IDEA Data collection (2020), 815,010 children aged 3-5 participated in Part B (public early childhood special education) services in the nation in the 2018-2019 school year. Due to the COVID-19 pandemic, these children no longer had access to in-person instruction or therapies as schools closed and learning transitioned to virtual/remote implementation methods. Families became responsible for providing childcare during the hours their child was typically in school, facilitating remote learning for their young children, and implementing new technology tools to access school and other special education professionals digitally.

1.2 Research Questions

The purpose of this study is to investigate the impacts of the COVID-19 pandemic and public health responses on families that include a young exceptional child, specifically focusing on perceptions of parental stress and changes to service delivery. This study will also compare perceptions of stress and changes to service delivery across family demographics including family type, socioeconomic status, race-ethnicity, and disability diagnosis.

The researcher will conduct the study to answer the following research questions: 1) To what extent, if any, did parents and caregivers of young exceptional children experience changes in stress during the COVID-19 pandemic and public health responses? 2) Do perceptions of stress differ across family demographics? 3) How was disability related service delivery impacted for young exceptional children during the COVID-19 pandemic? 4) How were changes in disability related service delivery perceived by parents and caregivers?

CHAPTER 2: REVIEW OF THE LITERATURE

2.1 Theoretical Perspectives

Urie Bronfenbrenner's Ecological Systems Theory offers a basis for understanding the reciprocal relationship between an individual and their environment. In a "nested arrangement of structures," an individual is understood to be at the center of the system--the "microsystem" level (Bronfenbrenner & Ceci, 1994). While only one individual is considered at the microsystem level, it also includes the relationships between the individual (e.g. a young child) and the immediate setting (e.g. home, school.) The microsystem includes all components of the setting: time, place, physical setup, activity, and role the child plays. Next is the mesosystem, described by Bronfenbrenner as "a system of microsystems." This would include the young child's parents, caregivers, and siblings, and components of each individual's settings. Within these two smallest levels we can begin to identify the reciprocity of relationships; for example, we might consider a newborn baby as our individual in the microsystem. Her role as the youngest child in the family impacts her siblings roles (e.g. they may receive less attention and become more independent in self-care tasks,) her parent's roles (e.g. her father may choose to stay home because childcare for two children is expensive,) and her grandmother's physical environment (e.g. there is no longer an extra guest bedroom in the home, so she must find a new housing arrangement.) Further, at the exosystem level are social structures that the individual is not directly involved in. These social structures include the workplace of caregivers, informal social networks, the neighborhood in which the child lives, the culture of the larger community, media, governmental systems, transportation, and the distribution of goods and services. Next, the macrosystem, defined as "the overarching institutional patterns of the culture or subculture...of which micro-, meso- and exosystems are the concrete manifestations" (Bronfenbrenner, 1977, p. 514). The exosystem is of particular interest to this study because of the drastic impact that changes in the exosystems of young children had on both micro- and mesosystem levels. When workplaces closed, informal social networks and neighborhood parks were no longer safe to engage with, governmental systems enacted new policies, and the distribution of goods and services was interrupted, the changes trickled down into the microsystems of young children. The final, overarching system included in Bronfenbrenner's theory, the chronosystem, includes the time period and development of the individual. The chronosystem exists independent of other system levels but can have direct impacts on each. In the context of the COVID-19 pandemic, use of Bronfenbrenner's theory provides the necessary framework to examine how each level of the system intertwine to impact families. While national policy decisions usually remain far-removed from the daily life of a child, this disaster created more direct and immediate links.

2.2 Applications of Theory in Research

Bronfenbrenner's theory has been used by researchers across fields to examine impacts of disaster because of its effectiveness in examining reciprocal effects across large strata of societies. Hoffman and Kruczek (2011) used Bronfenbrenner's systems theory to examine the effects of mass trauma on individuals, communities, and society at large. This application of the theory is ideal because it allows researchers to conceptualize disaster response at the individual, family, and community levels. Similarly, it can inform interventions that may be effective across all systems. It also may give researchers a structure for understanding the effects, intervening in the aftermath, and addressing prevention. Hoffman and Kruczek (2011) included one new system level based on Bronfenbrenner's work that focuses more on biomedical factors like temperament and emotional reactivity, called biophysical. This focus is important to their work because it details the physiological effects of disaster, an aspect not always examined in relationship to the other systems. Biophysical impacts of trauma largely are generally detailed as stress responses. Hoffman and Kruczek (2011) note that these stressors created by exposure to one mass trauma may have a ripple effect, and affect the future resilience of individuals, families, and communities. This sentiment almost identically echoes Bonanoo et al.'s (2010) work, building on the understanding of Ecological Systems Theory as ideal for studying disaster. Hoffman and Kruczek offer a concise and clear conclusion for the use of Bronfenbrenner's model in the study of disaster responses, "Reaction of an individual to a disaster can be fully understood only in the context of both these developmental processes and the ecosystems within which she or he functions" (Hoffman & Kruczek, 2011, p. 1094).

Bronfenbrenner's theory has also been used as a framework to analyze individuals' resilience to adverse changes in their environments, like those that took place in the time of the COVID-19 pandemic. Resilience, in this context, is defined by Boon et al. as "the capacity for successful adaptation, positive functioning or competence despite high-risk status, chronic stress, or following prolonged or severe trauma" (2012, p. 387). This definition applies to the individual, or the microsystem level and the relative ability to remain in a normal physical and mental state. At the mesosystem and exosystem levels, is described using a definition for community resilience; descriptions of community resilience in research varies, but has three fundamental components. These focus on a community's resistance, recovery, and creativity. During the COVID-19 pandemic, these components can be functionally applied with concrete examples. Resistance would be illustrated by a community's ability to shield itself from widespread virus transmission, economic strain, and disruption in community functioning. Recovery would take shape in the community's return to normal, and the pace and intensity of which this return would take place. Creativity is the ability of a community to "maintain a constant process of creating and recreating...so that the community not only responds to adversity but in doing so, reaches a higher level of functioning" (Boon,2012, p. 387.) Within the COVID-19 pandemic, this component can be exemplified by the larger number of people teleworking in some communities, and the response of companies who have embraced this change as permanent. Use of Bronfenbrenner's theory in the study of disaster responses, as exemplified in the former statements, acknowledges the deep interplay between individuals' emotional and physical responses, changes in family functioning, and community resilience with the changes at all levels of the system.

2.3 Resilience

Discussion of trauma and disaster is frequently linked in the literature to the concepts of resilience and risk factors. This link provides researchers direction and background with which to distinguish family contexts and characteristics that influence response to disaster. The study of family resilience began as an investigation of children who did not respond as expected to risk and trauma (Patterson, 2002). Researchers sought to answer the question, "What accounts for why some stay healthy and do well in the face of risk and adversity, and others do not?" (Patterson, 2002, pp. 350). In an overview of the research on resilience, Patterson makes a distinction between the functional definitions of resilience as used by practitioners and researchers in the field of child and family development. The researcher notes that practitioners (teachers, therapists, etc.) use resilience "to characterize an approach that focuses on family strengths vs. benefits" (Patterson, 2002, p. 349). This definition emphasizes the approach and focus on the creation of protective factors within the family environment. Conversely, Patterson (2002) states that resilience's functional definition as used by researchers encompass demographics, characteristics, or behaviors "...used to explain unexpected competent functioning among families (and individuals) who have been exposed to significant risk(s)" (Patterson, 2002, p. 349). This definition, in contrast with the former, emphasizes characteristics, demographics, and behaviors that can be linked to an outcome. Simply, practitioners take a preventative approach, and researchers look back to find discrete commonalities.

Research on family resilience also provides operational definitions of risk and protective factors, which both contribute to resilience outcomes. Risk is scaled and labeled "significant" because the large majority of the exposed population shows "symptomatic or dysfunctional" behavior (Patterson, 2002). Researchers on this topic sought to identify the characteristics and behaviors that moderated the relationship between significant risk and successful functioning; these characteristics and behaviors are widely referred to as protective factors. Patterson (2002) also asserts that the ability of a family to fulfil four functions as a way to conceptualize resilience. These functions include: 1) membership and family formation, 2) economic support, 3) nurturance, education, and socialization, and 4) protection of vulnerable members. These functions provide researchers with an identifiable set of "standards" by which to assess family's post-disaster.

Bonanno et al., (2010) linked the research basis of resilience to disaster outcomes for individuals, families, and communities. Two assertions of their research findings are directly related to both Ecological Systems Theory and Resilience: a) disaster outcome depends on a combination of risk and resilience factors and b) disasters put families, neighborhoods, and communities at risk (Bonanno et al., 2010). These assertions, applied simultaneously, would indicate that the functioning of the child within the microsystem is only as resilient as the protective factors in their larger environments allow them to be. However, their study found that within their three broad categories of factors related to disaster outcomes, variables only exert small to moderate effect sizes. “Ultimately, how these effects impact disaster outcome and determine whether a disaster survivor is resilient, struggles with a more gradual recovery, or develops enduring psychopathology depends on the totality of these factors” (Bonanno et al., 2010, p. 14). This statement speaks to the variability of both risk and protective factors in predicting healthy disaster recovery. There is no magic formula to produce positive results. However, one characteristic of individuals, is found to be predictive across research. This characteristic is the child’s age when trauma occurs. Very young children tend not to recall aspects of disaster events, and are found to exhibit a natural resilience, even in the aftermath of adversity. While Patterson (2002) would consider very young children vulnerable family members, Bonanno et al., (2010) have found that they may be less vulnerable to the long-term effects of trauma than other family members.

Parents are more likely to experience stress, anxiety, and other adverse reactions to traumatic experiences. Bonanno et al. (2010) contends that a likely cause of this difference is because of the increased parental burden as a result of disaster. This seems like a logical conclusion combined with Patterson’s four family functions; parents would be responsible for, and therefore burdened by, the ability of their family to recover those essential functions post-disaster. This conclusion is echoed by Hoffman and Kruczek (2011) in their meta-analysis. Their findings include identification of a common theme through traumatic events; they have found that individuals, families. and communities lose access to many or all of their traditional resources (Hoffman & Kruczek, 2011). COVID-19 compromised families’ access to education, childcare, income, and various other resources. One notable resource, especially within the discussion of resilience and protective factors, is social supports. In an ever-connected world, some may assume that social networking and virtual connections are sufficient for meeting this need during the pandemic. However, research on this subject indicates the possibility that the specifics of the current disaster may have more negative impacts on families than other similar events.

2.4 Social Supports

Bonnano et al. (2010) identified social support as the most consistently identified protective factor in terms of moderating response to trauma across studies. There is evidence to suggest that disaster and trauma has a mixed impact for one important resource: social relationships. Bonnano et al. (2010) asserts that the available literature suggests disasters have a meaningful impact on social relationships during and post- disaster. Families and individuals that experience disaster may receive support from family, friends, and social organizations in the community, leading to a sense of togetherness. However, studies have also found that trauma and stress erode the relationships within the immediate family structure, and interpersonal relationships outside of it (Bonnano et al., 2010; Hoffman & Kruczek, 2011). This gives important context to the COVID-19 pandemic because social supports are extremely different than in most disasters. Stay-at-home orders and social-distancing guidelines significantly reduced the ability of families to engage in their regular social relationships outside of the immediate family. While families were required to remain separate, the positive outcome of community togetherness may not be applicable.

Kilburn and Shapiro (2020) examined the structure and function of social networks of mothers of young children with disabilities in an exploratory study. Their outcomes supported Bonnano et al.'s (2010) assertion as these social support networks as an important factor in mitigating adverse effects on family functioning and investigated more detailed characteristics of successful social supports. Kilburn and Shapiro (2020) linked weak social support to negative outcomes, including increased parental stress. Diverse types of social supports were categorized and measured in effectiveness in their research, furthering understanding and application in the field. Kilburn and Shapiro made a distinction between “kin and non-kin” social supports. Kin included immediate and extended family, and non-kin included friends, professionals, and others in the community that provided social support to mothers. Parents in the study reported they were most likely to receive kin support for their family and young child, specifically from grandparents. This distinction is important because during the COVID-19 pandemic, families were commonly told to isolate from older family members to keep them safe from spread of the disease. This study found that non-kin support was most likely to be emotional support. Interestingly, researchers found this type of non-kin support to have a negative impact on maternal stress for mothers. Professional supports, however, when they provide emotional support, were found to have a mitigating effect on parental stress. These findings may have mixed connotations in the current context, considering the ability to access both non-kin and professional social supports. While mothers may have been active with kin and non-kin on social networks or through other virtual communication, they may not have engaged in the same types of interactions that they would in-person. Professional support may have been impacted in the same context, even if a family could interact with these professionals through video call or other means. While social supports have been identified across research as an important protective factor for families, they certainly have not provided the mitigating effects for all families in the current disaster.

2.5 Parental Stress

Parental stress has been identified by Hayes and Watson (2013) as the most researched experience of families that include a young exceptional child. Oelofsen and Richardson (2006) found that 84% of mothers with preschool children with disabilities scored within the clinical range for parenting stress, as compared with 5% of mothers of children without disabilities. In a meta-analysis of 15 studies, Hayes and Watson (2013) found that in comparison to parents of typically developing (TD) children, parents of exceptional children report more stress across studies, with a large effect size when comparing children with Autism Spectrum Disorder (ASD) to TD. However, they also noted the importance of considering distress in terms of the family's entire ecological system in that distress may arise for many reasons not linked to a disability diagnosis.

Higher levels of parental distress were also linked to poor health outcomes for parents by Masefield et al. (2020). This study focused specifically on parents of preschool aged children and included a variety of disability diagnoses. Levels of stress, depressive symptoms, and fatigue were examined, with the outcome supporting Hayes and Watson's (2013) analysis. Both Hayes and Watson (2013) and Masefield et al. (2020) identified the highest levels of parental stress for families of a child with ASD, indicating an association between this specific diagnosis and destress across populations. Masefield et al. (2020) also found a large association between caregiver ill health and mixed developmental disabilities, reflecting the common experience of parents who seek and receive a diagnosis and experience the beginning of nonnormative chronic stress, as identified by Patterson (2002).

Although parents of young children with disabilities report more stress, research has begun to balance negative outcomes with positive ones. There are a variety of factors that influence family coping and protective factors as well as parental distress; similarities can be drawn between research on parental distress and family resilience given these factors. Minnes et al. (2015) found that within their sample of families with a child with a developmental delay, there were significant predictors of both positive and negative outcomes. Coping variables of parent empowerment were found to be predictors of perceived positive gain across 155 families; financial hardship and lower parent empowerment emerged as predictors of parent distress. This study included a relatively large sample size and diversity in the child's diagnosis (ASD, Down Syndrome, developmental delays, genetic disorders) and may easily be generalized to other populations.

While no research currently exists to examine the impact of COVID-19 on American families, a researcher in Italy has begun to study families of young exceptional children in Italy. In a study of over one thousand families, Fontanesi et al. has found preliminary data to suggest negative outcomes on family functioning (2020). These data suggests that parents are experiencing higher levels of parental burnout and perceiving less social support. Most parents in the study also noted significant negative changes in child behavior, resulting in a change to increased verbal hostility used by parents and inability to regulate responses. This reported change in behavior is also identified by Bonanno et al. (2010), who asserted that young children have displayed increased temper tantrums, sleep disruptions, and incontinence in response to disaster. Aside from impacts on family functioning, research on previous disaster events may provide perspectives on academic and community impacts as well.

2.6 Perspectives from past disaster events

While there has not been a disaster at a similar international scale of COVID-19 in recent history, applicable perspectives can be found in disaster research as a whole. Boon et al. (2011) conducted a critical review of the literature focused on disaster planning specific to children with disabilities. This research asserts that because children spend as much as 80% of their waking hours at school, it is the responsibility of schools to plan for and execute care before, during and after public health emergencies. Children with disabilities are exceptionally vulnerable to disaster, and this risk is compounded when their families are considered. In their review of relevant literature, Boon et al. (2011) found that families caring for a child with a disability are uniquely vulnerable to impacts of disaster, since disabilities are strongly associated with social, structural, and financial disadvantage. Similarly, children with disabilities are more likely to experience intra- and extra- familial abuse and neglect, which may be amplified in the aftermath of disaster. The final outcome of this review was that children with disabilities were neglected in research on disaster preparedness; the only article found that specifically mentions children with disabilities was a government sponsored report and did not meet other inclusion criteria. While this study focused on planning for disasters, the following research provides real-life perspectives on recovery and impacts.

In a study of teacher perspectives following forest fires, Berger et al. (2018) reported varied impacts that correlate with changes in the educational landscape during COVID-19. Teachers reported difficulty helping students settle into new environments and routines, low student attendance, and disengagement among students with disabilities after school relocation. Most of these negative impacts are mirrored in the current crisis; children are either learning virtually or in socially distanced environments, with new routines related to health concerns. An additional concern reported by teachers were additional duties: additional paperwork, phoning students and families to notify them of changes to schedule/location, and managing student behaviors. With changes to the traditional school day and increase in remote learning, similar changes for teachers, families, and students are readily discernible.

Ducy and Stough (2011) found that there was a great level of loss associated with school closure and subsequent return. Teachers reported loss in academic, behavioral, and social skills after missing instruction for several weeks, and increased instruction was necessary to address their students' regression in skill levels. This finding is exceptionally important in the context of COVID-19; for children who have not returned to the school building, increased instruction to address regression is not possible. Also noted in this study was teachers' perceptions of a loss in professional functioning; after the disaster, they did not feel able to meet their students' increased needs. While teacher perspectives of impacts of the COVID-19 pandemic have not yet been studied, a concerning possibility is loss in self-efficacy in serving returning students.

2.6 Impact on Service Delivery

As noted by Minnes et al. (2015), a common stressor of parents with young exceptional children is learning about and navigating the service system. Preschool-aged children with diagnosed developmental delays or disabilities receive both special education and therapy-based interventions through the public school system, and many receive supplemental services outside of the school setting. Given the COVID-19 pandemic and resulting school closures, social distancing measures, and stay at home orders, service delivery may have been interrupted. Jeste et al. (2020) investigated access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. A large majority of caregivers (74%) reported no longer receiving one service during the pandemic and 30% reported losing access to all services. Some services were converted to a tele-education or tele-therapy model, utilizing technology to provide direct services. Caregivers reported positive perceptions of these services, with only 14% reporting tele-therapy not at all helpful. However, this positive perception has more negative undertones. Individuals lost access to a substantial number of educational and medical supports, potentially adding to caregiver burden and compromising child and caregiver well-being. Additionally, this study provides only limited application to parents of preschool-aged children because of the special characteristics of this population. Preschool-aged children with disabilities need support to use technology, attend to and engage in activities, and follow directions; these factors may have increased the parents' involvement in service delivery, and subsequently impacted stress levels. As previously noted, parents of young exceptional children experience elevated stress in daily lives, indicating a worrying potential outcome during the COVID-19 pandemic.

Child behavior change as noted by Fontanesi et al. (2020) might also be linked to changes in service intensity. Richardson et al. (2020) found that increase in service intensity (frequency and length) resulted in positive changes in functional gains. Heightened service intensity for young children was significantly linked to gains in cognitive and social abilities. The opposite can be inferred, then, that a decline or loss in services may lead to stagnation or regression in functional gains and skills, including emotional and behavioral regulation.

Summary

The available research on family functioning, resilience, parental stress, and service delivery points to a wide array of negative outcomes for families of young exceptional children impacted by the COVID-19 pandemic. Research across disciplines has demonstrated varied impacts across family predisaster contexts, emphasizing the need for a focus on building family and community resilience. While there are many perspectives and findings included in this review that may inform the current study, the novel characteristics of the COVID-19 pandemic have created a context in which the current and future impacts are truly unpredictable.

CHAPTER 3: METHODOLOGY

3.1 Participants and Setting

This study utilized a purposive sample of parents who choose to participate in the survey, contacted via social media group or through community partner contacts. To collect a wide variety of and include diverse families, an invitation to participate by completing an anonymous survey was sent out to parents within a school district, parents on a social media support group, and formal parent groups targeted towards families of children with disabilities. No identifiable information was be collected to protect the identities of families who choose to participate in the study.

As part of the qualification and consent processes, all potential participants self-identified as parents or primary caregivers of children aged 3 to 5 who have been identified or diagnosed with developmental delay, Autism Spectrum Disorder, Down Syndrome, or other developmental or intellectual delay or disability. Additionally, inclusion in the study was dependent on the child's participation in special education, early intervention, and/or other therapy services related to an identified delay or disability. This survey used the Qualtrics® software system for all questions, with data collected and stored securely via the integrated Qualtrics® system. If a participant met inclusion criteria and consents to participate, they gained access to the survey.

This research targeted residents of a southeastern city and its suburbs, including some rural areas. One school district confirmed support of the researcher conducting the study (Appendix A,) and contact was made with 3 local parent organizations through social media platforms.

3.3 Instrument

The survey instrument included 24 researcher-designed questions in a variety of formats (Appendix C.) The researcher developed questions to explore perceptions of impacts on family functioning, specifically related to service delivery. The survey included three question types: multiple choice demographic information, Likert-scale questions regarding parental stress, and open-ended thematic questions. Demographic information collected includes: race-ethnicity, family type, child's disability identification/diagnosis, enrollment status in services, general socioeconomic status, employment status and childcare resource types. Open-ended questions focused attention on disability related service changes, social supports, and stress levels. Participants' names, emails, IP addresses, or other identifying information were not collected.

The researcher sought peer review (or pilot) of the survey instrument prior to formal research. The survey was disseminated to 15 early childhood special education teachers in the same area that research was be conducted over a two week period. These participants were asked to respond as if they were a parent in their classroom, and provide feedback to the researcher via a Google Form (Appendix E) regarding instrument clarity, ease of use, and any recommended adjustments. This feedback was reviewed by the researcher, and related changes were made to the survey as necessary.

3.4 Design

To most effectively explore the impacts of the current COVID-19 pandemic, an exploratory study design was implemented. The survey used the Qualtrics® software, with data stored on the integrated system. Descriptive summaries using frequencies and percentages were be completed for participants' demographics in Table 1. Survey was conducted using Qualtrics®, a secure online platform. The platform is password protected, and survey responses were only be accessible by research team via. password protected computer. The survey was completely anonymous; no IP addresses or other identifiable information was gathered from participants.

3.5 Data Analysis

Demographics for participants are included in final report, and detail family characteristics relevant to the study. Likert-scale questions were analyzed and reported using simple frequencies. The research team deemed this level of analysis sufficient to report data, as the low response rate did not warrant further analysis to establish significance. Using the themes developed during the coding process, the researcher and a peer reviewer coded each open-ended response according to category/code. The researcher used these separate analysis results to connect and discuss data across questions and responses; for example, the Likert-scale question regarding increased stress, multiple choice question detailing pandemic stressors, and open-ended responses related to the impact of these stressors are discussed together in the final report. All participants answered more than 50% of questions and their responses were included in study data.

An analysis using qualitative techniques to categorize open-ended responses was conducted by the researcher in an effort to inform the field about parent perceptions of changes in service delivery and their impact on family functioning and parental stress. This review included 6 steps, as informed by an approach to thematic analysis described by Fereday and Muir-Cochrane (2006): 1) review and familiarization of data, 2) generation of initial codes, 3) searching for themes within data 4) reviewing themes 5) defining and naming categories, and 6) production of a final report on response themes. Because this is an exploratory study, codes were not be generated prior to survey dissemination. During the generation of initial codes step, the researcher made the decision to generate codes on an individual question level, rather than broader categories as informed by participant responses. Once data had been reviewed and initial codes generated, a peer reviewer assisted the researcher with coding responses. Given the limited data, the research team did not move on to the third step of the thematic analysis process. Thus, results are reported as broader coding categorization rather than themes across data. This reviewer reported level of agreement with the lead researcher's coding and categorization—there was no disagreement after clarification of responses during a brief discussion between researcher and peer reviewer. This conversation served as consensus coding, wherein discussion on definitions of each code were reached. This process served to aid in the credibility of the study results reporting.

Some responses contained data that warranted unique coding within the response; these responses were broken up by code before inclusion in Table 3. Responses were edited or shortened for clarity (ex. fixed a typo) to include portions relevant to the code and findings. Some responses or portions of narrative responses were not included in these tables due to relevance (ex. participant answered "I don't know) or did not address the question. These codes were developed by the researcher based on the content of question and responses. For example, the question detailing supports warranted a broad "support" category, and then coded for specific types of support detailed in responses.

3.6 Procedures

Recruitment: A letter of support (see Appendix A) was be emailed to community partners including school districts and local parent support groups to describe the study and reach participants. This letter included information about how they will support the study should they agree to assist in recruitment. Community partners assisted the researcher by providing access to email/listserv of potential participants, and researcher will send out 3 emails including survey link and information. This email (or post, if using social media forum) was be drafted using IRB guidelines, and sent/posted 3 separate times; initial email, reminder after one week, and final reminder two days before survey closed. In total, the survey remained open for 3 weeks. Inclusion criteria and consent information was included in the first page of survey questions (Appendix C); if participants did not meet inclusion criteria and/or consent, the survey did not advance.

Once the survey was closed, demographics will be generated using Qualtrics. Analysis and categorization of open-ended responses was conducted as described in data analysis section, with support from peer reviewer and research team.

3.6 Possible Limitations

Possible limitations to this study include limitations related to: instrument, timing, researcher bias, and generalization. Given the study design, there is also inherent limitation to survey data. Due to the anonymous nature of the survey, the researcher was not able to ask follow-up questions or clarify responses. Participant responses were dependent on the researcher’s question phrasing and participants’ motivation to provide thorough responses. Therefore, responses are dependent on participants understanding of questions and their ability to respond with clarity. Additionally, because the survey is being developed by the current researcher, the instrument itself has not been tested for validity or reliability. Because of the reflective and somewhat invasive nature of some survey questions, it may be stressful for participants to respond in this manner. This may lead to participants leaving some questions blank or withdrawing from the study. They will have this option on open-ended questions, or they may choose to navigate away from the page at any time without completing the survey.

As a novice researcher, there is potential for errors and/or bias in interpretation of data. This fact is mitigated in part by independent review of process coding, as well as supervision by the research committee comprised of faculty members with extensive research experience. An individual independent of the study was recruited to assist in consensus coding to mitigate the effects of researcher bias in interpretation. Both of these mitigating relationships will also work to address the inherent bias that the primary researcher enters the study with. As a current professional in the early childhood special education field, she holds her own views on the experiences of the families she has been serving during the pandemic. This close tie to the subject matter may also be beneficial in interpretation of responses, as new vocabulary (ex. asynchronous, "Seesaw") have become more widely used in the education field for both family members and professionals.

Timing is a very important component to this study. As research is being conducted, the COVID-19 pandemic will have been present in the U.S. for over a year. The crisis and public health responses are rapidly evolving, and responses may vary based on the current situation. However, questions will be worded in a way that emphasizes responses that encompass the entire disaster event beginning in March 2020.

Finally, this study may not be easily generalized across the entire population of young children and their families in the United States. The COVID-19 pandemic was managed by state-level policies related to social distancing, family resources, and school closures. Thus, the experiences of parents in this study (all respondents in one southeastern U.S. state) may be vastly different from a state that implemented different policies. However, participants include families of diverse demographics, allowing for application of some findings to a larger population.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 Introduction

The study gathered 6 responses that met the qualifications for analysis. The low response rate had impacts on the methods of data analysis and reporting, detailed in the presentation of results. Responses indicated that participants were diverse demographically and diverse in their experiences during the pandemic. Participants answered the majority of demographic questions (all of which had a "prefer not to respond" option,) and the majority of Likert-scale questions. About 50% of participants provided responses to the five open-ended questions. Relationships and correlations between data were found and reported by researcher during analysis and discussion, based on question type and responses.

Table 1
Participant Demographics

Characteristic	Response	Frequency, *n* (%)
Relationship to the child	Parent	6 (100%)
Child Age	3 years old 4 years old 5 years old	3 (50%) 2 (30%) 1 (17%)
Disability/Diagnosis	Autism Spectrum Disorder Developmental Delay Speech/Language Delay	3 (50%) 3 (50%) 4 (67%)
Race-Ethnicity	Black/African-American Caucasian/White Native American/Alaska Native Multi-Racial	1 (17%) 4 (67%) 1 (17%) 1 (17%)
Household Income Level	Less than $50,000 $50,000-$100,000 More than $100,000	3 (50%) 2 (33%) 1 (17%)
Participation in services pre-pandemic	ECSE (public) ABA Public Therapy Private Therapy	4 (67%) 1 (17%) 3 (50%) 3 (50%)
Marital Status	Married Single	5 (83%) 1 (17%)
Pre-pandemic Employment Status	Employed Full-time Unemployed (not looking for work) Prefer not to answer	4 (67%) 1 (17%) 1 (17%)

During-pandemic Employment Status	Indefinite Unemployment/Job Loss	1 (17%)
	Decrease in Employment	
	No Change	2 (33%)
		2 (33%)

n=6 for all responses
ECSE=Early Childhood Special Education program, usually within a school district
ABA= Applied Behavioral Analysis Therapy
Public/Private Therapy: Speech and Language Therapy, Occupational Therapy, or Physical Therapy offered either by a school district (public) or an outside agency (private.)

All participants indicated that they were the parent of an exceptional child, aged 3,4, or 5. The participants included parents of children with Autism Spectrum Disorder, Developmental Delay, and Speech/Language Delays. Participants reported diversity across race-ethnicity, family income, and pre-pandemic employment status.

Parents also completed questions detailing their social support network prior to the pandemic. When asked who makes up their social support networks, individuals included spouses/partners (3), friends (1), parents/child's grandparents (1), extended family (2), social networking/parent support groups (2), and professionals (1). Types of support reported by parents included general support, childcare, parenting support, emotional support, and physical support/household tasks. No participants indicated they received financial support before or during the pandemic from their social support network.

4.2 Pandemic Experiences

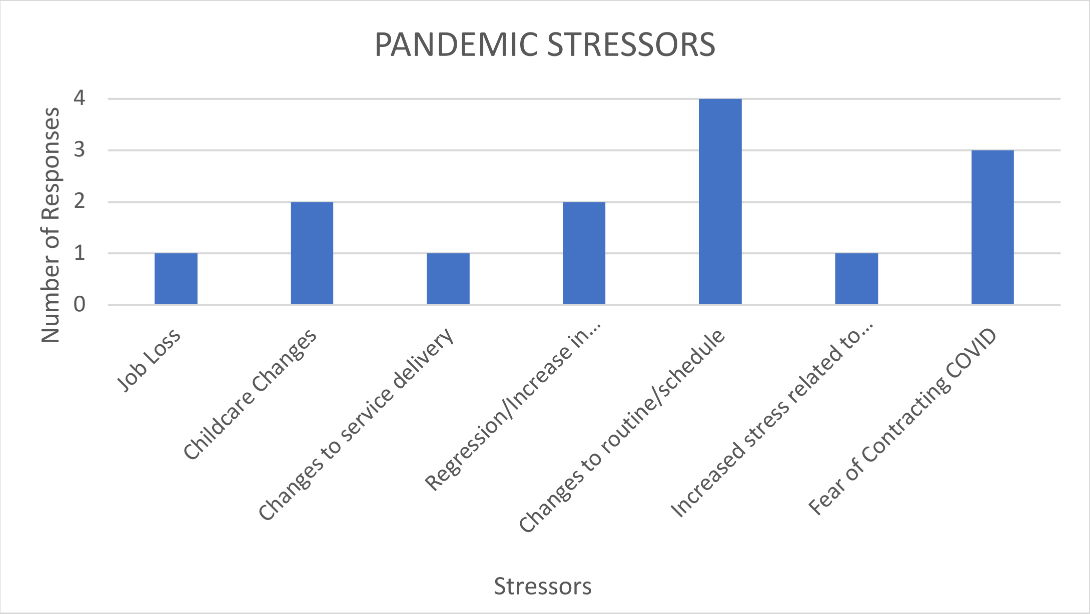
Following the demographic questions were questions related to families' experiences during the pandemic. When asked about childcare disruption, 67% of families reported that they experienced no disruption in childcare, with 33% reporting that they did experience a disruption in childcare related to closures of school and therapy service centers. When asked about disruption in disability-related services, 50% of parents reported a disruption in services (when school or therapy centers closed) and 50% parents did not report a disruption in services.

Similarly, data was split on reports of employment loss of any kind (3 participants) vs. no change in in employment (3 participants.)

When answering Likert-scale questions regarding pandemic experiences, participants reported mixed experiences across most responses. For questions referencing the following topics, responses were split evenly between agreement and disagreement: satisfaction with disability-related services, service sufficiency in continuing progress, and child regression in skills/behavior. Conversely, most parents responded similarly given questions detailing the following: receipt of adequate information/resources/support from professionals, and receipt of adequate social support from adults. All four participants (100%) that answered the question regarding increased stress levels responded that they “strongly agree” their stress levels increased during the pandemic. Finally, parents reported the factors that contributed to their increased levels of stress (Figure 1).

Figure 1

Pandemic Stressors



Because of the low response rates (n=6), the researcher was not able to group or compare responses across demographic groups as planned in study proposal. The quantitative data, however, indicates both diversity in family makeup of participants, as well as diversity in experiences across families surveyed.

The survey also included five optional, open-ended questions ; only 3 participants provided responses to these questions. The researcher reviewed these responses to gain familiarization with the data and generate initial codes through process coding as informed by Saldaña (2011.) Codes for questions can be found in Table 2.

Table 2

Codes by Question

Question	Codes
How did professionals, organizations, and systems provide support to your family during the pandemic?	Supports Codes: 1- Parenting Supports 2- Physical Resources 3- Services 4- Other
Do you feel there are ways that this support could be improved/modified to be more effective for your family?	Support Modifications Codes 1- More Services 2- Continuity of Care 3- Other
Why and how did the factors you identified impact your stress levels?	Stressors 1- Lack of Social Supports 2- Uncertainty 3- General/Other
How did your personal feelings of stress during the pandemic impact your interactions with your child(ren)?	Interactions 1- Positive impact 2- Negative impact 3- Other
How did your interactions with your social support network change during the pandemic?	Interactions 1- Positive impact 2- Negative impact 3- Other

4.3 ***Pandemic Supports***

Table 3

Pandemic Supports and Modifications

Supports			
Parenting Supports	Physical Resources	Services	Other
I was also able to learn so much about approaches that I may not have considered previously to help (after a transition to in-home and virtual therapy services)	They sent us workbooks and activities for the first three weeks… We were asked if we needed anything from pull ups to food.	We Zoomed twice a week for 15 minutes. We were able to obtain approval for ABA therapist to provide support during virtual schooling, which is impossible during in person teaching and during normal times.	At first we had no support provided by the school. It was the teachers who tried to help as much as they could with their own resources.

Supports Modifications		
More Services	Continuity of Care	Other
More frequent and longer Zoom times	This was all new to not only our family, but the local school system. When you have a child that thrives off of a consistent schedule there were some ups and downs as a result of school changes, ie schedule time changes and switching of teachers multiple times.	I hate to fault the school or teachers because they are trying to navigate this as much as we are…

Contradictory results were reported from participant's perceptions of supports families received during the pandemic. In Likert-scale responses, 50% of participants reported that they agree or strongly agree that they were "satisfied with the disability related services my child/family received during the pandemic." 83% agreed that they received enough information, resources, and support by professionals to support their child's progress towards disability related goals at home during the pandemic. With 83% of parents indicating that they received enough information, resources and support, but at least 33% of those not reporting satisfaction with the services, there is a contradiction. Because this was an anonymous survey, the researcher cannot clarify with participants on their thoughts or intentions between the two questions.

However, the narrative responses may provide insight. When asked how supports might be improved, one participant reported, “When you have a child that thrives off of a consistent schedule there were some ups and downs as a result of school changes, ie schedule time changes and switching of teachers multiple times.” In connection with the 83% of parents who received “enough” support from professionals, this response may indicate that it was the delivery of that support contributing to overall satisfaction. Another reason may be that the participants have alternate definitions of “services” that do not include “information, resources, and support” as providing direct services for their child. This theory is also supported by narrative responses in the data. When asked about how professionals provided support through the pandemic, participants listed a variety of categories: workbooks and activities, food and diapers, zoom meetings, in-home practitioners, and coaching/learning. Varied definitions of the terms “support” and “services” may have contributed to a disconnect between service satisfaction and resource satisfaction.

Table 4

Pandemic Experiences

Positive Impact	Negative Impact
Probably having my child at home, playing with him during breaks at work, and seeing his progress was likely the least stressful moments of my day. We came together and helped each other more.	If he was having a hard time any particular time it was hard to see him struggle, but we were mostly focused on how best to help him. My kids could tell I was stressed out and they could feel my energy was off. Definitely miss physically seeing my coworkers that are more so friends. Working from home we don't have any unscheduled social time like you do in the office. That is probably the largest change and the support missed the most. Those work friends were the ones I spoke to and vented to the most on work and personal issues. Things I may would have discussed with friends at work are mostly internalized and not outwardly voiced or addressed to other for comfort or advice.

	Personally the hardest part was I was managing how to handle a Grandmother placed in hospice and passing away in addition to my 1st biological grandchildren being born within a week of each other. Keeping safe while being involved with those events so close together was hard to manage and cope with on multiple levels.

4.4 Disability-related services

Another such disconnect in the responses can be tied to perceptions of disability related services. When asked if the services and supports that the child/family received during the pandemic were sufficient to help their child continue progress toward disability related goals, 67% of parents were in agreement on this statement. When in conjunction with the perception of adequate information, resources, and support by professionals to support child's progress towards disability related goals, it would seem as though the services offered through the pandemic were sufficient. However, 50% of parents also reported that they strongly agree that their child displayed regression in skills (academic and/or social/behavioral) during the pandemic. The reason for this disconnect may not be clearly confirmed by the current data. However, the researchers' hypothesis, given responses as a whole, rests on the efficacy of service delivery methods during the pandemic. In narrative responses, participants reported that "At first, we had no support provided by the school…it was the teacher who tried to help as much as they could with their own resources." Another reports, "I hate to fault the school or teachers because they are trying to navigate this as much as we are…" and a final participant indicated that they were sent "activities and workbooks for the first three weeks." With at least 50% of participants reporting that their child experienced regression (3 indicated strong agreement, 1 indicated somewhat disagreement), the aforementioned services and supports, while perceived to be enough in quantity, did not provide families with supports and services that were effective during this time.

4.5 Pandemic Stress and Social Interactions

As evidenced by the only question in the study that received 100% consensus among participants, parental stress increased during the COVID-19 pandemic. This result, coupled with responses detailing specific stressors and impacts on social interactions, is cause for concern and action among those who provided services for families of young exceptional children during this disaster. While 100% of responses indicate that participants agree or were neutral that they received adequate social and emotional support from other adults during the pandemic to help manage stress, the narrative responses indicate that increased stress did have negative impacts on parents. One participant noted that her children could "*sense my stress and feel my energy was off.*" Another participant noted that loss of access to her in-person support network while working from home was difficult.

> "Those work friends were the ones I spoke to and vented to the most on work and personal issues. Things I may would have discussed with friends at work are mostly internalized and not outwardly voiced or addressed to other for comfort or advice."

As expected given research on parental stress, social supports, and responses to disaster, the inability of parents to engage in their typical social networks had negative impacts on their stress levels.

CHAPTER 5: DISCUSSION

Although there was a low response rate among participants (we received only 6 responses total,) some overarching ideas can be surmised from this data. Diversity in family experiences and the impacts of these experiences indicates a variety of outcomes: increased stress levels, instability in schedules/routines, and development of parental self-efficacy. The data in this study cannot be used to describe the experience of all American families, but can be used in a larger societal discussion about how we can recover from this disaster. Results may also be used to highlight areas in which more research is necessary.

This study's results illustrated that each family's experience during the pandemic was markedly different. When asked about their pandemic experiences, participants responded half and half across 5 different questions. This demonstrates the need for practitioners to individualize supports and for leaders of organizations to recognize the diversity in access to supports and services during this time. However, one question received a unanimous response across participants: "My stress levels increased during the pandemic." This finding, although not unexpected, highlights a reality for everyone who has endured this ongoing trauma. As practitioners, schools, and systems begin to "return to normal," there is a need to address the mental health of the parents we interact with on a daily basis. From Oelofsen and Richardson's (2006) work, we know that 84% of mothers with preschool children with disabilities scored within the clinical range for parenting stress. Compounded by their reported increases in stress during the pandemic, there is an immediate need for these parents to receive increased access to social support and mental health services.

The work of Bonnano et. al (2010) and Kilburn and Shapiro (2020) highlight social supports for parents of young exceptional children as incredibly important in mitigating the effects of stress, especially in response to disaster. Data from the current study suggests that loss of access to in-person supports and the variety of stressors facing families resulted in negative outcomes, further demonstrating the need for intervention and support for parents.

Participants identified another theme across responses, the need for increased continuity of care. As one parent reported, “When you have a child that thrives off of a consistent schedule there were some ups and downs as a result of school changes, i.e. schedule time changes and switching of teachers multiple times.” This was echoed by response to the question detailing causes of increased stress during the pandemic; all participants identified “changes to family routine, activities and schedules” as a source of their increased parenting stress. While this unprecedented disaster was new to both practitioners and families, the instability in services and schedules became stressful for families. One parent noted that, “At first we had no support provided by the school. It was the teachers who tried to help as much as they could with their own resources.” While most narrative responses echoed this sentiment, it highlights a dark reality of the pandemic; systems, schools, and teachers did not have existing disaster preparedness plans in place.

Boon et al. (2011) found in a comprehensive review of literature that children with special needs and their families are neglected in disaster preparedness plans; their review identified zero studies in which they were specifically addressed in plans. This resulted in inconsistencies in services and supports, increased stress on families when accessing the service system, and a need to examine the services themselves. From the results of the current study, we cannot say conclusively what services and supports were effective for families. However, given that there are large inconsistencies between perception of “enough” supports and resources, and the inability of these supports in mitigating parental stress and child regression in skills, an inference about the efficacy of supports can be made. That is, simply, they were not effective in supporting families and children with special needs during the COVID-19 crisis.

While we know that the pandemic had negative impacts on families and young children across all strata of society, there were some positive opportunities that came as a result of the closures of many schools and other in-person services, One parent noted her opportunity to have outside services support her child at home during the school day with virtual lessons. While working remotely and having in-home ABA services, she reported “I was also able to learn so much about approaches that I may not have considered previously to help.” Others, with the support of their children’s teachers, developed increased self-efficacy in their parenting skills and tried out new evidence-based strategies modeled through video recordings or Zoom calls.. One parent explained, “After the initial change in schedule to being at home during therapy my child flourished in communication and we had a consistent schedule for potty training.” This time at home gave parents extended time to interact with their child, learn and implement new skills and strategies, and build skills at home.

Support for programs that build parent self-efficacy and education on interventions is widely available and positive across research. In a study examining a parent training program directed at supporting language development and positive behavior, Hancock, Kaiser and Delaney (2002) found growth across 6 distinct language categories for the children involved in the study. After the intervention was complete, all parents maintained learned skills well above baseline, continuing to support their children’s development. Of great importance to the current study, Hancock, Kaiser and Delaney also noted another important impact of parents’ engagement in the program; not only did they report success in the intervention, but subsequently were thankful for the “friend” that they had gained in the parent trainer. Their program, focused on parent education rather than providing direct services to children, proved effective in both child outcomes as well as providing social support for mothers. Another study by Lane et al. found that parents of children with Autism Spectrum Disorder were able to learn, implement, and retain naturalistic language strategies in only 3 hours (2016.) These studies, along with parent reports from the current study, indicate effective alternatives to the supports and services provided to families during the COVID-19 pandemic.

5.1 Recommendations for Practitioners and Researchers

As identified by participants of this study, there is a need for increased continuity of care and stability in scheduling for families of young children with special needs. Whenever possible, practitioners should keep regular schedules and avoid disrupting families' routines. Boon et al. (2011) asserts that it is the responsibility of schools to plan for and execute care before, during, and after public health emergencies. During the COVID-19 pandemic, schools and practitioners scrambled to create plans and activities that would meet the needs of children and families while they were not in school or attending regular in-person services. Many of these services and strategies were implemented on a trial and error method, with the expectation that teachers and professionals would "figure it out" and create, from the ground up, plans and schedules to meet the needs of the children in their care. This disaster demonstrated a desperate need for systems, schools, and practitioners to have plans and strategies in place to serve children with special needs, and be versed in skills they may not have learned in their pre-service programs.

Pre-service education for most professionals who work with young children with special needs is largely focused on classroom instruction, direct intervention/service delivery, and inclusion of parents during planning and progress-sharing. However, the results of this study highlight the need for professionals to be prepared for alternatives to these direct, in-person services. One such alternative is the use of parent coaching, training, or education programs or strategies. As reported by one parent in this study, during the pandemic their family engaged in two, 15-minute Zoom sessions with their teacher per week. In comparison to a full-day early childhood special education program, this child was receiving ½ hour of interventions vs. 30 hours in a typical week. While these programs have not been studied in relation to disaster like COVID-19, there is significant evidence to their efficacy both short and long term for parents and children. Parent-focused supports and services should be considered in development of future disaster plans, as well as in "returning to normal" planning. Providing parents access to the skills and strategies to support their children's development at home would only provide increased protection against the traumatic events of a disaster like COVID-19.

Further research is needed to identify more decisively both the impacts of the COVID-19 pandemic, and what plans should include in the future. This small study demonstrated the diversity in experiences of families, even within a small geographical area. As identified by researchers on disasters across disciplines, these impacts will span across all strata of society and studies should include individuals, communities, and society at large in an effort to inform recovery efforts now, and prevention efforts in the future (Hoffman and Kruczek, 2011.) Far larger studies are necessary to determine the magnitude of impacts identified in the current study, as well as to address issues not investigated in this research. It is also recommended that future research includes interviews or the ability for follow-up clarification. Some of the "mixed" results in the study might be attributed to the varying definitions used and understood by researchers, practitioners, and parents. A comprehensive study including a large sample size and the ability for further clarification or discussion is necessary to inform intervention and preparation efforts.

Investigation of service delivery methods for families of young children should be conducted to identify effective methods and strategies, specifically those that can be included in disaster preparedness planning. Similarly, widespread studies should be conducted, and services provided, to address the increase in parental stress during this crisis, as well as what practitioners can do to mitigate parental stress of families of young exceptional children. The low response rate of this study also made it impossible for the researcher to examine demographic trends correlated with pandemic experiences; a larger study may be able to discern whether or not there were disproportionate impacts for families based on predisaster contexts and inform allocation of recovery and prevention efforts.

5.2 Conclusion

The study of the impact of the COVID-19 pandemic will be the focus of academic researchers for years to come. This study, while small, did investigate the impacts on some families at the microsystem and mesosystem levels, and included themes and ideas from all system levels that had impacts on families. In response to the study's questions, a few answers were found. First, parents of young exceptional did experience increases in stress during the pandemic; this study also detailed the stressors of some families during the pandemic, although experiences across families were significantly varied. Second, service delivery was negatively impacted for families of young exceptional children, specifically because of the instability of these services. Finally, while families reported satisfaction with services and not wanting to "blame" teachers, the services were not effective to meet the needs of families and their instability contributed to increased parental stress.

Using Bronfenbrenner's Systems Theory, this study demonstrated the impact of various system levels on the microsystems of families and young exceptional children. While further study is necessary to make conclusions about communities and society as a whole, this study pointed to a few recommendations that might promote recovery and future planning for supporting families in times of disaster.

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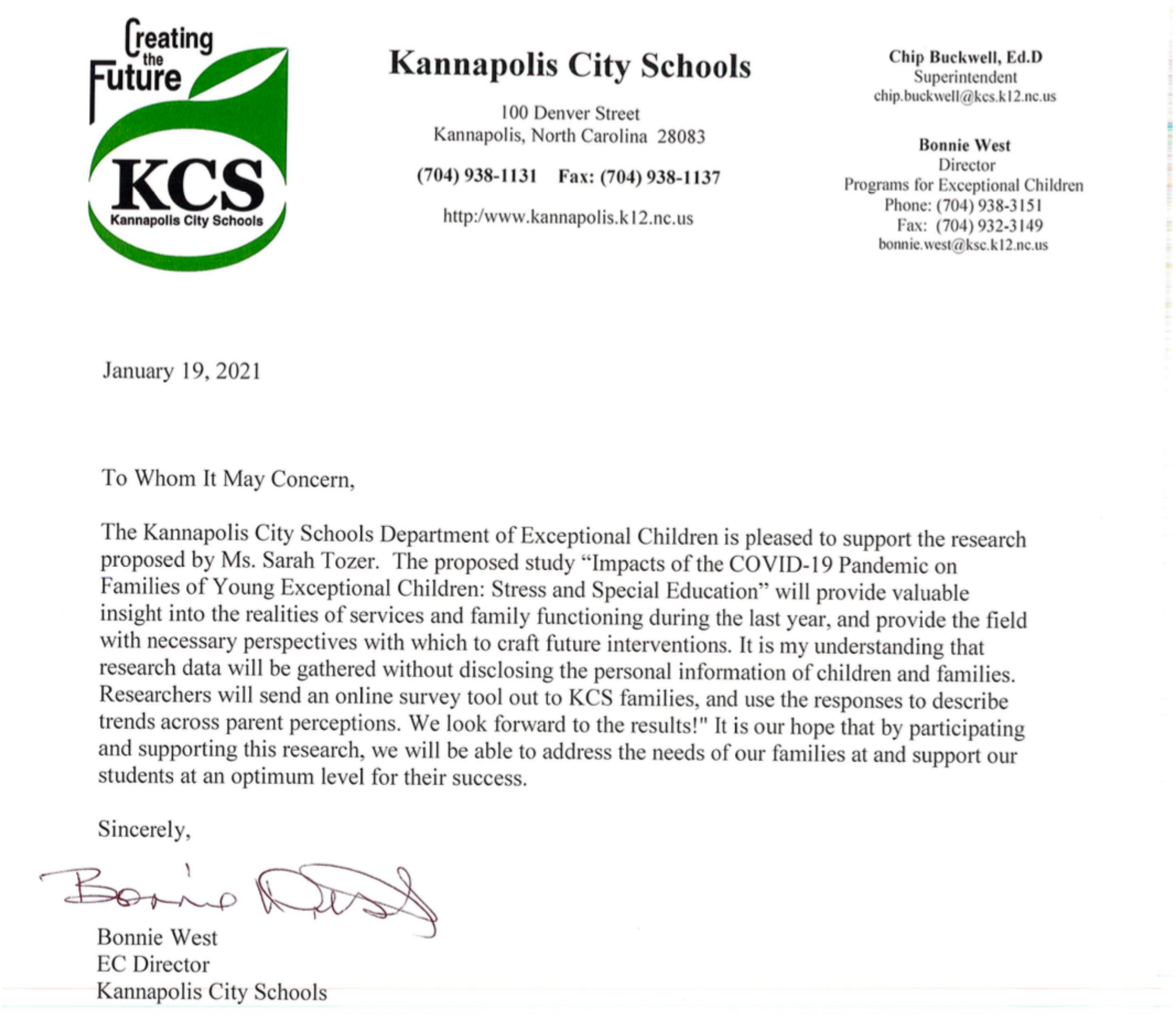
APPENDIX A: LETTER OF SUPPORT



Creating the Future
KCS
Kannapolis City Schools

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Chip Buckwell, Ed.D
Superintendent
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Director
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Phone: (704) 938-3151
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bonnie.west@ksc.k12.nc.us

January 19, 2021

To Whom It May Concern,

The Kannapolis City Schools Department of Exceptional Children is pleased to support the research proposed by Ms. Sarah Tozer. The proposed study "Impacts of the COVID-19 Pandemic on Families of Young Exceptional Children: Stress and Special Education" will provide valuable insight into the realities of services and family functioning during the last year, and provide the field with necessary perspectives with which to craft future interventions. It is my understanding that research data will be gathered without disclosing the personal information of children and families. Researchers will send an online survey tool out to KCS families, and use the responses to describe trends across parent perceptions. We look forward to the results!" It is our hope that by participating and supporting this research, we will be able to address the needs of our families at and support our students at an optimum level for their success.

Sincerely,

Bonnie West
EC Director
Kannapolis City Schools

APPENDIX B: QUESTIONNAIRE

Q1 *Dear Participant, The purpose of this study is to examine the impacts of the COVID-19 pandemic on families that include a young exceptional child (i.e. a child with special needs.) The information gathered in this research study may help to improve the supports and services available to families during the pandemic. Your perspective is extremely important to further understanding of practitioners in the fields of Early Intervention and Early Childhood Education, as well as other professionals you interact with to support your child. Your participation in this research is completely anonymous; researchers will have no way to connect responses to participants and will not be collecting identifying information. The survey should take about 15-20 minutes to complete. By answering the following questions, you are certifying that you meet the inclusion criteria below and providing consent for your answers to be included in the final report. Thank you in advance for your valuable contribution to this research! To participate in this research, you must be: · 18 years old · English speaking · A parent or primary caregiver of a 3-5 year old child with an identified delay or disability, who was or currently is enrolled in special education or therapy services related to delay or disability*

○ I consent (1)

○ I do not consent (2)

Skip To: End of Survey If Dear Participant, The purpose of this study is to examine the impacts of the COVID-19 pandemic... = I do not consent

Page Break

Q2 What is your relationship to the exceptional child?

○ Parent (1)

○ Other primary caregiver (describe) (2) ____

Q3 How old was the child as of July 2020?

○ 3 years old (1)

○ 4 years old (2)

○ 5 years old (3)

Q4 What disability or delay has your child been identified with? (select all that apply)

☐ Autism Spectrum Disorder (1)

☐ Developmental Delay (2)

☐ Down Syndrome (3)

☐ Oppositional Defiant Disorder (4)

☐ Speech or Language Delay (5)

☐ Other (describe) (6) ____

Q5 Please select your race-ethnicity (select all that apply)

- ☐ Asian/Pacific Islander (1)
- ☐ Black/African American (2)
- ☐ Caucasian (3)
- ☐ Hispanic (4)
- ☐ Native American/Alaska Native (5)
- ☐ Other/Multi-Racial (6)
- ☐ Prefer not to answer (7)

Q6 What is your marital status?

- ○ Single (1)
- ○ Married (2)
- ○ Widowed (3)
- ○ Divorced (4)
- ○ Cohabitation and Co-parenting, Unmarried (5)
- ○ Prefer not to answer (6)

Q7 What is your household income level?

○ Less than $50,000 (1)

○ $50,000-$100,000 (2)

○ More than $100,000 (3)

Q8 Please select your employment status before the pandemic began (December 2019)

○ Employed full time (1)

○ Employed part time (2)

○ Unemployed looking for work (3)

○ Unemployed not looking for work (4)

○ Retired (5)

○ Student (6)

○ Disabled (7)

○ Prefer not to answer (8)

Q9 Did you or your partner experience a disruption in employment during the pandemic?

○ Yes, one or both of us experienced indefinite unemployment (terminated, quit, or other.) (1)

○ Yes, one or both of us experienced a decrease in employment (decreased hours, temporary furlough, impact to personal business income.) (2)

○ No (3)

Q10 Did your child/family experience a disruption in childcare?

○ No (1)

○ Yes (describe) (2) ____

Q11 Before the pandemic, which disability related services did your child/family participate in? (select all that apply)

☐ Early Childhood Special Education (Public Preschool/Pre-Kindergarten) (1)

☐ Applied Behavioral Analysis Therapy (ABA) (2)

☐ Public therapy services through school system (Speech and Language Therapy, Occupational Therapy, Physical Therapy) (3)

☐ Private therapy services (Speech and Language Therapy, Occupational Therapy, Physical Therapy) (4)

☐ Home visiting program (5)

☐ Other (describe) (6) ____

☐

Q12 Did your child/family experience a disruption in disability related services at any time during the pandemic?

○ No (1)

○ Yes (describe) (2) ____

- -

Q13
Please select your level of agreement with the following statement:

I was satisfied with the disability related services my child/family received during the pandemic:

○ Strongly agree (1)

○ Somewhat agree (2)

○ Neither agree nor disagree (3)

○ Somewhat disagree (4)

○ Strongly disagree (5)

Q14
Please select your level of agreement with the following statement:

The services and supports that my child/family received during the pandemic were sufficient to continue progress toward disability related goals.

○ Strongly agree (1)

○ Somewhat agree (2)

○ Neither agree nor disagree (3)

○ Somewhat disagree (4)

○ Strongly disagree (5)

Q15
Please select your level of agreement with the following statement:

My child displayed regression in skills (academic and/or social/behavioral) during the pandemic.

- ○ Strongly agree (1)
- ○ Somewhat agree (2)
- ○ Neither agree nor disagree (3)
- ○ Somewhat disagree (4)
- ○ Strongly disagree (5)

Q16
Please select your level of agreement with the following statement:

I was given an adequate amount of information, resources and support by professionals to support my child's progress towards disability related goals at home during the pandemic.

- ○ Strongly agree (1)
- ○ Somewhat agree (2)
- ○ Neither agree nor disagree (3)
- ○ Somewhat disagree (4)
- ○ Strongly disagree (5)

Q17 How did professionals, organizations, and systems provide support to your family during the pandemic?

Q26 Do you feel there are ways that this support could be improved/modified to be more effective for your family?

Q18
Please select your level of agreement with the following statement:

My stress levels increased during the pandemic.

○ Strongly agree (1)

○ Somewhat agree (2)

○ Neither agree nor disagree (3)

○ Somewhat disagree (4)

○ Strongly disagree (5)

Q20 During the pandemic, my increased stress level can be attributed to (check all that apply):

☐ Loss of job/income (1)

☐ Childcare changes (2)

☐ Disability related service delivery changes (3)

☐ Child's regression in skills or increase in challenging behaviors (4)

☐ Changes to family routine, activities, and schedule (5)

☐ Fear of contracting COVID-19 (6)

☐ Other (describe (7) ____

☐ Not applicable—my stress did not increase (8)

Q21 Why and how did the factors you identified impact your stress levels?

Q25 How did your personal feelings of stress during the pandemic impact your interactions with your child(ren)?

Q19
Please select your level of agreement with the following statement:

I received adequate social and emotional support from other adults during the pandemic to help me manage my stress.

- ○ Strongly agree (1)
- ○ Somewhat agree (2)
- ○ Neither agree nor disagree (3)
- ○ Somewhat disagree (4)
- ○ Strongly disagree (5)

Q22 Who makes up your social support network? (check all that apply)

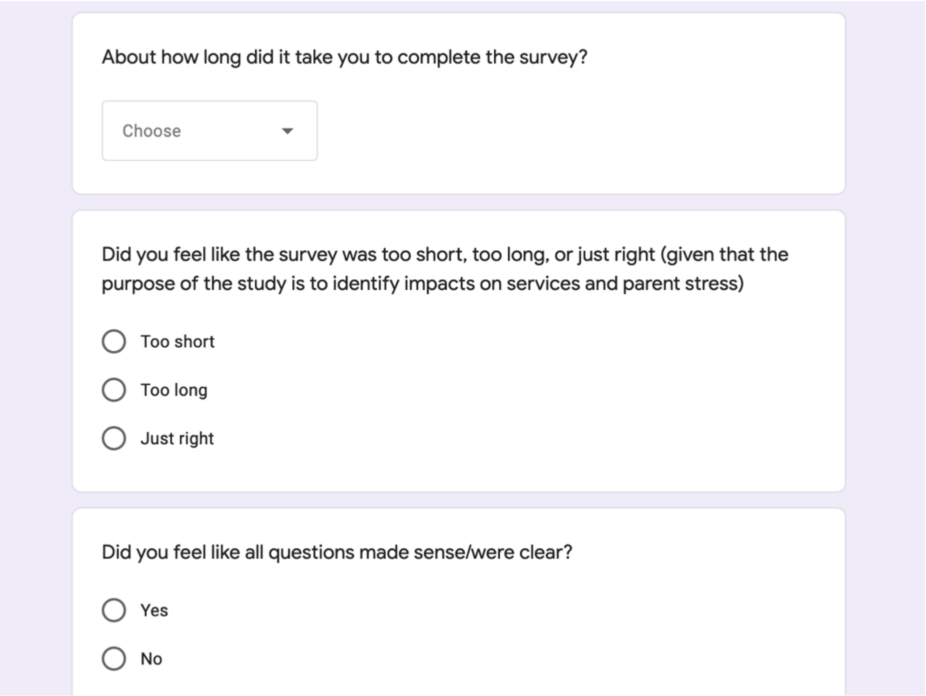
- ☐ Spouse/partner (1)
- ☐ Friends (2)
- ☐ Parents (child’s grandparents) (3)
- ☐ Extended family (4)
- ☐ Social Networking (ex. parent support groups) (5)
- ☐ Professionals (home visitor, child’s service providers, healthcare professionals, etc.) (6)
- ☐ Other (describe) (7)

Q23 What kinds of supports does your network typically provide?

- ☐ General social engagement (1)
- ☐ Childcare (2)
- ☐ Parenting support (ex. advice, childrearing discussions) (3)
- ☐ Emotional support (4)
- ☐ Financial support (5)
- ☐ Physical support (ex. support with household tasks) (6)

Q24 How did your interactions with your social support network change during the pandemic? ____________________

APPENDIX C: PILOT FEEDBACK FORM



About how long did it take you to complete the survey?

Did you feel like the survey was too short, too long, or just right (given that the purpose of the study is to identify impacts on services and parent stress)

○ Too short

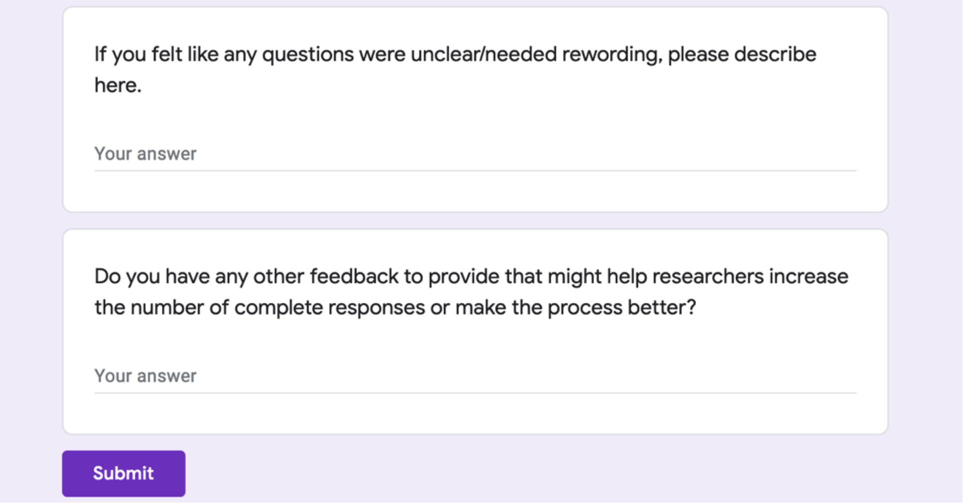
○ Too long

○ Just right

Did you feel like all questions made sense/were clear?

○ Yes

○ No



If you felt like any questions were unclear/needed rewording, please describe here.

Your answer

Do you have any other feedback to provide that might help researchers increase the number of complete responses or make the process better?

Your answer

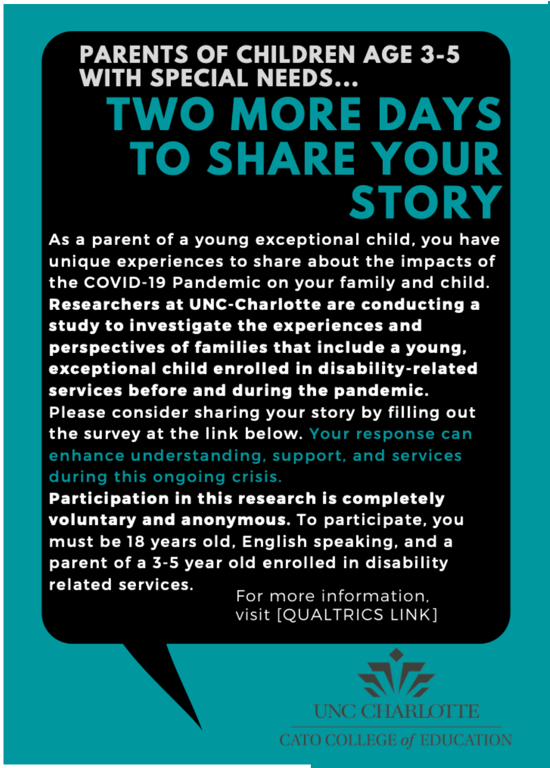
APPENDIX D: LETTER TO COMMUNITY PARTNERS

Dear____________,

My name is Sarah Tozer and I am currently a candidate for the M.Ed. in Special Education and Child Development at the University of North Carolina at Charlotte. I am writing to ask your support for a study I am conducting under the supervision of Dr. Ann Mickelson, Dr. Sloan Storie, and Ms. Pamela McIntyre. This study will examine the impact of the COVID-19 pandemic on families of young exceptional children, with a focus on parental stress and changes to service delivery for preschool aged children. The information gathered in this study will help to inform the field of Early Intervention and Early Childhood Special Education by providing practitioners with family perspectives during the pandemic, hopefully enhancing understanding, support and services for families. Under the supervision of the University and the Institutional Review Board, all data will remain anonymous including the agency supporting the study. If you agree to support this study, you will receive an email with an invitation and link to the online survey through Qualtrics, a secure survey and data analysis software provided through UNCC. Then, you would share this invitation through email, social media post, or a combination of these; two reminders spaced over 2 weeks would be sent as well. Once participants open the survey, they will be asked inclusion criteria questions including: their age, child's age, child's disability/diagnosis, and level of participation in services to support their child. No identifying information (ex. name, county, school district) will be collected or included in the study. Participation in the survey is completely voluntary, and should take participants about 15-20 minutes to complete. Some questions are multiple choice/scale questions, and others are short answer. Hopefully, participation in this survey will provide families with an opportunity to voice their experiences; their participation in this research is extremely important during the ongoing crisis. Thank you for your consideration in supporting this work! Please feel free to reach out to me or other members of the research team with any questions.

Graciously,
Sarah Tozer
stozer@uncc.edu
847-312-7618

APPENDIX E: RECRUITMENT MATERIALS



PARENTS OF CHILDREN AGE 3-5 WITH SPECIAL NEEDS...

TWO MORE DAYS TO SHARE YOUR STORY

As a parent of a young exceptional child, you have unique experiences to share about the impacts of the COVID-19 Pandemic on your family and child. **Researchers at UNC-Charlotte are conducting a study to investigate the experiences and perspectives of families that include a young, exceptional child enrolled in disability-related services before and during the pandemic.** Please consider sharing your story by filling out the survey at the link below. Your response can enhance understanding, support, and services during this ongoing crisis.

Participation in this research is completely voluntary and anonymous. To participate, you must be 18 years old, English speaking, and a parent of a 3-5 year old enrolled in disability related services.

For more information,
visit [QUALTRICS LINK]

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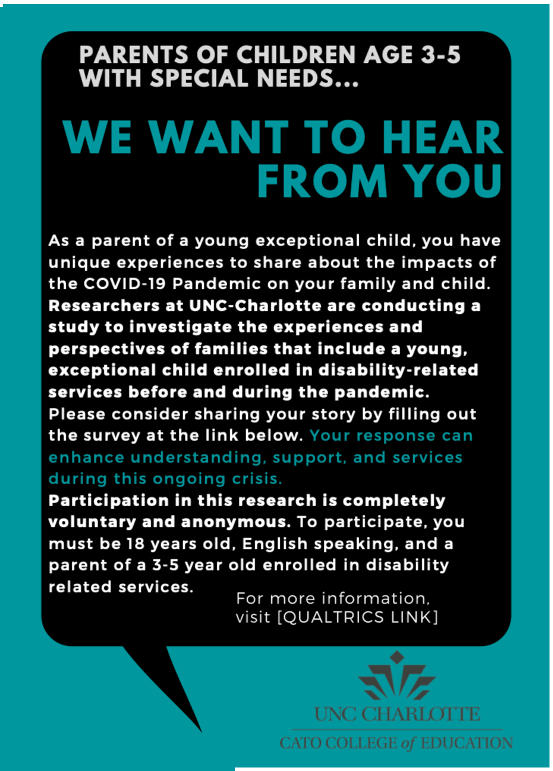

PARENTS OF CHILDREN AGE 3-5 WITH SPECIAL NEEDS...

WE WANT TO HEAR FROM YOU

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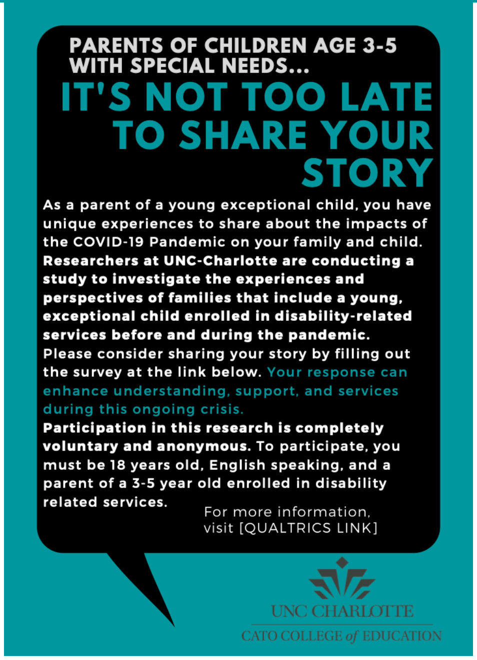

PARENTS OF CHILDREN AGE 3-5 WITH SPECIAL NEEDS...

IT'S NOT TOO LATE TO SHARE YOUR STORY

As a parent of a young exceptional child, you have unique experiences to share about the impacts of the COVID-19 Pandemic on your family and child. **Researchers at UNC-Charlotte are conducting a study to investigate the experiences and perspectives of families that include a young, exceptional child enrolled in disability-related services before and during the pandemic.** Please consider sharing your story by filling out the survey at the link below. Your response can enhance understanding, support, and services during this ongoing crisis.

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