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Kristi Cheyney-Collante
University of Florida, cheyneyk@ufl.edu

Lindsey Chapman
Boston University, Wheelock College of Education & Human Development, lchapman@bu.edu

Shaunté Duggins
University of Florida, Lastinger Center for Learning, shaunte@coe.ufl.edu

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Abstract

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Keywords

school closures, students with disabilities, mothers, narrative inquiry

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“We’re Not Walking Schools”: Storying the Pandemic Schooling Experiences of Mothers of Children with Disabilities

Kristi Cheyney-Collante¹, Lindsey A. Chapman², and Shaunté Duggins³

¹School of Special Education, School Psychology, and Early Childhood Studies,
University of Florida

²Boston University, Wheelock College of Education & Human Development

³Lastinger Center, University of Florida

This article describes a study designed to better understand the fallout of extended school closures and staggered re-openings for one group heavily impacted by the pandemic, mothers of children with disabilities. Using feminist ways of knowing as the backdrop, we explored how a small group of mothers experienced pandemic-related educational shifts. We aimed to provide solidarity and a space of care. We employed narrative methods to support the storying of their individual and collective experiences. Data were synthesized vis-à-vis participants’ ethic of care, particularly in relationship to the power structures they traversed. Taking a deep dive into the experiences of a small group of mothers allowed us to contribute to the field’s understanding of mothers’ multiple identities and underscores the importance of including them in discussions around educational supports for children with disabilities, particularly in times of crisis.

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Introduction

In March 2020, the World Health Organization declared the novel coronavirus, COVID-19, a worldwide pandemic. Preventive measures to combat the spread of the virus in the U.S. included statewide shutdowns of school buildings. A noted challenge of COVID-19 school closures and the subsequent shift to remote learning was the provision of special education services for 14% of school-aged children with disabilities in U.S. public schools (Nadworny & Kamenetz, 2020). While some special education services could be provided virtually, more intensive, one-on-one support for students with significant educational or behavioral needs were much more challenging (or impossible) to deliver remotely (Nadworny & Kamenetz, 2020). In such instances, the provision of educational continuity became a primary responsibility of students’ families.

The COVID-19 pandemic provides critical context for understanding the experiences of mothers of children with disabilities in unprecedented times. Mothers in the U.S. engage more often and more intensely with their disabled children’s schooling than other family members (Landsman, 2009; Valle, 2009). Not surprisingly, mothers were uniquely and disproportionately impacted by the global pandemic, with higher rates of emotional distress and significant disparities in the distribution of childcare responsibilities, even in two-parent homes (Miller, 2020). Likewise, nearly 80% of mothers reported managing most of their child’s remote learning needs (Gewertz, 2020). Many mothers faced disproportionately increased childcare and family support responsibilities during the pandemic and described the fallout as draining and overwhelming (Collins et al., 2020; O’Reilly, 2020). O’Reilly (2020)

labeled their experiences as "unfunctionable" (p. 7). However, the pandemic did not affect all groups equally. Families experiencing poverty and single-mother households felt the economic effects disproportionately (Miller, 2020). Black, Latinx, and indigenous groups carried a heavier burden in the economic downturn, while simultaneously shouldering higher rates of severe COVID-19 infection, hospitalization, and death (Tai et al., 2020).

In this article we describe a study designed to better understand the fallout of extended school closures and staggered re-openings for one group heavily impacted by the pandemic, mothers of children with disabilities. Using feminist ways of knowing (Cook & Fonow, 1986) as the backdrop, we endeavored to explore how a small group of mothers experienced pandemic-related educational shifts. We aimed not to produce broadly generalizable imperatives, but to provide solidarity and what Averett (2021) termed a "space of care" (p. 7) for our participants. We employed qualitative narrative inquiry methods (Clandinin, 2022) to support the storying of their individual and in some ways, collective experiences. Narrative inquiry, which starts and concludes with a sincere regard for the experiences of everyday life, allowed us to focus our attention on participants' living, telling, retelling, and reliving of their stories (Connelly & Clandinin, 1990). Our findings also contribute to the broader understanding of the current and lingering impact of COVID-19-related school building closures for children with disabilities, as well as the unique location of mothers within these challenging times. The research questions we addressed were: What are the lived stories of mothers of children with disabilities navigating COVID-19 school closures? How did they make meaning of their experiences through staggered re-openings?

At the outset, we would like to include a note on terminology. While person-first language is a commonly accepted practice in some forums for scholarly writing, identity-first language has become the preference of most disability advocacy groups in the U.S. (Dunn & Andrews, 2015). Identity-first language stems from the idea that disability is not deviant but rather a part of one's identity and culture. Though this landscape is sometimes contested, in this article, we chose to adopt the judicious use of both, paying close attention to inherent power differentials. While we use the commonly accepted "children with disabilities" to describe our sampling procedures, we simultaneously use "autistic" (instead of "child with autism") to reflect expressed preferences among members of the autistic community (Kenny et al., 2016). We have maintained the language used by participants within direct quotes.

Mothers of Children with Disabilities Before/During/[After] COVID-19

One of the lasting consequences of COVID-19 and the resulting nexus of global health crises is a division of life before, during, and after the pandemic ("after," referring to the nebulous space post-vaccine availability in the U.S. that was marred by divisions over mask-mandates, quarantine protocols, and the continued death toll). Though we are still learning about family experiences during the pandemic, decades of research into the experiences of mothers of children with disabilities already exists. However, this literature lives in a space of hotly contested philosophical foundations and varying frameworks. The medical model of disability has shaped traditional discourses of mothering children with disabilities, where researchers focus on burdens, stressors, and deficit-oriented depictions of disabled individuals (e.g., Thomas, 2007). However, Green (2007) cautions against an overly simplistic view that positions mothers as, "victims of individual tragic circumstances...mired in emotional distress" (p. 161). Ryan and Runswick-Cole (2008) echo this call for movement beyond "static positions and stereotypical representations and understandings of both disabled children and other family members" (p. 200).

Some scholars have attempted to shift conversations away from mothers of children with disabilities as saints/martyrs—or conversely, as overprotectors—to an active interrogation

of systems that have failed to adequately support disabled individuals, and that have thus transferred the burden on families, and often to mothers. Traditionally, mothers of children with disabilities live in what Ryan and Runswick-Cole (2008) call a “position of liminality” (p. 199). Though often not disabled themselves, they lead lives inextricably interwoven with disability. In recent years, Runswick-Cole and Ryan (2019) have further shifted their perspective towards a focus on what they term “unmothering” (p. 10), a turn away from mothers as lone rangers in advocating for their children, towards community responsibility as a response to social injustice experienced by disabled individuals. This shift towards a philosophy of unmothering simultaneously upholds the intrinsic value of motherhood while interrogating the idea that mothers should shoulder the primary responsibility for raising children.

The complexity of how parents—and mothers in particular—negotiate their child’s care and education often leads to misinterpretations of their actions, where mothers of children with disabilities are painted with binary strokes, as either oppressors or allies. This portrayal discounts the discrimination and mother-blaming they often face indirectly (Courcy & des Rivieres, 2017; Ryan, 2005). These reductive portrayals of mothers and the misanalyses of their choices can be challenged when researchers deeply explore the perspectives of mothers as well as their meaning making at decision junctures. This corrective perspective (see also McKeever & Miller, 2004) exposes failings of systems rather than deficits of children or shortcomings of mothers and recognizes the intersectionality of other factors such as race and economic and social factors (Bower & Hayes, 1998).

Theoretical Foundations and Researcher Positionality

Understanding limitations in the current literature undergirding our study, we drew from ecological systems theory (Bronfenbrenner, 1979) as a theoretical foundation. This decision stemmed from our desire to resist traditional approaches to studying mothers of children with disabilities that have constrained or misunderstood their experiences and represented them one-dimensionally. According to Bronfenbrenner’s (1979) ecological framework, the experiences of children are situated within micro-level factors (such as parental relationships), meso-level factors (including parent-teacher relationships), exo-level factors (such as the influence of a parent’s occupation on a child’s home life), and macro-level factors (encompassing educational and healthcare structures). When both children with disabilities and their mothers are framed within the larger socio-political structures that encapsulate their experiences and constrain their choices, a more faithful narrative of their stories can unfold. We endeavored to situate our findings within this nested approach, recognizing not only that the disabled child exists within these systems (Coomer, 2019) but that mothers do as well (Runswick-Cole & Ryan, 2019).

As a research team, we acknowledge both insider and outsider statuses in relationship to our participants (Dwyer & Buckle, 2009). We all identify as cisgender women, all mothers of our own school-age children (some with disabilities) navigating the system of schooling in times of crisis. We all hold Ph.D.’s in special education and are employed in academia. Cheyney-Collante identifies as white and is married with a blended family of seven children. She connects with this research not only as a teacher, but also as a mother of children with diverse identities (mixed-race, queer, disabled, neuro-divergent). Chapman also identifies as white. She has both personal and professional connections to this line of research as a teacher educator who prepares preservice teachers to collaborate with diverse families and perhaps more importantly, as a mother to an autistic teen. Duggins is a person of color and a literacy researcher. Her interest in contextual factors that impact education is directly related to her

experiences as both a parent and former elementary classroom teacher of racially, culturally, linguistically, and ability diverse students.

We see our identities as realities to be addressed through our commitment to reflexivity built into our methods (Dwyer & Buckle, 2009). We were guided in our inquiry by a perspective of feminist mothering (O'Reilly, 2014) and a commitment to both hear and privilege diverse voices (hooks, 1984). For us this meant acknowledging our individual privileges and the danger of "othering" participants and situating ourselves as benevolent academics speaking on their behalf (Spivak, 1999). As Dwyer and Buckle argue, "engaging in research from a feminist perspective also means not intentionally drawing boundaries between those doing the research and those being researched, although each person has a different relationship to the work being done" (p. 59). To this end, we employed participant-driven qualitative methodology (Koro-Ljungberg et al., 2015) and integrated narrative data collection and analysis procedures (Gilligan et al., 2003) with peer debriefing and member checking (Lincoln & Guba, 1985) to reduce power differentials and to center participants voices above our interpretations. A further exploration of our methods will be addressed in the next section.

Methods

The aim of this research was to gain a deeper insight into the repercussions of prolonged school closures and phased reopenings, specifically for a group significantly affected by the pandemic – mothers of children with disabilities. We utilized qualitative narrative inquiry methods (Clandinin, 2022) to facilitate the narration of their individual and shared experiences.

Participants and Sampling

Following approval from our Institutional Review Board, we used purposeful sampling (Gentles et al., 2015) to identify our participants, all mothers (and/or custodial grandmothers, aunts, and other guardians) of school-aged children with disabilities (Pre-Kindergarten to 12th grade) who were impacted by school building closures due to the COVID-19 pandemic. We defined "mother" as a person who identified as a woman with custodial care of a minor child, and "child with a disability" as a minor, birth to age 18, with a documented disability (developmental, intellectual, psychological, and/or physical). Secondly, children within these families were given the opportunity to participate, under parents' discretion. Child participation was not a condition of adult participation.

We recruited participants through social media. Those interested were asked to complete a brief demographics survey to determine eligibility. Of the pool of eligible participants, we selected participants to reflect the highest degree of diversity in terms of ethnicity, profession, geographical region, and disability category. Participants are identified by pseudonyms of their choosing throughout this article. Sheri and Dan, children of Sally, participated in all the interviews. The other mothers came to the interviews alone. To protect their privacy surrounding these decisions, we did not ask for explanations. Even though child participation ended up uneven across our sample, we chose not to exclude Sheri and Dan's contribution to Sally's interviews, but rather treated the content and context of her transcripts holistically throughout analysis. Our final sample is described in Table 1. It is important to note that we did not require participants to disclose their race/ethnicity, marital status, or other features of social identity beyond their roles as mothers of children with disabilities, either in the recruitment phase or during interviews. Instead, we allowed participants to share the information they felt was relevant to their experience as an organic outcome of our conversations. The purpose was not to exclude this information but to ensure that participants'

perceptions of relevant details could be foregrounded. Some participants shared these details, and others did not.

Table 1
Demographic Information for Study Participants

| Mother | Profession | Child(ren) with Disabilities | Disabilit(ies) |
|--------|--|---|---|
| Sally | Stay at home mom. Previously employed in higher education | *Sheri, 6 years old *Dan, 10 years old | Hypermobility disorder and chronic fatigue Autism, Hyperlexia, Motor dyspraxia |
| Amelia | Works in housekeeping at a nursing home | Jada, 14 years old | Autism, Language Impairment, previously diagnosed with Catatonia and Psychosis |
| Kim | Political Campaign Organizer | William, 12 years old | Autism, Intellectual Disability |
| Janine | Stay at home mom. Previously employed as a lawyer | Ana, 7 years old | Alagille syndrome, Hypertonia and Attention Deficit/Hyperactivity Disorder |
| Amira | Teacher | John, 14 years old | Autoimmune brain condition, Autism, Intellectual Disability |

Note. This table outlines demographic profiles as participants described. *Sheri and Dan participated in Sally's interviews.

Data and Data Collection

We collected three types of data: transcripts from individual virtual interviews; transcripts from child (with mother present) virtual interviews; and publicly accessible information about the schools and districts serving our participants. Each individual participant was asked to provide a minimum of two interviews (initial and follow up). Each interview lasted approximately one hour. The time span between the initial and follow-up interviews varied, ranging from six to twelve months, depending on the participants' availability. Sally completed an additional interview at her request because she had more to share. The semi-structured interview protocol used in the first round of interviews was designed to both establish rapport and elicit targeted information. After initial formative analysis of the first round of transcripts, the research team met to develop follow-up prompts for the next round. These prompts were focused on clarifying critical events and the plot of their emerging narratives. Though we used our semi-structured prompts as a guide, we aimed for a conversational experience.

We used video conference recordings to transcribe our discussions verbatim. Data collection, which extended over a year, ran concurrently with data analysis. We discontinued interviews once the analysis reached the stage of saturation, or the point at which the addition of new data would no longer contribute to findings (Lincoln & Guba, 1985). Though interview transcripts served as our primary data source, we also curated a file of publicly accessible data related to the schools, districts, and agencies our participants referenced in their interviews. This secondary data was used to add depth to our understanding of the transcripts.

Data Analysis and Reporting

During the formal data analysis phase, we analyzed transcripts using Gilligan et al. (2003) listening guide procedures, which included four steps or “listening” (i.e., complete readings of the transcripts, each with a unique goal). In Step 1, *Listening for Plot*, we endeavored to unpack the participants’ stories, experiences, identities, and contexts. This involved listening for what was happening in their stories, where, when, and how, as well as listening for the silences (i.e., what participants did not talk about, what was not expressed). In Step 2, *Listening for I Poems*, we explored and explained the unique lens through which they saw themselves vis-à-vis the research questions. The I Poem procedures are described in greater detail in subsequent sections. In Step 3, *Listening for Contrapuntal Voices*, we identified emergent themes across participants’ experiences and how they diverged. Finally, in Step 4, *Composing a Synthesis*, we explored how our findings from these previous listenings coalesced into a meaningful whole in the context of related literature and theory.

We conducted these analyses first individually and then collaboratively. We completed individual analysis by hand, using colored pencils on hard copies of transcripts. Then we transitioned to a shared document for collaborative analysis. An essential aspect of the listening guide procedures (Gilligan et al., 2003) was memoing about our subjectivities and responses to participants’ narratives. This step allowed each listening to further reveal our positionality and make explicit our assumptions and associations with participants. The aim of this study was not to extrapolate broadly generalizable take-aways from our participants’ pandemic experiences. Rather we wanted to reduce the size of the room – to provide space for them to live, tell, retell, and relive their stories (Connelly & Clandinin, 1990). The listening guide provided a pathway to achieve these goals.

We conducted an initial analysis of the narrative data as it was collected, using the first step of the listening guide (Gilligan et al., 2003). Based on this formative analysis, we created a protocol for follow-up interviews, which included opportunities for participants to provide feedback on our initial analysis. These methods allowed for the flexibility needed to ensure saturation before the data collection phase concluded. At that time, participants were sent a summary of our analysis in an outline format for member checking, and the team revised our analysis as needed. All the mothers participated in member checking, but we encouraged them to contribute to this process to the degree their busy schedules could accommodate. For example, Amelia provided me with detailed member checks (via email) on how her daughter’s schooling evolved over the months of our engagement. This evolution meant that Amelia and Jada’s story ended very differently than we had first anticipated. We also sent the initial draft of this manuscript to a special education expert unaffiliated with our university for peer debriefing. During these discussions, we delved into both our analytical procedures and the interpretation of our findings. The peer providing debriefing offered different perspectives, scrutinized certain analytical decisions, and proposed adjustments, ultimately enhancing the analytical rigor of our research. Credibility measures (Brantlinger et al., 2005) that buttressed the trustworthiness of our findings included triangulation of three data sources (Mertens, 2014), member checking, peer debriefing (Lincoln & Guba, 1985), collaborative analysis (Cornish et al., 2014), and transparency of researchers’ positionality (Koro-Ljungberg, 2008).

Findings

The purpose of this study was to story the nuanced experiences of mothers of children with disabilities amidst the COVID-19 pandemic. Analysis revealed contrastive narratives, but also many similarities across contexts. Though it was not a requirement for participation in our study, in all cases, the mothers we interviewed took on the primary caregiving roles in their

families regardless of marital status. This section reports our findings following each step of the listening guide procedures (Gilligan et al., 2003). It is important to note that these four steps are deeply connected and iterative in nature, and each section of the narrative includes reflection of data analysis across all listenings.

Step 1: Listening for Plot

Amelia and Jada

Amelia is a mother of one child, Jada (14). Though originally from Jamaica, Amelia has lived in the Southeastern U.S. for most of her adult life. She has worked in housekeeping at the same nursing home for over 15 years. Jada was diagnosed as autistic during her elementary school years. She initially received instruction in a full inclusion model but was shifted to a “self-contained ASD cluster” for middle school. According to Amelia, Jada began to regress immediately. “Regressing, as in not doing anything at all, like shut down completely from doing work,” Amelia explained. This resulted in additional diagnoses of psychosis and catatonia. Amelia described Jada’s placement as completely segregated from the “general population.” Soon Jada began to vehemently oppose entering the school building. At the time of our first interview, Amelia was attempting to navigate a world with a deeply traumatized child, now schooling at home, and a full-time job as an essential worker—all during a global pandemic.

Jada’s school building will be closed in March of 2020. Amelia described the transition as a mix of good and bad, explaining, “So, when the COVID came around, it was like a blessing in disguise for her because she didn't want to go to school.” At the same time, the options provided to Jada by the school did not align well with her needs. She said, “By that time, she had regressed so badly she was not communicating, not participating in anything at all. So, even though there was virtual [instruction], she wasn't participating.”

Thanks to the help of a community advocate, Jada was placed in a new, specialized school for students with disabilities for the new school year. Though she elected to continue the digital schooling option for Fall 2020, Amelia described the new school as a good fit for Jada’s needs. In our last interview, she explained that Jada was speaking more and engaging even in the virtual format, achievements Amelia attributed to more one-on-one support.

Sally, Sherri, and Dan

Sally is a married mother of two children with disabilities, Sherri (6) and Dan (10). She has a Ph.D. in special education and is currently “staying at home” to school her children. Her husband works from home. Dan’s diagnoses include autism, hyperlexia, and motor dyspraxia. He has a 504 Plan as well as a Gifted Education plan. Sherri has an Individual Education Plan (IEP) under the category of “health impairment,” and her various health diagnoses cause gross motor and chronic fatigue issues, and chronic pain. Sherri and Dan transitioned to online learning in March 2020 when their district schools closed. Sally watchfully monitored their virtual lessons. She expressed concern with Sherri’s long-term literacy development, a concern that intensified after transition to e-learning. She also reported a lack of coordination and communication from the school about IEPs or 504 Plans during the transition, and a significant history of teachers not honoring accommodations both before and after school closures.

When the time came to make decisions about Fall 2020 schooling, Sally felt that none of the options provided by her district were adequate, and because she was already not working outside of her home during the pandemic, she chose to pull both Sherri and Dan out of school so that she could manage their education at home. She felt that her background as a special

educator uniquely positioned her to meet their needs in a way the school district could not. In both interviews with Sherri and Dan, they expressed satisfaction in being homeschooled, though Sherri missed in-person music and art classes. Dan reported feeling “relief” in not having to daily negotiate his accommodations with teachers that he felt did not understand his abilities and disabilities.

During initial school closures and eventual reopenings, Sally found herself increasingly in the role of advisor and sometimes advocate for other mothers. This included friends, friends of friends, neighbors, and her social media contacts, who started reaching out for advice. “It started organically,” Sally described, but she soon found herself in the unofficial role of advocate, a role she was happy to take up. Sally was clear that her children enjoyed privileges that softened their experience in the pandemic, and she wanted to use her “relative power” to assist others, particularly mothers of children with disabilities navigating inconsistent communication about IEPs and service delivery across the “new normal” for brick/mortar and digital school options. “I would wish for everyone to have all of the things that have made it possible for my family and children to have a relatively positive distance learning experience.”

Kim and William

Kim is a divorced mother of two boys including William (12) who is autistic and has an intellectual disability. William attends a private Catholic school for students with disabilities located approximately one hour from their home. Kim chuckled at the idea of being an atheist who sent her child to a Catholic school but recognized the specialized instruction and environmental approach to be more supportive for her son than public school. Kim and her ex-husband share custody of both children. The school was forced to close for in-person instruction starting in March 2020. According to Kim, William participated minimally in synchronous sessions via Zoom. His teacher labeled him as a “distraction to other students” and opted to provide one-on-one options such as assigned iPad games. William’s younger brother was finishing the 5th grade during the Spring 2020 semester and was also attending virtual schooling at the time.

During the shift to remote learning, Kim maintained fulltime employment as a field organizer for a political campaign working from home. She described herself as well-known and well-respected in this line of work and took great pride in the successful campaigns in her area. But COVID-19 related restrictions caused unprecedented demands, and she felt as though she was being required to “reinvent” her job using virtual platforms. At the same time, she maintained nearly full responsibility for William’s daily living and educational needs, which intensified drastically as the pandemic progressed. Balancing these competing demands was difficult for Kim and she often wondered when (not if) she would be fired. She explained, “I’ll lose a bit of my reputation because people just don’t, I can’t explain... [that] I got fired from that one job because I have an autistic kid.”

Kim described William as a “creature of habit” and noted how the significant shifts in their daily routines yielded profound regression in almost all aspects of his life. She estimated that this regression was the equivalent of five years. At the time of the interview, William was no longer eating, speaking, or sleeping regularly. Kim also experienced emotional exhaustion and sadness to the point she sought professional help from her doctor. She cried as she explained that she had very little support from family and the community (e.g., services that William was previously entitled to) because of restrictions and social distancing guidelines associated with COVID-19. She said, “My mom won’t let me within 100 feet of her house because she is 70...I can’t get anybody to help.”

Amira and John

Amira is a married mother of five who works as a school instructional coach. With COVID-19 school building closures, she was reassigned to provide direct virtual, synchronous instruction to students from home. She also managed remote learning for her son, John (14), who has an autoimmune condition and dual diagnoses of autism and intellectual disabilities. At the same time, Amira's college-aged children returned home to complete their college classes remotely. With her husband also working from home, Amira had almost all her family under one roof for the first time in several years. Though there were many people around, the responsibility of John's daily living and learning needs fell to Amira.

John attended a specialized school for students with intellectual disabilities, the only school of its kind in their district. Prior to the shutdown, he also attended an after-school program that provided additional job training and respite for Amira. She described wide variability in what John was able to do depending on the status of his illness. With the shift to remote learning and the sudden absence of these schools and community supports, John needed constant monitoring to avoid what Amira called "destructive behavior". This presented Amira with many challenges, working from home, and attending to the needs of John and the entire family.

John's school did not offer virtual/synchronous instruction; instead, they sent home worksheets to be completed by the students. She had to guide him through all aspects of the worksheets as they were impossible for him to do independently. Amira felt they were not well-matched to John's individual goals. In helping John complete the worksheets, she began to believe that the school had low expectations for him, stating that it was "eye-opening" to see what he was capable of with one-on-one support as opposed to what they expected of him at school. She described feeling guilty that she was not able to do more to supplement his learning beyond what was provided by the school.

Janine and Ana

Janine, originally from Puerto Rico, is a "stay-at-home mom" who previously worked as a lawyer. She lives with her husband, and they have one daughter, Ana. At the time of the first interview Ana was seven years old and had been diagnosed with Alagille Syndrome (a rare and often painful genetic disorder affecting the heart and liver), hypertonina, and ADHD. Ana also experienced anxiety, depression, and frequent and severe emotional overwhelm. Ana attended a public school out of her zoned community because of a school choice initiative in her state. Prior to school closure, she was in a general education class and received 45 minutes of co-teaching consultation with a special education teacher, as well as speech and occupational therapy. Janine's husband is an essential worker. Janine is Ana's primary caretaker. After schools closed in March of 2020, she took on full responsibility for Ana's learning. With virtual learning, Janine needed to sit with her and physically assist with all aspects of technology.

Janine was displeased with the options or information shared by her district to transition for the 2020-2021 academic year. Her family decided that the fully virtual option was the best choice given her daughter's "medically fragile" condition. However, she felt that the district rushed the process and left teachers with very little time to plan for the new year. She felt Ana's individual needs were "an afterthought." For Janine, lack of planning and sparse communication from the district contributed greatly to her exhaustion and distrust. Despite this, Janine was able to see a bright side. She shared that because of school closures she had bonded more with Ana and felt an immense appreciation for teachers, who often went "the extra mile." As a stay-at-home mom she recognized that she was in the position to not only advocate for her child, but for other families of children with disabilities.

Step 2: Listening for I Poems

For Step 2, we reread the transcripts, listening for passages where the participants spoke about their experiences in the first person. These first-hand accounts were then transformed into what Gilligan et al. (2003) call “I Poems.” During this step of analysis, the researcher extracts first person “I” passages. Each “I” phrase becomes its own line in a poem, with less important words dropped, but verbs and select modifiers retained. The process of creating the I Poems is more important than the actual product, as the focus of this step is “tuning into another person’s voice and listening to what this person knows of her- or himself before talking about him or her” (Gilligan et al., 2003, p. 162). Though we completed the I Poem procedures for all participants for analysis purposes, we provide only three examples that exemplify this *tuning in* process.

Figure 1

Amelia’s I Poem

“I Couldn’t Fight So Many Battles at Once”
Amelia on juggling work and Jada’s needs at home

Sometimes I’m so late for work
 Sometimes I’m crying
 I couldn’t fight
 so many
 battles
 at once
 I couldn’t fight
 for Jada
 and
 my job
 I’m so glad that last year is gone.

Note: I Poem (Gilligan et al., 2003) created in Step 2 of analysis.

Figure 2

Janine’s I Poem

“This is Crisis Educating”
Janine’s I Poem about Pandemic Parenting and Schooling

I’m a stay at home mom now
 I was a lawyer
 I go: *Okay, so let’s do this.*
 I have to be
 her OT
 I have to sit
 in Zoom
 I say: *This isn’t homeschooling-*
 This is crisis educating
 I love her teachers
 They’re doing the best they can
 I think

depression
anxiety
I just think
I just don't
I just want
I don't know
I don't know
This is crisis educating

Note: I Poem (Gilligan et al., 2003) created in Step 2 of analysis.

Figure 3

Kim's I Poem

"I think I might get fired"

Kim's on juggling work and parenting an autistic child during the pandemic

I think I might get fired,
I'm just not sure yet.
I do
I'm the best at what I do, where I live.
I have a lot of connections
I still...
still...
I've been trying

I'll be
fine
I'm not that freaked out
I'll lose
a little bit
of my reputation,
but--

I can't explain it to everybody,
*I got fired from that one job because
I have an autistic kid*

And I...
I mean...
I can't...
I can't say all that
You know?

It is what it is.
It is
what
it
is

Note: I Poem (Gilligan et al., 2003) created in Step 2 of analysis.

In these I Poems, we can hear similarities in the cadences of the mothers' narratives. Amelia and Kim are working mothers of autistic children; their focus vacillates between job responsibilities and nurturing their children through such challenging times. Janine begins her passage identifying herself as "a stay-at-home mom" but also clarifies "I was a lawyer", then goes on to detail how hard it has been to navigate schooling for a child with intense medical and educational needs. This timing of her self-identification allows the listener to tune in to her belief that she is smart and capable yet struggled to do right by her child during the pandemic, an idea that we further elucidated in the subsequent steps of analysis. Across all participants we found first-person passages reflecting these same concerns about doing "enough" for their children, despite their varying professional situations and marital statuses. The I Poem step elucidated this common worry. Both the unique and shared features of our participants' first-person narratives set the stage for analysis of contrapuntal voices (i.e., the interplay of themes), which is described in detail in the following section.

Step 3: Listening for Contrapuntal Voices

In Step 3, we reread transcripts, listening for distinctive "voices." The term "voice" refers to the participant's inner speech, as well as "the participant's unique standpoint or expressed experience" (Cheyney-Collante & Cheyney, 2018, p. 2160). Across transcripts we identified two: the voice of weariness and the voice of advocacy. Though we heard these voices in the transcripts of all participants, we provide here only the most vivid examples rather than a comprehensive list from each participant.

Voice of Weariness

We operationally defined the voice of weariness as pervasive mental and physical exhaustion or depletion. Amira described a sense of weariness in juggling multiple, disparate tasks, teaching her own classes while simultaneously managing the schoolwork of all her children without additional support services. "My mind was so busy with so many things," she lamented. "We went from everything to nothing. Because of the level of his disability his school did not do virtual learning," she explained. John's school provided packets of worksheets for him to complete every three weeks. "There wasn't like, you know, visuals, recorded lessons and just nothing. Just these worksheets. And it was so difficult because he hated the worksheets. I hated the worksheets." Amira and John had to navigate a meaningful discrepancy between his pre-pandemic services and their new reality.

When the occupational therapist gave Amira a list of activities she could do with John at home, she did not experience this as "support" but rather another unrealistic expectation, given that she needed to keep her own job and see to the continued progress of her other children. School personnel calling to check on their progress only added to her sense of exhaustion and shame. "I'd say nothing," she admits. "I can't. I just can't do it." It is important to note that Amira's transcripts show a sizable list of work she "did" do for her children at home; however, she was unable to escape the feeling that it would never be enough to keep John on the right track. In Amira's story we hear two layers of weariness: physical exhaustion from the sheer volume of work and mental exhaustion from the shame of the perceived inadequacy of her efforts.

Similarly, Kim described her son William's difficulties transitioning to the "new normal" of school and the resulting difficulty he experienced in terms of eating, sleeping, and speaking. These regressions created a cascading effect for the family, and for Kim in particular, as William's primary caregiver. "You're only as happy as your unhappiest child," she

explained. “I don't even sleep for two days. But then by the third day, I go to bed at eight and I wake up at seven...it's like I have to catch up. Exhaustion, it is, it's pure exhaustion.”

The voice of weariness was particularly evident in Janine's transcripts. Having already shifted pre-pandemic from the role of lawyer to mothering at home, Janine described the utter fatigue that came with performing her new home-schooling roles as special education teacher, occupational therapist, guidance counselor, and more. “It's not a realistic expectation to put on parents,” she explained, adding: “We're not a school. We're parents. Most of us have no teaching history.... We can't expect parents to carry the load of five teachers and a lunch lady, and counseling staff and, you know. We are not walking schools.”

Later in her interview, Janine further elaborated, “this isn't homeschooling, this is crisis educating.” When asked how she was getting through she shared, “a lot of persistence and giving yourself a lot of grace.” However, she believed the expectations for both her and her daughter were unrealistic. She longed for support and help to ameliorate the weariness she experienced, “there should be a support group for parents who are doing crisis educating and have a child with special needs who have no idea...who are tired and exhausted and could use the support.” During the second interview early in the 2020-2021 school year, Janine still expressed the same feeling in response to the lack of options and communication from her district, “It's exhausting to be in this process and not know... they're [the district] failing the schools and they're making you so weary, so distrusting.”

Finally, Amelia described her year navigating the COVID-19 pandemic alongside Jada's needs as “a rollercoaster: You never know what's going to come on the next day.” The challenges they faced in trying to secure the best instructional services for Jada prior to school building closures were only exacerbated by the transition. In essence, Amelia's weariness was fed by multiple sources including worry for Jada's current and future general well-being (which she related to her academic growth in particular), and a constant stance of vigilance, pushing back against what she saw as unresponsive teachers and administrators. Prior to Jada's transition to virtual learning, Amelia had worried for several years that she was not making adequate academic progress for her to reach adulthood with the knowledge and skills to live a somewhat independent and happy life. When Jada did not respond well to virtual instruction and was unwilling to engage with most teachers in that format, Amelia's concern escalated. This concern was unfortunately not met with demonstrable action by the school. Though Amelia asked for traditional, paper-pencil activities to be sent home so that she could work with Jada herself in the evening, this never happened. The “teacher turned me down,” she said simply.

Amelia describes her weariness throughout the transcripts. “It's tiring. It's very tiring,” she states. “There are days when I just cry, but I just keep trying...It's overwhelming, especially emotionally.” Amelia was weary. She was weary of bearing the tremendous burden for Jada's daily care, while also being forced to maintain a vigilant stance towards the school, hoping for a helpful response to Jada's unique educational needs. “I'm not sure they did the right thing,” she explains, “because I don't know what the right thing was...I'm feeling for the teacher. It's not easy for them.” However, in the final analysis, Jada spent those months at home with virtually no engagement with her teachers, and Amelia was exhausted from trying to fix the situation. “I think they gave up on her,” she states. When asked what the school or teachers could have done to be more helpful, Amelia explained simply, “Services that will be able to help her. Someone that is trained...Because if she gets the right professional, she will come around. I believe that.” Indeed, at the time of our last correspondence, Jada's placement in a more specialized school setting seemed to be bringing the desired results.

Voice of Advocacy

We operationally defined the voice of advocacy as the participant's intent and action to secure good outcomes for their child; to intercede; to champion. This voice emerged time and again throughout participants' transcripts, though the form of advocacy differed dramatically.

During interviews, Janine described myriad episodes of advocacy. Given her daughter Ana's complex medical and educational needs, the pandemic brought with it a flurry of compound challenges. She described initiating the request for an IEP meeting to inquire about how Ana's services would translate virtually. She offered ideas and solutions to the school, like setting aside virtual office hours where students could receive support more regularly beyond virtual class time. Most importantly, Janine described the need to feel heard. Like many of the other mothers we interviewed, she often felt like Ana was brushed aside, that because the school did not know how to handle the situation, they just moved the responsibility to her as the mother. Janine explained, "People like [Ana] need a voice...People like me need a voice." This quote should be interpreted carefully. Janine did not present herself as a mother sitting in the background, waiting for someone to "give" her an opportunity to speak. Rather, she detailed the many ways she demanded to be heard, though she often felt that it fell on deaf ears.

This demand to be heard can be seen in the way Janine jumped into action not only to advocate for Ana, but also for other families. In her words, "I have to fight for my kid, and I have to fight for other kids." Janine attended eight hour long virtual school board meetings for the first time, wrote to leaders on state and local levels, and joined advocacy groups on social media. She shared, "It's grueling. You should not have to advocate this hard in public education...to get them the bare minimum...If teachers weren't doing the kinds of work they do, these kids would be lost." This is a theme that also emerged in Sally's interviews, who described myriad advocacy activities related to pandemic schooling issues: fielding families questions via phone, email, and social media, related to IEPs and disability services and school closures/reopening; writing school board members and district leaders with concerns and ideas; live streaming school board meetings on social media; writing op-eds for her local newspaper; publicizing issues well beyond those that applied to her children specifically.

We can also see the voice of advocacy in the way Amelia navigated Jada's complex medical and instructional challenges, and especially in her commitment to learn about Jada's conditions and the systems they must function within, as well as her commitment to seek out resources and use them to improve Jada's situation. A critical feature of Amelia's advocacy was her vast reservoir of knowledge about Jada's disability and the systems they are embedded within (medical, legal, and educational). In our conversations, Amelia spoke extensively about state-, district-, and school-specific procedures and policies. For example, she talked about how Jada's middle school determined Least Restrictive Environment (LRE) and eligibility for one-on-one support, but also about mandatory standardized testing requirements in her district, and various diploma and graduation routes available to autistic students in her state. "I have to," Amelia explained:

Because, as I told them, I don't want her to fall through the cracks. I think she can be successful. I don't think I should say, okay, she has ASD. I'm going to just let them do whatever. I don't think that's fair for her because she can't make decisions for herself right now, so I have to be her advocate.

Another meaningful feature of Amelia's advocacy of Jada was her commitment to find and access resources that were not readily provided by the school system. For example, as Jada began to experience difficulties in middle school, Amelia took it upon herself to contact an advocate that had been provided by a local non-profit several years before. Amelia was able to

avail herself of the advocate's advice on Jada's struggles in transitioning to online learning as well as her impending transition to high school amidst rising COVID-19 cases in her state. Amelia also reached out to her community in search of legal support when she encountered difficulties from her employer as she needed to take time off to deal with emergencies that arose in Jada's care and schooling. As these emergencies increased with remote schooling, this community legal support gave Amelia the terminology and language to use to advocate for her lawful use of provisions in the Family Medical Leave Act (FMLA). Not surprisingly, Amelia reflects, "it has been the roughest time in my life." However, she also describes confidently advocating for herself and Jada with her employer: "I said, 'I'm under the FMLA, what are *you* talking about? You're not supposed to be complaining about me not being here. I'm covered under the law'."

Kim's advocacy for William took a slightly different form. Though she didn't recognize her actions as advocacy, several of the meaningful events she described fit our definition of this voice. As William began to regress amidst drastic changes in brick/mortar schooling, Kim went directly to the principal of the school to brainstorm solutions. She reported feeling the support of the principal, who started as a special education teacher and had "worked her way up to principal." Kim appreciated her knowledge about autism, and the potential solutions she brought to the table. They invited in a therapy dog for William. The thing more important than the results of this step was Kim's trust in this school leader. While Kim often described feelings of powerlessness, she was able to parlay this one act of advocacy into action on the part of the school. Like the other mothers we interviewed, she sought out resources for her child, and in this case, the school worked with her to find unique remedies.

Alternatively, Sally described how she had taken on an advocacy role for parents of children with disabilities through her involvement in a social media group in her county. Both parents and teachers started reaching out to her, knowing that she was a former special education teacher, mother of two children with disabilities, and had expertise in special education services and policy. "Even when I started the advocacy, it wasn't really for me," she said. "It's one of those situations where somebody has to do it." Teachers came to her with concerns for their own safety given a lack of information from the district. Mothers came to her with concerns about their children's needs being met. Initially Sally's district did not have a plan that included a synchronous digital option, but she knew many students would need real time interaction with teachers, particularly children with disabilities. She rallied a group of parents, who attended virtual school board meetings, wrote letters to the school board members and the superintendent, and letters to the editor in the local newspaper. Eventually, a digital option was reinstated. Sally described this as their first real success, even though her own children would not benefit from the victory (she had chosen to homeschool).

When the new school year began, Sally's advocacy group campaigned for new schoolboard leadership because they felt frustrated the current board appeared to dismiss "the voices of Black parents and community members and employees." During the new school year, they seated a new board member, which led to a new board chair, and eventually a new superintendent. Sally and this vocal group of parents also advocated for better safety precautions for teachers and district staff. At the time of this writing, Sally has been newly elected to the schoolboard herself, where she continues to advise families of their rights to free and appropriate public education for their children with disabilities.

Discussion (Step Four: Synthesis)

In the 1970's, Carol Gilligan, then a student of famous psychological researcher, Lawrence Kohlberg, put forth the idea that women are morally socialized differently than men (Gilligan, 1977). Whereas Kohlberg held that men were socialized into an "ethic of justice"

(characterized by personal autonomy and achievement, and “right” and “wrong”), Gilligan (1977) observed in her female research participants an “ethic of care.” “Ethic of care” refers to the idea that women are socialized to see the self and others as interdependent and to view decision-making with the end goal of maintenance of important interpersonal relationships. Gilligan et al. (2003) describes women’s moral development in stages, beginning with self-interest and survival, transitioning to self-sacrifice, a centerpiece of old notions of motherhood. Just as feminist ideas of motherhood as suppression (Rich, 1986) transformed into the idea of mothering as empowerment (Kinser, 2010; O’Reilly, 2014), Gilligan describes the final stage of women’s development as her deep understanding that “care” is balance between self and others.

We did not seek to evaluate the decisions of our participants using these stages of moral development, nor did we conceptualize an ethic of care purely from Gilligan’s perspective, which has been rightfully criticized as western-centric. In response to Gilligan’s early work, MacKinnon (1989) argued that we focus not on gendered differences in our orientation to care, but on differences in power. She wrote, “The problem then is not that differences are not valued; the problem is that they are defined by power” (p. 219). However, we found an ethic of care—painted with wide strokes—provided a meaningful backdrop for synthesizing our participants’ unfolding stories particularly in relationship to the power structures they traversed. The full continuum of the ethic of care can be seen throughout individual participants’ data as well as in across-participant synthesis.

We can see the ethic of care at work in multiple participants’ descriptions of their caregiving and caregiver fatigue, and particularly for those navigating more complex disabilities and medical issues. Amelia’s I Poem elucidated this, specifically in the first stanza:

Sometimes I’m so late for work
 Sometimes I’m crying
 I couldn’t fight
 so many
 battles
 at once

However, Amelia’s ethic of care does not end with her as a martyr to the inadequate socio-structural constraints of the educational system. Through her advocacy of Jada and herself, she surrounded them with helpful resources (e.g., a disability advocate, community legal representation) and worked to increase her own knowledge of Jada’s disability and of the systems they must work within. Likewise, Kim didn’t function as a lone advocate for William isolated in her endeavors to improve his situation. She reached out to the school principal, who in this case, worked with Kim to improve William’s experience. According to Sevenhuijsen (2003), “the guiding thought of the ethic of care is that people need each other in order to lead a good life” (p. 184). In Amelia’s case, the people she was able to draw into the fight made a meaningful impact. “When I have more knowledge, I can advocate more because knowledge is power... You can’t go to the school and say something when you’re not sure if you’re right or wrong,” she explained. She needed a community behind her to clarify her rights and provide a clear pathway. This work on behalf of her daughter resulted in demonstrable improvements in Jada’s situation when the new school year began.

However, not all the women we interviewed had such outcomes. In fact, adequate service delivery was sporadic for most participants. Sally’s organic development into an advocate in her own community is admirable, but also speaks to the vacuum of needed support available within formal community structures. Moreover, these mothers’ challenges in navigating the educational system extend beyond the school room, virtual or brick/mortar. In

one interview, Janine described an upcoming medical appointment, Ana's fear of hospitals, and the resulting emotional toll for them both. Other mothers in our study described similar trials related to dental and doctor visits. In Janine's case, these were challenges she navigated alone. However, Janine used the description of this event to reinforce her commitment to care for her daughter despite the increased challenges to appropriate medical access created by the pandemic and a dearth of adequate supports for families and children with disabilities. "This has been a tough situation to navigate because she doesn't stop having, you know, chronic disease, just because there's a pandemic," Janine explained. Interestingly, her concern was not limited to her own child, as she went on to describe her hopes for other children and families: "I would like to tell them, especially other parents, that they're not alone. That we're all in this together. And that we need to support each other." Janine's experience highlights a common experience of feeling both alone and yet connected to something bigger than their own stories. Mothers felt isolated but simultaneously, a sense of belonging to other mothers of children with disabilities because of their shared reality.

These mothers' stories provide a vivid example of how mothers of children with disabilities must navigate both socio-structural and emotional burdens in the absence of the usual, though sometimes inadequate, support provided through the public education system. Where school-based resources were minimized or eliminated in COVID-19 plans, these mothers marshaled their own internal reserves to ensure their children's needs were addressed, and in some cases, they rallied support for other mothers with children in similar circumstances. The goal of this study was to both better understand the pandemic experiences of diverse mothers of children with disabilities, and to provide solidarity and a space of care as they shared their stories. One limitation of this study was the pandemic itself. Our participants were under enormous stress for the duration of the study, and this likely had a negative impact on their availability for follow-up communications. Additionally, quarantine and social distancing rules meant we could not meet with participants in person to establish rapport face-to-face. The use of video conferencing and email communication, however, provided us with the opportunity to include participants outside of our region. Another limitation is the small number of children who were willing to participate in the study. Many children of the women who served as primary informants had communication-oriented disabilities, perhaps making the video conferencing option a less attractive tool for engagement. Overall, we feel we were able to meet the goals of the study despite the challenges. Janine shared the following in her final interview: "Thank you for having me...Because we feel very tired and very unheard."

Future research is needed to study the ongoing impacts of the COVID-19 pandemic on children and families, and the lingering effects for children and mothers. Despite Jada's improvement in a new school, Amelia described the enduring sense of overwhelm: "You can't enjoy the real happiness until that overwhelm is gone. I'm still in recovery mode." Continued research is needed, including small-sample, qualitative studies that provide a rich description of women's lives in real time. The landscape of mothering children with disabilities in the time of global crises is highly complex. However, taking a deep dive into the experiences of a small group of mothers allowed us to contribute to the fields' understanding of women's multiple identities as well as the larger socio-cultural burdens that contribute to their subjugation (Damant et al., 2008). Findings from this study also underscore the importance of including mothers of children with disabilities in discussions and decision making around educational services, and to listen closely to their voices amidst the noise of a traumatized world. As many of our participants articulated, children with disabilities and the mothers who care for and for them deserve a seat at the table. As Sally ended our last interview, "thank you for listening."

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Author Note

Kristi Cheyney-Collante, Ph.D. (<https://orcid.org/0000-0001-6430-1695>), is a Clinical Associate Professor and the Graduate Coordinator of the School of Special Education, School Psychology, and Early Childhood Studies (SESPECS) at the University of Florida. She also serves as the Assistant Director of the University of Florida Literacy Institute (UFLI). Dr. Cheyney-Collante's scholarship efforts focus on early literacy teaching and learning, particularly in communities experiencing systemic inequities in access to effective instruction. She has exhibited multiple photographic installations, photo essays, and other creative projects that highlight the experiences of young children and their families, and the teachers that serve them.

Lindsey Chapman, Ph.D. (<https://orcid.org/0000-0001-7515-5013>), is a Lecturer and Director of the Special Education program at Boston University Wheelock College of Education & Human Development. She teaches undergraduate and graduate coursework on disability-related issues and provides seminars for field-based experiences. Her scholarship and teaching focus on social perspectives of disability, accessibility/Universal Design for Learning (UDL), and inclusive teacher preparation/development across the career span.

Shaunté Duggins, Ph.D., is the Associate Director for the New Worlds Reading Initiative at the University of Florida's Lastinger Center for Learning. In this role, she manages all aspects of the statewide book distribution program, including recruitment and enrollment, book selection and distribution, family engagement resource development, district and community partnerships and corporate tax contributions. Her research includes early literacy, teacher education and professional development, particularly in high-poverty schools.

Correspondence concerning this article should be addressed to Kristi Cheyney-Collante, School of Special Education, School Psychology, and Early Childhood Studies, University of Florida, E-mail: cheyneyk@coe.ufl.edu.

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