

The Fight Within: Parent- Educators Advocating for Their Children With Autism Inside Their Own School Districts

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Abstract

Parents have advocated for the educational rights of their children with disabilities for decades, and more so since the reauthorization of the Individuals With Disabilities Education Act (IDEA). Advocating for one's child while working as an employee in the same school district where your child receives special education services comes with unforeseen complexities. Using a heuristic case study approach, this inquiry intended to discern the experiences, barriers, and perceptions of job security of two parent-educators with children with autism. Findings suggest unanticipated experiences and challenges within their dual, parent-educator role as indicated by the theory of responsible advocacy. Perceived employment consequences related to advocating from within the school system are also discussed along with implications for such parent-educators and their role in improving parent-school partnerships in special education.

Keywords

parent-educator, parent-school partnerships, special education, advocacy, heuristic case study

Parents play an important collaborative role within the educational system. Moreover, they value positive relationships with the personnel who support their children at school (Hess, Molina, & Kozleski, 2006). Indeed, positive collaborative relationships between parents of students with autism and educators are an important ingredient for the success of these students (Stoner et al., 2005). For many parents of students with autism and related behaviors, however, there can be multiple barriers that interfere with the development of such relationships compared to parents with typically developing children (Fishman & Nickerson, 2015). Barriers include differing perceptions among parents and school personnel about what educational services should be included in the Individualized Education Program (IEP; S. E. White, 2014) and about what should be appropriate staff qualifications for

those teaching children with autism resulting in distrust (Spann, Kohler, & Soenksen, 2003; S. E. White, 2014), limited parental knowledge and understanding of special education jargon (Park & Turnbull, 2003), a power differential between parents and educators (Turnbull & Turnbull, 2003), and failure of parents and school personnel to value each other's perspective (Mueller & Piantoni, 2013).

Advocating as a Parent and Educator

Certainly, there is evidence within the literature that collaboration requires commitment from parents and professionals alike to meet the needs of students with disabilities (Fiedler, 2000; Mueller & Piantoni, 2013; J. White & Weiner, 2004). Mueller and Piantoni (2013) called for a “leveling of the playing field” (p. 13) to seek a collaborative balance in relationships among parents and educators. When trust breaks down or when parents feel their perspective is not valued, advocacy becomes challenging (Athanasos & de Oliveira, 2007). Parents of students with autism and autism-related behaviors who also are educators for students with disabilities have constant and continuous access to learning about the disabilities of their children and how to work within and around the institutional system of special education. They are situated through their dual perspectives to inform the field about how to improve parent–school relationships and thus outcomes for students with disabilities. These advocacy efforts place them in a quandary, caught between their need to ensure the educational rights of their children and their obligation to adhere to the expectations of their employer. The uncertainty that exists between these roles is explained within the theory of responsible advocacy (Fitzpatrick & Gauthier, 2001) and evolves when one person occupies two roles tangled by disparate forces. The theory, initially conceived in the field of communication, outlines the ethical identities of the public relations professional serving as an advocate to a client and their needs while also maintaining a social conscience for the needs of their employer. This amalgamation creates difficulties in balancing the advantages and disadvantages of serving an employer and a client at the same time. The same can hold true for parent-educators in special education as they advocate for their own children and their students (Koch, 2011), while also obligated to follow school district policies and procedures. Complicating the balance, parent-educators acquire a sense of power in academic arenas

through access to social and cultural capital. This theory proposed by Bourdieu (1986) postulated that individuals access the assets they gain by means of their associated social and cultural networks. As such, parent-educators know their child and the disability and they also know the inner workings of the school system because of their networks. They have access to both knowledge and key individuals within the school system. This affords them the opportunity to advocate in and around an institutional system more so than parents who are not educators, and to diligently do so for the benefit of their child (Koch, 2011). In relation to this inquiry, these two theories, responsible advocacy and social and cultural capital, bring into perspective how a parent-educator harmonizes advocacy and social conscience, advocating for their child while also serving the interests of the school district.

Considering the struggles that can arise while advocating for one’s own child, questions arise as to what such dual role, parent-educators experience in advocating for their children with disabilities and what might we might learn from them. To date, there is limited literature on how parent-educators in their dual roles navigate the inherent conflicts that arise from advocating for their own children, for the children with disabilities who are not their own, and whether doing so as an employee within the school system that serves their children impacts their social conscience or job security (Gross, 2011; Harry, 2010; Koch, 2011). Harry (1996) illustrated the impact on each of her identities as a parent, educator, and researcher. Gross (2011) provided readers the perspective of both a parent and an educator and her difficulties in accepting her adopted son’s learning disability. Koch (2011) used her personal experience to study similar parent-educators regarding the degree to which they advocated for other students with disabilities. Although each of these authors has provided a viewpoint as a parent-educator, none has investigated the conundrum individuals in dual, parent-educator roles may face in special education.

One overlooked group is parents who are *both* advocates for their own children with autism and autism-related behaviors and educators (teachers, teaching assistants, administrators, etc.) for students with disabilities. These parents who are also educators for students with disabilities possess unique perspectives that can inform the field about how to improve relationships between parents with children who have autism and the educators who serve their children. Therefore, this study sought to better understand the experiences of parent-educators whose children have been identified with autism and autism-related behaviors and to what degree, if any, those experiences affected job security. The three research questions developed to guide this study were the following:

Research Question 1: What are the experiences of dual role, parent-educators who challenge their own districts in the interest of their children with autism?

Research Question 2: What barriers do these dual role, parent-educators feel they encounter in advocating within their own districts?

Research Question 3: How do these dual role, parent-educators perceive their involvement in advocating for their own children in relation to their job security?

Method

The intent of this research was to understand the lived experiences, barriers, and perceptions of parent-educators who advocated for their own children with autism inside the school districts where they work. To appreciate the experiences of parent-educators who live in these multiple roles within the educational system, this investigation used a combination of qualitative case study and heuristic inquiry methods so as to maintain alignment within the theoretical perspective of interpretivism as suggested by Koro-Ljungberg, Yendol-Hoppey, Smith, and Hayes (2009). Case study research permits a researcher, who has an intrinsic interest in the topic of the case, to investigate how participants make meaning and reflect on their expe-

riences using in-depth storytelling and rich and thick descriptions of the case (Stake, 1994). Heuristic inquiry is a method of discovery that allows the researcher to connect a topic of personal interest and interpret the participant's experiences using tacit knowledge, the intuition of knowing more than we can tell (Polyani, 1966). This intuition allows the researcher to understand the unseen and invisible, uncovering the meaning behind the experiences of the participants, who share their experiences through dialogue and providing a collection of documents (Moustakas, 1990). Using an interpretivist lens, the researcher essentially seeks to understand and share the meaning-making of the participants formed within a constructivist perspective. Through an intense and systematic means of exploration (Yin, 2003), the researcher is guided by the research questions, which are designed to unite the personal with the impersonal, to investigate the experiences of others in similar situations (Moustakas, 1990). As such, case study research is only meant to represent unique individuals in their individually constructed circumstances, not to represent the population at large (Stake, 1994). The interpretive nature of the heuristic case study method also places the role of contextualizing the participant's experiences on the researcher so readers may draw their own conclusions. Taken together, an intensely descriptive and interpretive method concludes with a synthesis of the experiences from the researcher's perspective of the participants (Stake, 1994).

Collecting the Heart of Their Stories

This heuristic case study was meant to provide detailed descriptions representing the experiences and barriers for the case study's parent-educators. The meaning and understanding of their experiences is an evolving process and develops through the heuristic case study. With true attention to the heuristic process, a researcher is able to fully understand what is not openly expressed within the participant's experience, thereby formulating a written representation for readers to understand.

Table 1. Demographic Information of Each Participant and Child.

	Ruby and Chuck	Kate and Eric
Age of participant	42	33
Teaching position	General education teacher	Special education teacher
Years in education	9	5
Grade level of child	10th	Fifth

Selection of the cases. Participants were selected using a purposive, critical case sampling process that allows the researcher to find participants who will “yield the most information and have the greatest impact on the development of knowledge” (Patton, 2001, p. 236). As the experience of parent-educators advocating from the inside out was the focus of this study, participants had to be current teachers and have a child with autism who was served within the same school district where they worked. Two participants were selected (see Table 1). Both participants selected pseudonyms for themselves and their children to maintain anonymity as they and their children were employees and students within their school districts at the time of this inquiry.

Data collection. Heuristic case study design is meant to be information rich. Therefore, multiple interviews, documents (IEPs, psychological reports, parent and teacher conference notes, and emails), and journals were collected to probe deeply into the experiences of the participants with respect to their advocacy for their children and their educational services. Interviews, which allow the story to evolve, were the primary means of data collection while the documents permitted for triangulation of data and supporting the narrative of their historical experiences in advocating for their children. The first author also utilized a researcher reflexive journal to capture subjectivity and ascertain neutrality in the data collection and analysis phases, noting her reactions to the interviews and analysis of the IEPs and other documents. Participants were interviewed individually, using Seidman’s (2006) three-interview sequence, across a 3- to 4-week time period. The interview sessions focused on the experiences and differing roles

of the participants as both parents and educators. The first interview captured the history and details of the participant’s lived experiences in advocating for their child. The second interview investigated those experiences in more depth from the role as a parent, while the third interview focused on the participant’s role as an educator. All interviews were transcribed and returned to each participant to check for accuracy and maintain credibility and trustworthiness of the inquiry process.

Data analysis. The heuristic process was used for data analysis. The three interviews for each case were analyzed in a systematic and intense manner consisting of seven step-by-step stages of analysis (see Figure 1). In outlining heuristic inquiry process, Moustakas (1990) dictated that each case be analyzed in its entirety before beginning the interview process with the next participant so individual themes can be identified. Cases are not meant to directly inform one another, thereby allowing the researcher to identify similarities before drafting a group depiction. The themes resulted from key ideas underlying the participants’ experiences using words and phrases from within the interviews. For example, a theme was established surrounding advocacy when a participant repeatedly referred to attempting to support the needs of the children in their classroom. Corresponding data from the journals, documents, and researcher reflexive journal were used as supporting evidence for the themes.

Bracketing and positionality. Transparency is fundamental when conducting rigorous qualitative research (Trainor & Graue, 2014). Therefore, it is important within the context of this study to bracket the role biases of the

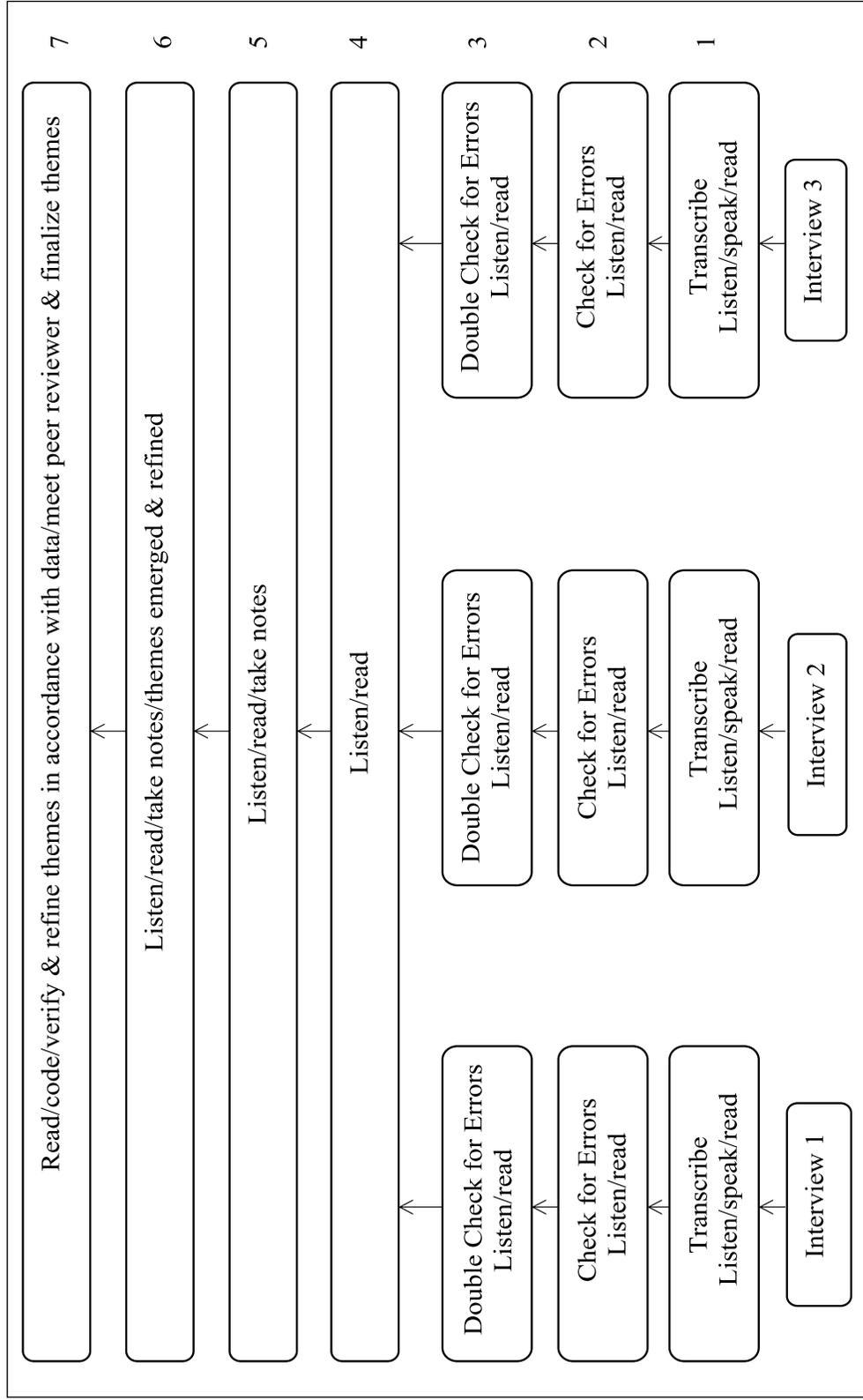


Figure 1. Layers of interview immersion and data analysis.

researchers. While acting as a researcher within this study, the first author is a parent of a child with a disability and was a teacher of students with disabilities. She experienced barriers in advocating for her son's special education services in the two school districts where she worked. The experience in acquiring services and accommodations to support his specific learning disability from first grade until his graduation from high school and the limited research base on parent-educators in special education led to the initial wondering questions that supported this inquiry and whether her experiences were only singular in nature. In addition, as Trainor and Graue (2014) stipulated, positionality is central to methodological and interpretive transparency. Positionality refers to the manner in which a researcher's personal and professional identities and experiences impact their position (Trainor & Graue, 2014). Thus, the first author's multiple roles and identities provided a particular vantage point as an insider in viewing the research problem using an interpretivist lens as defined by Stake (1994), yet requiring rigorous data collection and analysis procedures (Yin, 2003) which required reflexivity and attention to how the researcher's position was informed by those identities. This required bracketing the first author's experiences before engaging in this inquiry so the experiences of the participant(s) could emerge during the study. While former special education teachers themselves, the second and third authors are not parents of children with disabilities but served as the first author's doctoral advisors.

Credibility and trustworthiness. The credibility and trustworthiness of the heuristic case study was enhanced as the research incorporates multiple interview sessions with each participant and triangulation of data using artifacts such as IEPs, psychological reports, teacher and parent planning notes, and participant journals. Credibility and trustworthiness are also improved in heuristic case study through repetitious seven-stage data analysis process that ends with a written case depiction to answer the research questions. Although a

heuristic case study is meant to rely on the intuition of the researcher, peer debriefing and member checking were used as a means to strengthen the credibility and trustworthiness of the conclusions made. The first author met with two peers, both who were educators unassociated with this study, to discuss the emergent themes relative to specific evidence. Similarly, member checks were utilized with participants after completing each written case. Participants and peers provided feedback leading to adjustments of the themes to more appropriately represent the data by clarifying ideas and reducing redundancy that improved the case descriptions. Changes were discussed with second and third authors.

Findings

The themes that evolved from the process of this intense heuristic case study provide a glimpse into the lived experiences of two parent-educators who advocated for their own children with autism and related behaviors inside the districts where they work. First, we introduce you to each mother and son to provide context within her efforts to advocate. Next, we discuss significant themes for both mothers pertaining to the research questions surrounding their experiences, barriers, and perceptions of job security in relation to their advocacy, and then examine the impact of those experiences on their advocacy. Finally, implications of this study related to parent-school relationships and teacher education are shared.

Meet Ruby, Kate, and Their Sons

Ruby and Kate are mothers of students with autism and autism-related behaviors. Ironically, both mothers were drawn to education from previous professions because of their children's struggles. Ruby was a journalist and Kate had planned to go into the human services industry following a career in the Army. Neither ever imagined becoming a teacher. Ruby never dreamed of it: "Why would I want to be a teacher?" Kate had not heard any reasons why she should: "I didn't

want anything to do with the school system. No, you hear horror stories about the school system. You don't want to work for them." But circumstances changed the entire direction of their lives. Their sons needed help in their educational settings, so they both became educators.

Ruby and Chuck. Ruby turned her attention to education after pursuing a career in journalism. After receiving word that Chuck had been diagnosed at the age of 3 with autism and attention deficit hyperactivity disorder, Ruby knew her only choice was to help her son overcome his challenges. Chuck struggled with adaptive behaviors, sensory regulation, social interactions, expressive and receptive language, intellectual functioning, and fine motor skills. He began receiving support for his academic, social/emotional, and communication needs in a prekindergarten therapeutic setting. Chuck's resulting needs led to a higher calling for Ruby. She left her career, began working as a paraprofessional, and returned to school to become a teacher in both elementary general and special education settings serving students in Grades 5 and below. She believed that working on the inside would help her ensure Chuck got what he needed for his education:

Well at first when I thought about going into it, because I could help him, because I could be more present, because I could learn more. But then, I realized this is what I need to do so that I can advocate for him.

Over time, however, Ruby experienced the highs and lows in Chuck's education. She periodically struggled with schools, educators, and the extent to which she believed Chuck's needs were being met. She used advocates and quoted research regarding least restrictive environment for children with autism: "He was having some difficulties in first grade and they wanted him to be in self-contained, and at that time I said it wasn't appropriate for him and they weren't really giving him a chance." A few years later when concerns arose over a teacher's treatment of

students in the class, her intuition led her to exercise a school choice option, placing Chuck in a private elementary school:

As a parent of a child with a disability, especially one like autism, I feel you sometimes get a sixth sense and you're given this thing as a gift to say, ok something's not quite right. So I knew something wasn't quite right.

Ruby sought a change in Chuck's placement once again when he reached middle school, moving him from an all special education school, where she also happened to be working, to a regular middle school setting. Ruby felt the personnel at the special education school did not understand Chuck's disability as children with autism spectrum disorder (ASD) were not widely served there: "They had never come across kids that had parents that knew about those things or that came to their school saying this is a need that my kid has." Ruby exercised her right of school choice once again when she believed Chuck was not receiving the accommodations outlined on his IEP in the local public high school and placed him in a charter school serving only students with disabilities. Chuck's IEP listed accommodations such as extended time, guided notes, extra textbooks, copies of notes, the teacher's notes, and organization assistance with his classwork and homework in high school:

I would say a lot of my advocating probably began in middle school and high school. Even in private settings where I never thought I would have to do that. That's probably been my biggest challenge and where a lot of my fear and anxiety has come in over the years.

Kate and Eric. Like Ruby, Kate began her career in education as a paraprofessional. Hoping her time spent in an elementary self-contained special education classroom for students with emotional/behavioral disorders (EBDs) would help her advocate for Eric, she accepted a teaching position in the same elementary school the very next school year in a self-contained special education classroom

for students in kindergarten through fifth grade. At the age of 4, Eric was diagnosed with pervasive developmental disorder, disruptive behavior disorder, developmental disorder (language and phonological), and difficulties with speech. He immediately entered a prekindergarten therapeutic program under the eligibility of developmental delays and speech and language impairment to address his academic, social-emotional, and communication needs.

Kate's and Eric's experiences spanned two different states from pre-K through fifth grade. The family moved to another state as Eric entered kindergarten where he was placed in a general education classroom. Initially, Eric was provided support for his academic and language needs, but these supports began to diminish as he progressed through elementary school. His eligibility for developmental delays was removed when he turned 6 years old as required by state regulations. Kate could have considered eligibilities under ASD or EBD to obtain the services Eric needed. Instead, she found herself at odds with the concept of *labeling* because she was concerned with the long-term implications such labels would have on Eric's future. Therefore, Eric only retained academic special education support services through the third grade until he no longer met criteria for the language impairment category. Although he remained eligible for an IEP under speech impairment, he lost access to certain classroom accommodations linked directly to his disability, such as more time for completing assignments, proximity control, reminders of rules, cueing and prompting, and access to supports which were put in place to help with his behaviors. Eric's remaining special education eligibility was removed at the end of his fifth grade year, which also culminated with the conclusion of this inquiry, when he no longer met criteria for speech impairment. To outsiders, Eric appeared to be making progress. To Kate, there was evidence to the contrary. Eric's IEPs provided documented evidence that he was struggling with appropriate school-related behavior such as tantrums, oppositional defiance, and physical

aggression. According to Kate, Eric had run away from class, and had verbal and physical outbursts toward peers and adults that resulted in frequent trips to the school's administrative office: "We've gone up to the assistant principal's office and spent the day there, several times. We've gotten kicked off the bus, we've almost gotten kicked out of [after-school care], a lot of times."

The Fight Within: Advocating as a Parent-Educator

The stories of Ruby and Kate and their sons, Chuck and Eric, illustrate their struggles navigating the dual role of parent-educator, their desire to advocate for their children while working as an employee of the school district where the child was being served. Analysis of their experiences, barriers, and perceptions revealed several themes. Findings uncover their experiences with the unknown barriers that resulted in internal conflict regarding their dual roles, concerns about their job security in relation to their efforts to advocate for their children and the students with disabilities they served, and their experiences developing as advocates.

Experiences they never anticipated. Ruby and Kate each entered the field of special education with a purpose, to learn enough to help their sons. They found they had much to learn. They had to learn the inner workings of the school system, understand the disabilities facing their sons, how to meet their sons' needs, and the types of accommodations which supported them best. They also learned that they came to know more about students with autism than the many educators they and their sons encountered. This came as a surprise, especially to Ruby:

He [Chuck] had a resource teacher who just did not understand the autism part of it, and just the constant [complaints]. I just don't have patience for that. Like you're the educator, you're supposed to know about autism. These are related behaviors, a manifestation of his disability. Like why are we having this conversation?

Evidence of teachers who were unaware of Chuck's needs and the accommodations outlined in his IEP was captured in a planning note document Ruby kept from Chuck's ninth grade IEP meeting. Aside from the lack of positive information within the planning note, there were indications the teacher was unaware of Chuck's testing accommodation. The IEP in effect at the time indicated Chuck had an accommodation that allowed him to write on tests rather than bubble in answers on an answer sheet due to his delayed fine motor skills. The IEP also included a classroom accommodation for an organizational system. Yet, the complaints voiced by the teacher in the planning note about having to fill out the Scantron and help organize the papers stashed in Chuck's unorganized backpack pointed to the lack of understanding the nature of his disability nor reasons why the IEP team determined he required accommodations to support his disability-related needs.

Kate found it difficult as well to communicate with teachers who were unfamiliar with the characteristics of autism and related behaviors: "So every time we have a problem in school, it's because he's black and white and you [teacher] went a little too grey for him. He needs concrete concepts." Therefore, Kate found herself continuously providing teachers with ideas on how to be proactive and help Eric avoid outbursts with the use of simple accommodations:

You know how many parent-teacher conferences I had over carpet? It had to have been over a dozen. Over carpet. He just doesn't want to sit on the carpet, he doesn't engage with us, all he does is move around, it's like he's unhappy. No [expletive] he's unhappy. Did you give him something to sit on top of? He'll sit on the carpet if you'll give him a chair, give him a pillow. He doesn't like the feel of it.

Yet, it became clear to Kate that many of Eric's teachers had never read his IEP, which explained why they did not know what to do:

How many of them really read it? So then you go to conference night and you start telling them, you know I've heard you say this over

and over again about he has this problem or that problem. Did you read the IEP? Because let me bring it out and show it to you. And then they're like oh, that makes sense. It makes sense? This is my kid you're torturing in this classroom and if you ever had any question I've always provided my phone number, my cell phone number, my email, you can get ahold of me how many different ways, personally and professionally. But you don't see you're just torturing my kid. No wonder he hates school.

The awareness these mothers acquired regarding Individuals With Disabilities Education Act (IDEA, 2004), their children's disabilities, and the policies and procedures within the school system placed them in a unique space. They were more than just an informed parent. They were parent-educators who had valuable insider knowledge that allowed them to see how their children fit into the larger picture of special education.

Barriers and challenges of their dual role. Upon learning of their child's educational needs, each of these mothers decided they needed to take action to understand the system. Each chose to leave behind previous careers and become educators. It was the idea that working on the inside, learning the language and the laws, would lead each of these women into positions better suited to advocating for their sons. Instead, they described their positions as conflicting and found it difficult to live in their dual roles as parents and educators while also advocating for their students.

Mothers becoming advocates. For these two mothers, wrestling with how to be a responsible advocate (Fitzpatrick & Gauthier, 2001) was a daily struggle, one that left them at odds within their dual roles. Ruby articulated this ongoing dilemma:

There's no separation for me. I live where I work, I work where I live, it's all related. And so I think that for me it is more emotional because I see kids that go through struggles like my own son does. And they are not getting their needs met. Or if they are getting their needs met well, why is this happening over here but it's not

happening for my kid? Or I don't really think that's quite right but what can I do about it?

Ruby and Kate dealt with the disparate forces and the resulting ethical conflicts of their dual roles on a daily basis. The expectations and understanding of their responsibilities as an employee conflicted with their responsibilities as a parent. It was a barrier none expected to encounter. Kate tried to connect with parents as their child's teacher, communicating to them that she understood more than the typical teacher because she too was raising a child with unique needs. Yet, much to her displeasure, she also had to convey to them that at times her hands were tied because of district policies:

I tell my parents in my classroom, I understand where you're coming from. I have a child with an exceptionality. I've been there. And I'm doing the best that I can for your child. But please understand that we're working within a system, and I hate that.

Ruby even expressed the challenge of sitting at the IEP table serving the role of a teacher charged with making decisions on eligibilities and placement based on district special education regulations, while also identifying the struggles of the parents sitting on the other side, feeling what was being offered just was not enough:

It can be emotional for me as a parent because I'm a teacher and it can be emotional for me as a teacher because I'm a parent. And I don't think that I would be as emotional if I just had one of those roles.

Advocating for other children with disabilities. Equipped with significant knowledge regarding the laws that govern students with disabilities and the inner workings of the school districts where they worked, these mothers developed identities as advocates for other children with disabilities. They advocated for children while sitting in the doctor's office, in online advocacy groups, or outside the walls of the IEP meeting room. They carried on the fight for others, advocating for

services and/or accommodations because they believed their students needed it. Kate stated, "I don't want to be the person who has to go home knowing I didn't do what was best for that kid." Ruby also embraced her role because she experienced it each and every day as Chuck's mom:

I think that it's affected me as advocating for my students as a teacher because I feel like I have more knowledge and I'm able to do that. And I also feel like I'm just more likely to do it [advocate] naturally. It's just part of who I am.

Defining her advocacy as doing what is best for her students, Kate pointed to secretly advocating and sharing information that she may not otherwise be allowed to discuss with parents during IEP meetings regarding services and other placement options due to implicit meeting expectations:

We're helping those who are likely in the same boat we are in. I mean I hate to tell you how many meetings I have, parent-teacher conferences, or IEP meetings, and I have to say, "Let's take a walk. Now that we're off campus, I'd like to recommend something. Now I'm not talking to you as Mrs. Teacher. I'm just talking to you as this random person you heard something from, just this wild rumor."

These two mothers were even strategic in their approaches to advocating in their classrooms and, as Ruby explained, placed a priority on ensuring they addressed their students' needs:

If I know a kid is not going to write down his homework because of the processing and the multi-step of looking at the board and then looking at his planner to write it down. I know from being a parent and from knowing special ed practices that that kid's going to need that help. So I may go over and remind them or I may write it down for them.

Kate noted in her journal that it was the experience of hearing mostly bad information concerning Eric that guided advocacy by keeping open and positive lines of communication with parents:

As parents we always need good news! I haven't seen much with Eric, so I push to find something to share, because I send home daily communication with each of my students. I often jot down progress towards a goal, an observation, something cute done/said. I don't know if it makes a difference for mom/dad/foster/grandparent/g-grandparent, but I wanted and still want to hear good things, beyond "he can play (blank) or likes (blank)."

Perceptions of job security. Among the unexpected difficulties in advocating for their children inside the school district where they worked was a common perception carried by these mothers that was not openly discussed within the educational rank and file. It was the fear that advocating for Chuck and Eric would negatively impact their job security. It was a fear they never anticipated, but a fear they clearly perceived. Kate stated, "I know that my job, whether they say it or not, is in limbo if I throw the biggest hissy fit on earth." Ruby spoke more openly about that fear and worrying whether the words she used or the position she took in meetings would come back to haunt her:

No one's ever going to say it, but it's expected. And then you go home and then you start analyzing everything that you said and everything that they said, and then it's like, "Did I say this okay? Are they going to think I was being disrespectful? Are they going to think I was being rude? Am I going to lose my job?" It's a fear. It is a constant, constant fear.

Ruby's fear may have been predicated by real circumstances. She was called to her principal's office and was questioned about advocating for Chuck, who attended another school at the time. Ruby said she called the district transportation office parent helpline when a mistake in Chuck's special education paperwork left him without his IEP-mandated specialized bus transportation. It was already 2 weeks into the school year and Ruby was left without a means to get Chuck to school because she had to be in her own classroom. When she questioned the district, she found herself being questioned by her principal:

She [principal] shouldn't have been in that position. I shouldn't have been in that position. None of us should have been in that position. And I didn't do anything wrong. And even if I had, it shouldn't have been brought to my boss.

Although Kate never experienced a scenario like Ruby, she believed she was more reserved in Eric's IEP meetings than other parents because she carried the fear of retribution:

You know you've had those IEP meetings where the mom is like, it's smack down time and she's going to drag you through the mud, because she's getting what she wants, because this is her kid. But if I did that, what would happen?

Regardless, Ruby's or Kate's perception that each faced scrutiny and could possibly lose their jobs because they advocated for their own children in the system where they worked served as a barrier for these parent-educators. They had to fight from within while at the same time they had to worry about the perceived consequences. Ruby summed it up best: "If I didn't work for the district I would've pushed to get things done and I wouldn't have been afraid I was going to lose my job."

The evolution of these parents as advocates remains unfinished. Ruby and Kate both entered education to secure a meaningful education for their sons. Yet, neither discussed plans to remain. Not because of their challenging experiences in advocating for Chuck and Eric, but because they aspired to advocate and impact students with disabilities beyond their current context. Ruby dreams to pursue avenues of parental advocacy outside the school district: "I just want to change the world and the way that they perceive the needs of our children, being the needs of our children have not changed." Kate hopes to leave behind some of the conflicts of living in the dual role of parent and teacher, no longer serving students in special education to instead become a district reading coach for students in general education. Her new passion will not separate her from kids with

unique needs. Instead, her desire will take her down a different road, working with children who struggle to read.

Discussion

This research was designed to uncover the experiences and barriers of parent-educators who work within the district where their child with autism attends school as well as how they perceived advocating for their own children in their dual role as parent and educator affected their job security. These parents became educators to advocate for their children, yet they experienced conflict not only in their partnerships with schools but also within their teaching roles. Findings of this study illustrate how individuals, living the dual roles as parent and educator, can experience unique forces that inhibit their advocacy efforts for their children as well as their students. The findings also provide a glimpse into the difficulties parents can experience as they advocate for their children with autism, even those who are not limited by lack of knowledge or understanding of special education jargon. Ruby and Kate found it frustrating when they and their sons encountered teachers who were unfamiliar with special education needs and/or requirements, even when those teachers were special education teachers. To them, special education teachers are supposed to be the disability experts in schools. They did not mind working collaboratively with their sons' teachers, but did mind when those teachers had no understanding about autism or sensory-related behaviors or the importance of accommodations and why such supports are necessary. In addition, Ruby and Kate experienced instances where they believed their job security was threatened as they advocated for their own children's educational needs. These scenarios made advocating challenging and left Ruby and Kate to question that if they knew the ins and outs and still had difficulties, how would other parents who knew less manage to advocate for effective outcomes for their children? Similar concerns have been previously noted (Spann et al., 2003; S. E. White, 2014).

Experiences of and Barriers to Parent-Educator Advocacy

Although much has been written about what parents or educators do or do not do when advocating for and serving the needs of students with disabilities, little has been written about how those who occupy the dual roles and perspectives as parent-educators can lend insight into improving parent-school partnerships. Parents of students with autism and other disabilities typically encounter more stress when meeting with school officials than parents of students without disabilities (Bitsika & Sharpley, 2004; Hsiao, Higgins, Pierce, Whitby, & Tandy, 2017). Parent-educators hold specific, insider knowledge from both a consumer and a practitioner point of view that districts could use as assets to improve family-school relationships in special education. Furthermore, the experiences of parent-educators like Ruby and Kate can help parents as well as educators better understand the forces that both support and inhibit successful partnerships.

Burke, Goldman, Hart, and Hodapp (2016) called for national, state, and local policy makers to provide both parent training and special education advocacy training so those who advocate for students with disabilities can do so confidently without creating adversarial relationships with schools. One promising idea, that is unexplored in the literature, is to use the knowledge and experience parent-educators like Ruby and Kate have for such parent advocacy and training. Dual role, parent-educators have much more access to educational knowledge than the typical parent. They understand what it is like to advocate as the parent of a child with a disability and they have the in-depth knowledge of how school systems work and how IDEA should be applied in school settings. Hess et al. (2006) suggested that education professionals further their own understandings of parent-school collaboration in special education. Schools districts should explore options for creating roles and responsibilities for parent-educators like Ruby and Kate to develop comprehensive parent education programs and training

materials to educate parents about the complexities of their rights under law while offering support for parents of students with disabilities. These efforts could focus on first understanding the law and include strategies for parents to use as they navigate the challenging waters of advocating for their children with teachers and administrators. Such efforts have the potential for helping address the concern of parents feeling lost in a system they find challenging to comprehend (Huang, Kellest, & St John, 2010; Kalyanpur & Harry, 2012; Spann et al., 2003) and countering the dilemmas parents of students with autism encounter as they advocate and fight educational professionals for the services they feel their children need but do not receive (Stoner et al., 2005). Indeed, the multidimensional view of parent-educators like Ruby and Kate may hold unique insights into how schools and families can enhance collaborative efforts.

Barriers, however, clearly existed for Ruby and Kate. They struggled with obstacles they never anticipated, particularly the knowledge they had acquired as both a parent and an educator and the lack of knowledge they encountered by those charged with the education of their sons. While it is not surprising that parents who are as finely tuned to their child's disability as Ruby and Kate have such a vast expanse of special education knowledge, it is surprising to find the imbalance left them feeling constrained by the system and the educators within it. As a result, their relations with schools broke down. Research has identified a lack of special education knowledge among others as a contributor to failed collaboration between parents and educators (Hess et al., 2006; Mueller & Piantoni, 2013; Rosenzweig, 2009). Therefore, it is evident that teachers need to know more, general and special education alike, about autism (Loiacono & Valenti, 2010; S. E. White, 2014) and how to effectively collaborate with their parents (Collier, Keefe, & Hirrel, 2015; McLeskey et al., 2017; Vitelli, 2015). The experiences for Ruby and Kate may have been improved by teachers who knew that children with autism and autism-related behaviors may have an aversion to the feel of sitting on the

carpet or why they would continue to require classroom supports even while in high school.

The Complexity of Responsible Advocacy as a Parent-Educator

Another consideration from the findings of this study is the ethical dilemma created when advocacy intertwines with job expectations for such parent-educators. The theory of responsible advocacy (Fitzpatrick & Gauthier, 2001), although originally used in the field of communication, supports the notion of identity conflict when roles converge in the workplace. These two mothers both found themselves at odds with the expectations of their profession and their desire to advocate for other children much like their own. The literature informs us of parents in various roles of advocacy and agents for change (Trainor, 2010) in education, yet little has been investigated related to the intersection of these roles. The identity crisis that can exist among parent-educators in special education has been discussed by a few researchers (i.e., Authors, 2018; Koch, 2011). Although these studies are few in nature, they do enlighten the field as to the existence of such ethical dilemmas and raise questions regarding how to access insider knowledge in relationship building and how to provide a safe space for those with identities that collide within their workplace. Perhaps by allowing these parent-educators a voice in advocacy, school district training, and educator preparation as we have suggested, they will become agents of change in parent-school relationship building, while also finding a space for their voices to be heard instead of feeling conflicted by what they perceive is unheeded.

Creating a safe space for such parent-educators in special education also requires safety from work-related reprisals. Ruby was called to her principal's office because she advocated for Chuck's transportation in another school. We can think of few professions where such an occurrence is possible and where the roles of being a parent and an employee are blurred. The number of parent-educators inside school districts like Ruby and Kate is

unknown. It would, however, behoove school districts to reflect not solely on building relationships with parents on the outside but also on the relationships they forge with those they employ on the inside.

Implication for Teacher Education

Aside from the considerations found within the unique insights of parent-educators like Ruby and Kate is an implication for practice as it relates to preparing educators in special education. Educator preparation programs and district in-service professional development play a vital role in preparing teachers to work effectively with students with autism and other disabilities. Koch (2011) suggested parent-educators are better situated to support educator understanding of students with disabilities and their parents; therefore, accessing parent-educators with inside knowledge and experiences like Ruby and Kate could help teachers learn the necessary knowledge, skills, and dispositions toward collaborating with families of students with disabilities. This can be accomplished by incorporating such parent-educators into teacher preparation coursework and school district-level trainings. For example, Ruby and Kate can use their knowledge as insiders within a system to help teachers understand the systems they work in from a variety of perspectives (e.g., teacher, student, parent, and administration). They can provide concrete examples for teachers to discuss and unpack in their learning communities. Learning from parent-educators who are innately attuned to both roles can positively impact the experiences and outcomes of students with disabilities, their parents, and the educators who provide the supports toward a meaningful education.

Limitations and Future Research

The limitations within this inquiry provide opportunities for further research about dual parent-educator roles. These areas include replication of the study and expanding the number of participants, and differentiation among the participants in the bounded case,

such as including the voices of parents who are educational administrators. One limitation is that this heuristic case study is designed to allow a reader insight into a select group of individuals based on the evidence within the cases, as opposed to making generalizations for all. This inquiry focused on the voices of two individuals; therefore, the extent of such experiences and barriers of those who work on the inside cannot truly be recognized. Law-makers intended for parents and schools to collaborate when they reauthorized IDEA more than a decade ago, yet special education complaints continue. Studies have focused on the separate perspectives of parents and educators, yet few have appraised parent-educators. Future research with this group has the potential for further identifying barriers that impede parent-school collaboration and further insights into how parent-school collaboration can be enhanced. Including the voices of parent-educators who are also school site based or district administrators is an avenue for future research as well. The role they serve within school districts may or may not lend itself to different experiences advocating for their own children with disabilities.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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