

*Parents are the Experts: Understanding Parent Knowledge and the Strategies They Use to Foster Collaboration with Special Education Teams*

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*Abstract*

The Education for All Handicapped Children Act (1975), PL-94142, mandated parent participation as a required component of the provision of special education services to children with disabilities. It is widely recognized that a collaborative teaming approach is the most effective strategy to foster parent participation (Friend & Cook, 2010; A. Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011; R. Turnbull, Turnbull, & Wehmeyer, 2010). This article explores selected findings from a qualitative research study that investigated the perspective of parents of children with disabilities in order to understand: 1) how they acquired and shared knowledge about their child's disability, 2) how they navigated and negotiated special education processes and 3) how they fostered collaboration with professionals. By exploring the issue of collaborative teaming through the lens of parents, the study offers insight about the expertise of parents, the dynamics of collaborative teaming and the multi-faceted nature of the "parental role."

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Throughout the history of special education, parents have played a fundamental role in guaranteeing that all children with disabilities in the United States of America have the right to public education. Parent advocacy in the 1960s and 1970s helped to ensure that the doors to public schools were opened to children with disabilities. Moreover their efforts established parent and student participation as a key principle of the Education for All Handicapped Children Act (EAHCA) in 1975. This principle has been upheld in subsequent reauthorizations of the law as evidenced by the following language in IDEIA (2004):

*Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by...strengthening the role and responsibility of parents and ensuring that families...have meaningful opportunities to participate in the education of their children at school and at home.*

Despite recognition of the legacy of parent advocacy and subsequent legal requirements for parents to participate in the special education process, many families of children with disabilities continue to feel marginalized in special education meetings and processes. This sense of inequity grows from a perception that the professionals in the meeting hold more power and that their "expert" knowledge carries more weight than parental knowledge (Valle, 2009).

Much of the recent literature on collaborating with families in special education focuses on strategies, which professionals can adopt to foster increased parent engagement (Edwards & Da Fonte, 2012; Lo, 2012). For example, Staples and Diliberto (2010) offered strategies for engaging parents with a primary focus on establishing communication systems. Other scholars suggested tips for facilitating successful Individualized Education Plan (IEP) meetings, (Cheatham, Hart, Malian, & McDonald, 2012; Lo, 2012; Mueller, 2009). In addition, recent literature has unpacked many of the barriers parents faced in collaborating with schools, including the challenges school professionals encountered when working with families from diverse backgrounds (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Harry, 2008).

Although the literature on strategies for professionals and the literature on barriers to collaboration have provided some insight into what is not working in collaborative teaming, it is important to note that both bodies of work have focused primarily on professionals' perceptions of and solutions to challenges related to collaboration between parents and school professionals. To improve parent and professional partnerships and outcomes for children with disabilities, it is necessary to understand parents' perspectives on the experience of collaborating with schools (Blue-Banning et al., 2004; Valle, 2011).

### **Interpreting the Law**

Over the last 30 years, schools and families have grappled with how to best meet the intent of the law and how to form effective partnerships. Research on parent participation in special education has evolved from examining rates of participation and parental satisfaction to offering frameworks and strategies for creating equitable teams (Harry, 2008; Shepherd, Giangreco, & Cook, 2013). Early studies conducted after the passage of the EAHCA in 1975 revealed that participation was mainly characterized by getting parents to sit at the table (Vacc et al., 1985; Vaughn, Bos, Harrell, & Lasky, 1988) whereas now researchers and professionals are grappling with what it means for parents to achieve equity in decision-making (Cook, Shepherd, Cook, & Cook, 2012; Ruppert & Gaffney, 2011; Staples & Diliberto, 2010). An underlying assumption about parent participation in special education has been that collaborative teaming is the model for assuring equal participation. By collaborative team it means that parents are considered to be equal partners in making educational decisions. However, this partnership is not explicitly stated in the language of the law (Welch, 1998). Although there is a legal requirement for shared decision-making, little direction is provided to special education teams about how to meet that expectation. As a result, a number of researchers have examined the practice of partnering with families and collaborative teaming in special education (Blue-Banning et al., 2004; deFur, 2012; Edwards & Da Fonte, 2012; Harry, 2008; Turnbull et al., 2011; Turnbull, Blue-Banning, Turbivell, & Park, 1999; Welch; Whitbread, Bruder, Fleming, & Park, 2007). The literature provides not only definitions of collaborative practice (Friend & Cook, 2010; Mostert, 1996; Villa & Thousand, 1999) but theoretical frameworks, which offer strategies to enact collaborative practice (Blue-Banning et al., 2004, Fialka, 2001, R. Turnbull et al., 2010, deFur, 2012). Researchers have deconstructed the complexity of the task and have continued to probe different facets of the teaming experience including parent voice (Hess, Molina, & Kozleski, 2006; Valle, 2009), parent satisfaction in the IEP process (Fish, 2008) and the interpersonal elements of teaming (Angell, Stoner, & Shelden, 2009). In practice, effective collaboration is a

complex process that requires intentional effort. Despite an overwhelming response from scholars and practitioners about how to collaborate with families effectively, there are still significant barriers that impact parent participation (Blue-Banning et al., 2004; Harry, 2008; Staples & Diliberto, 2010). To some degree, special education teams face challenges struggling to comply with the law while navigating the complexity of forming collaborative partnerships (Mueller, 2009; Turnbull et al., 2011). This is complicated by the rhetoric “parents are the experts” but in practice what does that mean? If professionals abide by that philosophy, why do so many parents of disabilities feel that their knowledge and expertise are undervalued by school systems? This study deeply explored what parent expertise means to parents and how parents operationalize it to foster effective collaboration with school professionals.

### *Research Design*

This research was a qualitative case study bounded within a northeastern state. The unit of analysis was the stories of 12 parents. This article captures two primary themes from the study that explore how parents express their expertise and form collaborative relationships with professionals.

#### **Site and Participant Selection**

**Sampling.** Purposeful sampling was used to recruit participants. Purposeful sampling is a strategy used to select participants who will “purposefully” contribute understanding of the research problem (Creswell, 2007).

**Recruitment.** Recruitment of families occurred through several channels including contacts with a non-profit advocacy organization for families of children with disabilities, special education professionals and word of mouth. The 12 participants were drawn from different geographical regions of the state representing nine different school districts and at least 22 different school experiences.

**Demographics.** The study included 10 mothers and two fathers, nine of who had completed four-year college degrees. The remaining three had completed some level of college education. Ten of the participants identified themselves as Caucasian with two identifying as non-Caucasian. Additionally, of the 12 parents recruited, seven had children with high incidence disabilities including autism, learning or language disabilities or emotional disturbance. Five parents had children with multiple disabilities or developmental delay. Seven parents reported being partially satisfied with their experiences with special education whereas four reported being very satisfied and only one stated “less satisfied.” The ages of their children at the time of the study ranged from pre-school through post-secondary. Demographics of the participants are summarized in Table 1.

Table 1  
*Study Participants*

Participant Pseudonym	Current age of Child	Disability Type
Will	Preschool	Multiple Disabilities
Andrew	Elementary School	Autism
She’ Ra Monroe	Elementary School	Developmental Delay

Kelly	Elementary School	Traumatic Brain Injury, ADHD, LD
Lulu	Elementary School	Language Impairment
Lindsay	Elementary School	Autism
Bethany	Middle School	Multiple Disabilities
Lina	Middle School	Multiple Disabilities
Holly	High School	Emotional Disturbance
Jane	High School	Multiple Disabilities
Katie	High School	Language Impairment
Maggie	Post-Secondary	Language Impairment

### Data Collection

**Interviews.** Data were collected primarily through interviews. Twelve interviews were conducted with either a mother or father of a child with a disability. The interviews lasted between 45 minutes to two hours and used a semi-structured interview protocol. Questions were primarily open-ended and designed to allow the parents to reflect on their experiences with collaboration and teaming. The interviews also provided an opportunity for parents to draw, sketch or visually represent their experiences. This technique has been found to elicit deeper emotional responses from participants (Kearney & Hyle, 2004; Vince, 1995). Participants were asked to visually represent their experiences with their child's special education team and then to describe what the image represented.

**Focus forum.** Upon completion of the interviews, a focus forum was scheduled as a follow-up to the interview process. Five parents elected to participate in the focus forum. It was held in the evening and entailed a two hour structured conversation focused on emerging themes from the interviews.

### Data Analysis

Several methods were used to analyze data: memoing, coding, and cross-case analysis. Through these techniques themes about parents' experiences with collaboration were identified.

**Coding and memoing.** Field memos were written after each interview and the focus forum. Through memoing, preliminary codes emerged that informed analysis of the interview transcripts and focus forum notes. The initial coding phase was characterized by recording first impressions of the data (Saldana, 2009). Subsequent coding and analysis of the interview data revealed six themes. Codes were finalized after conducting the focus forum and through this process resulted in 39 codes embedded within five themes.

**Cross-case analysis.** A third type of data analysis employed was cross-case analysis (Miles & Huberman, 1994). Each interview represented a case. Using cross-case analysis, a matrix was created that identified which participants provided data to support identified themes. Cross-case analysis of the data provided an accessible structure to examine codes and analyze themes that emerged.

## **Data Representation**

Qualitative research is characterized by providing the reader a “complex description and interpretation of the problem” which includes voices of the participants (Creswell, 2007, p. 37). Data are presented in this article in two primary ways: 1) giving voice to parents’ unique or composite experiences within analysis of the themes, and 2) visual representation. Themes are written to maximize the voices of participants and to use their narrative as the vehicle to explore the main ideas of the theme. Additionally, participants were asked to draw their experiences with collaboration. According to Kearney and Hyle (2004), drawings allow the researcher to explore emotion. Through their research they found drawings unlocked participants’ feelings. Using a drawing prompt provided an alternative method to generate the perspective of parents beyond the interview questions posed. This article includes one participant drawing.

## **Data and Methodological Limitations**

### **Trustworthiness**

Creswell (2007) recommended adopting at least two strategies to evaluate the accuracy of qualitative research findings. The following procedures were employed in this study: a.) Triangulation of data through analysis of several types of data including interviews, focus forum and artwork; b) peer review through soliciting input from a colleague; c) member checking by having participants read transcripts before coding began.

## *Findings*

Two primary themes that emerged from this study included:

- “Knowing My Child”- in which parents express their roles as experts about their children and reflect on the degree to which their knowledge is valued by school teams.
- “Constructing a Seat at the Table”- in which parents, reveal the strategies they employ to form collaborative relationships with school professionals.

## **Theme 1: Knowing My Child**

### **Adopting a Role**

Throughout the interviews participants conveyed the explicit knowledge they had about their children’s needs and the multitude of ways they share that knowledge with professionals. Participants articulated numerous roles they adopted in caring for their child. Through these roles parents revealed not only the knowledge they held about their child, but displayed the complexity of what it means to be “the parent” of a child with a disability.

**Parents as case managers.** Although the term “case manager” is often used in the context of professional roles, participants in this study communicated many examples of how they view themselves as case managers and as the ones who had a clear understanding of the whole child. Therefore “knowing my child” from the parent lens meant not only having long term intimate knowledge of their child’s needs, but also coordinating all facets of their child’s life, including multiple service providers.

Early in her son's life, Bethany created a visual display to share with service providers to help them understand the vast network of individuals providing service to her son as well to help convey an understanding that she viewed herself as his ultimate "case manager." Bethany shared, "I kept hearing that everyone was [her son's] case manager, but everyone was a case manager in their own realm and so there were six or seven of them and I was ultimately the case manager who connected all of those hubs." When children have complex needs, oftentimes there can be a variety of agencies and professionals providing services. Parents saw themselves as the cornerstones, managing the professionals, to ensure that the child's needs were getting met. This often included managing opposing personalities in order to keep the focus on what parents viewed as their long-term goals.

For Holly this process of "managing" the team became quite burdensome. As lines of communication broke down between the agencies serving her child, she found herself making multiple phone calls and having numerous separate meetings outside the team meetings to make sure each individual was clear about her perspective and what her son's needs were. Managing the relationships of all the team members was a central piece of how she ensured that her son's needs were getting addressed. Holly was very upset about this, recalling:

*It's ridiculous because everyone has their own agenda, everyone has their own defenses, so like I want to have a conversation with like case management on what they're doing, I can't have it at that meeting because school's jumping all over them for something and then DCF is putting their two cents in, which is fine because I do like our DCF worker a lot, and then I have the LEA saying we should do this, so I can't, and nothing is settled. It's awful.*

She remembered counting 40 emails that circulated among team members with regard to picking dates for one meeting. Her frustration mounted as her son's behavior escalated to the point where she had to call the sheriff's office on a frequent basis. At one point the sheriff's office stepped in as respite providers on days her son was sent home from school or was struggling at home. Her son experienced five different school settings in multiple locations with rotating teams of professionals. Like Holly, other participants described juggling multiple personalities and coordinating up to 20 service providers in meeting the needs of their children. This reality was captured through a drawing Maggie produced in the focus group (Figure 1) in which she represented the parent as a "juggler" who had the sense of the whole child and coordinated the integration of all the different types of services the child accessed some school related, some not. In describing the drawing she noted:

*That parent is a juggler, although the balls interact and overlap but I feel like the parent is the one who has all the balls, is the one touching all of them. There's mental health, emotional health, education, there's social life, the family interactions and just at home life and how things go there. That all this is part of the whole picture of your child's life and making their life run smoother and part of their overall education.*



*Figure 1.* Maggie’s depiction of parent knowledge. When asked to depict “parent knowledge” Maggie captured the multiple parts of the child’s life that the parent is knowledgeable about and manages including: 1) physical health, 2) education, 3) mental health, 4) social and 5) family.

**Parents as interventionists.** The reality is that many children with disabilities are not just receiving interventions in school settings; they are also receiving intervention at home. Andrew and his wife were actively engaged in networking with others and using their own resources to bring to bear on educational decisions for their son. He recalled referencing books on child development and tracking his son’s progress towards meeting developmental milestones. Additionally, he and his wife spent hours working with their son to develop eye contact. He described an exhausting routine early in his son’s life where he and his wife were juggling work and providing intervention:

*She’s coming in and I’m going out. And so she’s doing the tuck to bed and then she gets some sleep and gets up in the morning and does the morning feeding, getting him washed and clothed and I come stringing in. I take him off to daycare, come home and go to sleep. Get up in the afternoon, run over to pick him up, we start daddy “face time” and the weekends it’s the other way around. She’s doing it and I’m working and sleeping and so 100% coverage by parents.*

Lina applied her training as a nurse to assist the medical professionals in resolving her daughter’s feeding challenges. At first she faced resistance when sharing her perspective that oral feeding should continue to be a goal despite concerns by medical staff that her daughter might aspirate. She recalled:

*Yeah I said “I would aspirate also if you squirt stuff in my mouth that I don’t want and leaving me flat on x-ray table.” So they said, “It’s my choice. You can go ahead and do it and if she aspirates that’s what it is.” She never aspirated. She never had aspiration pneumonia.*

She’ Ra Monroe spoke of the importance of bridging between home and school and how much she appreciated when professionals would work with her son on skills or concerns that were being raised at home. Likewise, she envisioned that she also played a role in providing intervention. She expressed:

*I'm there for him to solidify or to reinforce a lot of the learning. I'm by no means a teacher but I can give him the things they give me to teach him. I offer some different input on what might be motivators for him. I bring a lot of that into the school...so I bring all sorts of tools and stuff from home to create that bridge...*

**Parents as experts.** Maggie shared the perspective that there is bridging between home and school and that the parents use their knowledge to provide intervention at home too. She recalled hours spent helping her daughter with homework and that she used the fact that she knew her daughter's memory was assisted by music to create songs to help her memorize information. Later she and her husband accessed music therapy through their own resources as an additional intervention to help their daughter. As she explained,

*When you see your children you know what the, I guess what you could call, what the symptoms are. You might not know what they mean, whatever the disability or the issue, but you've seen them grow up. You know that age four she can't count to 10 so something is wrong here. I can't tell you what it is, but I'm the expert and can tell you this is what I see. And then when they start some of their information in the meetings and it's like they then, okay we'll take whatever we know from here but some what they know isn't, they're not seeing the whole picture. They're sort of seeing okay, we'll take this and we'll put a label on it and we'll run the ball with one play in mind. You have to look more than one play here because things kept showing up. So you have to keep looking back to the parent as, you are an expert here.*

For Will and his wife, due to the rarity of their daughter's disorder, the information they shared with the team was often the most contemporary information available to assist professionals in developing interventions. He acknowledged that they provided 100% of the information regarding his daughter's needs to each new professional that they encountered. Will stated:

*We provide all the information; we provide links to information and things like that. There's not a ton of information out there because it's a rare disease so there's only like 700 confirmed cases in the world right now so yea, we provide, nobody's ever heard of it whenever we talk to anybody.*

Service providers change and in reality are only delivering intervention for a portion of a child's day. Participants universally expressed the importance of their role as a constant in their children's lives and acknowledged their long-term role as case manager, interventionist and expert on their children. As Bethany summarized: "We've been doing this for 13 years. Most of them are coming in for one. I respect their professional expertise and their knowledge and I expect them to respect mine which is, this is my life's work is raising my kids....".

**Validity of Parent Knowledge** One of the dynamics that some participants shared was the experience of feeling as if school based teams discounted information that parents brought to meetings about their children. Although parents did not always experience this as an outright dismissal, some parents noted feeling frustrated that items they felt were particularly important or urgent were overlooked or appeared to require additional professional expertise to validate

their perspective. Jane recalled turning to her son's pediatrician to reinforce a point she was trying to communicate to school professionals:

*At the time [my son] had a pediatrician that had been with him since birth who was very supportive of us and I remember on at least two occasions and probably more, trying to make a point to the school but them not really hearing me. I didn't feel like they were understanding what I was trying to say or they were just flat out disagreeing with it and on at least two occasions I asked the pediatrician about this subject and he agreed with me and I asked him to write a letter. One time he wrote a letter and one time he actually came to a meeting and he said the same thing I did and they were like oh, okay, it was very immediate acceptance and agreement with him. I remember feeling simultaneously thank goodness he's here and why did he have to be here? He was saying the same thing I was.*

Lulu experienced a similar dynamic in her role as an advocate for adoptive parents. She found that in her professional role she recommended to other parents that she accompany them to meetings so that school professionals would be more apt to listen. Lulu contrasted this with her experience as a parent where she did not feel heard but did not have the energy to fight with professionals over a service or decision that she did not believe was appropriate for her child.

Like Lulu, Kelly juggled the world of both parent and professional and noticed that even though the school-based teams that she has collaborated with around her daughter knew that she was an educational professional, it did not feel that her professional role afforded her more clout in meetings. She expressed:

*And then the other piece is kind of the challenge of things, it seems like whatever the information about [my daughter] is being provided to any professional is more valid if it comes from a professional and it's really particularly interesting because I know that they know that I'm a professional and I know that they give me, I can tell, I know that they give me a different level, they assume a different level of knowledge and credibility on my part, but I still can tell at times like until I give them this information on a piece of paper, signed by a physician, it's not gonna be as real as it is just with me telling them and I don't really know why that is but I think it's a very real phenomenon.*

### **Establishing Equity**

Participants articulated a variety of ways that school professionals could foster a greater sense of equity beyond simply demonstrating that they valued parent knowledge. They articulated ways in which information could and should be shared and emphasized a need for frequent and open communication.

**Sharing resources between school and home.** Maggie and Lina felt that the elementary school professionals they worked with not only were receptive to their opinions on their daughters' needs but also were willing to share resources generously. Lina's daughter's medical needs were very complex and required numerous interventions by a variety of service providers. Lina valued the willingness of service providers to come to her home to watch how she provided care as well as their willingness to include her in decision-making and experimenting with new

equipment. She shared a specific example of the way in which she felt she was partnering effectively with a professional on her daughter's team:

*The [physical therapist] is very good at introducing me to different like equipment or different opportunities that can go, like a tricycle, fitting special kids into a tricycle...so they had her try on those tricycles and then they said this is a better one for her and I go wow, I saw other kids doing this also. That was impossible for me to think she can ride a tricycle...that was a very good experience.*

For Maggie, the experience of feeling like the team was sharing resources with her came when professionals on the team offered books as resources to provide her with more information about her daughter's language development. She' Ra Monroe echoed the value of feeling as if the team was providing resource beyond the scope of what was happening at school. After relaying a harrowing experience of her child letting himself out of her apartment in the middle of the night, she was touched by the special educator's advocacy to build a social story for him that addressed that home concern. He brought the social story home for her to be able to implement. That being said, participants highlighted that finding mechanisms to communicate information and establishing the nature of what information is important to share is also an essential component of "knowing the child".

**Mechanisms for communication.** One of the frustrations that some participants conveyed was that the structure and constraints of IEP meetings often negatively impacted their ability to share and receive information that they considered important to their child's program. Many of the parents interviewed noted that the traditional IEP structure did not allow nearly enough time for parents and school personnel to fully discuss the child's needs at home and at school and/or for parents and teachers to build positive and collaborative relationships. Lulu talked about opening up additional avenues for communication:

*Really that piece is such a cliché but parents really are the expert on their children and I think, a lot of what I see it goes back to that piece about clear agenda for meetings because they often see professionals getting frustrated in meetings because we're sort of, the parent is sort of rambling about stuff that's not really on the agenda but pertinent to what's happening to the kid and I'm watching the special educators look at the clock because we have an hour and we're not even talking about the IEP goals yet. It sort of goes back to like making sure that there's other times and venues for the parents to talk about that stuff and they understand that, so they aren't saving up all the little concerns about homework or social stuff and for me an IEP meeting for where we really need to adjust goals or whatever it is. I think that's why parents do that because they feel like okay we've got everyone here.*

Ultimately whether information was being shared through meetings or through other avenues, participants acknowledged that the process was extremely important and that school-based teams needed to recognize that information was flowing to other service providers. They wanted recognition that the point person for information distribution was the parent. Lindsay discussed a shift she has noticed in the medical system and urged others to consider the implications for special education teams. She explained:

*It almost seems that a generation or two generations ago you went to a doctor, you didn't bring a lot of your own information, you didn't challenge what the doctor said, you took what they said and did it and it seems like the whole special ed area... still runs like an old school doctor's office where you show up and they will tell you what you will or will not do and instead it needs to be, "here's my information" and "here's how we are going to make it work for all of us" and "this is what I don't agree with," and it's okay for me to say that. I shouldn't be shut down for not agreeing.*

While there have been advances in medicine in relationship to the ways patients share their knowledge with medical professionals, Lindsay believes that education is stuck in an old medical model. As parents talked about the process of information sharing and the importance of feeling heard in the process, they were also sharing the many strategies they employ to create a sense of collaboration with professionals.

## **Theme 2: Constructing a Seat at the Table**

There are numerous resources that guide professionals in strategies to establish collaborative partnerships with families of children with disabilities (e.g., Lo, 2012; Staples & Diliberto, 2010; Turnbull et al., 2011). However, often times embedded in recommended practice is an assumption that the responsibility for creating and facilitating collaboration lies with professionals. The participants revealed a number of strategies that they use to facilitate collaboration with school professionals, evidence that creating collaborative relationships is not solely a professionally driven process.

### **Parent Strategies**

One of the assumptions professionals may make in special education is that parents play a passive role in collaboration or that collaborative practice is achieved solely through the actions of professionals. Participants shared a number of strategies that they used to foster collaborative relationships with professionals. Some of these strategies were more visible and recognizable such as advocating for services, initiating meetings or requesting communication systems, while other strategies were subtler and reflected a side of collaboration that is not often identified in the literature such as the use of emotion. The process of collaborative teaming around a child is an emotional process, and parents utilized a variety of strategies that were emotional in nature. These included injecting emotion into the often bureaucratic structure of meetings, intentionally self-regulating their own emotions at times when they believed an emotional response might derail collaboration, or employing strong advocacy when they felt their child's rights were being violated. At other times it meant intentionally taking a more passive role as a strategy for self-care or to show confidence in the team's approach. The role of emotion is significant when we think about parent participation in meetings; often the meaning behind parents' actions may be misinterpreted as reactive or passive, yet from participants' perspectives those actions may be quite intentional. Lastly, interviewees described the importance of employing strategies to become as informed as possible about their child's needs as well as ensuring that team members had the best information available to inform programming. Parents used a variety of strategies to continue learning not only about their child's individual needs but how to navigate the system in order to effectively collaborate to ensure their children's needs were being met. Participants identified a variety of communication strategies that they felt contributed to a strong sense of collaboration on their teams. These strategies included frequent meetings, both formal and

informal, communication systems outside of meeting times and the use of questioning to promote deeper dialogue. I will address each of these strategies separately.

**Meetings.** Participants acknowledged the value of face-to-face meetings as one means to promote collaboration. Lina identified meetings as an important strategy for building collaboration with her team. She stated, “The meeting is a good time. Yeah. That you have your input in there. They always give you a chance to speak. School is very nice of giving me to share my concerns or expectations for them.” She added that the school also invited her input through a yearly survey on her level of satisfaction, which she appreciated. For Kelly, the meetings served as a time where she could not only contribute some of her ideas but also strengthen relationships with team members. She shared:

*You know I try to come to meetings or conversations from a perspective of appreciation for everything that they're doing and appreciation for the effort and skill and energy that's going into what they're doing which I hope gives me a little bit of room to also make some requests or suggestions.*

Kelly also identified that scheduling meetings at times of transition was essential to ensure that no ground was lost between school years. Kelly found that initiating a meeting as a mechanism to prepare new team members in understanding her daughter's needs started the year off on the right foot. She recalled:

*This year was the first time that I kind of insisted on a meeting with her teacher and special educator within the first two weeks of school and I know that's really hard to pull off and I felt uncomfortable doing it and I hadn't done it in the past but I felt like this is the way that I can be sure that her teacher, that she's real to her teacher. That we as a family are real to her and that [my daughter], the bigger picture of [my daughter] is sort of real to her because it's not going to be coming to her in the what do we know section of the IEP.*

She' Ra Monroe conveyed the importance of having informal meetings rather than the periodic more formal team meetings. She identified her presence in the building where her son goes to school as an intentional strategy she employed to remain in frequent communication with team members:

*I'm present. Honestly that's my best strategy. When he was in day care, I volunteered for about an hour every morning and every afternoon, and everyone knew I was there. At his school now I'm just there. We do have to have formal meetings but I touch base with his teacher, his para, the principal, and his special educator at least once a week. I just saw the OT at [convenience store] the other day and we had a little impromptu meeting there kind of just eating a Snicker's bar. Yeah, so that's my best way. I don't do email well and I don't do that like real formal thing really well. Just kind of be there. “Hi”, I'm here.*

Lulu also valued meetings, expressing that her main strategy for fostering collaboration was “lots and lots of meetings.” Although She' Ra Monroe and Lulu found that impromptu meetings

worked well to establish communication, other parents identified that systems for communication like email or communication books were equally important.

**Alternate forms of communication.** In Maggie’s experience teachers were busy and with her work schedule she could not be present during the school day to informally check-in on her daughter’s progress or relay concerns. She found that email or communication books were useful in establishing more frequent communication between school and home. She stated, “I know how busy they are and so to do email, or notes that was another thing back and forth, keeping a notebook or a journal that went back and forth. That was really helpful.” Bethany’s son had multiple service providers and two paraeducators who worked with him, so to her, daily communication was essential. Furthermore she expressed that an important strategy she used at the beginning of the year was to ensure that all team members were up to speed on her son’s personality, abilities, and needs. Part of her strategy was to ensure that the community in which her child attended school was aware of who he was, and therefore could use that information to build more authentic relationships. The process of sharing critical information to strengthen team members’ awareness in building effective programs was a strategy that many interviewees identified was part of the roles they played to promote collaboration. Jane emphasized the significance of sharing that information, noting that it deepened the team’s understanding of how to read her son in order to maximize the effectiveness of the interventions:

*I think it’s a really strong understanding of what is going to work and not work. So if they’re thinking of how are they going to do certain lessons or how are they going to manage a behavior problem, how tired he is at the end of the day, what are the signs that he’s tired. Those are all really important things to know to be able to teach him well and those are the things that the parents are going to know better than anyone I think. I mean I can look at them and say, well, when his left foot turns in a little bit, he’s starting to get tired, but not everybody is going to notice that, you know? Or I can say, well, when he starts talking like this, then it’s getting to be overwhelming for him.*

Parents can provide a very “real” picture of the child and this information can prove invaluable in designing effective programs for children. However, there were times participants found that it was more difficult to have their voices heard. They recognized that the process of collaboration could be emotional and needed to involve a range of strategies to ensure that team members were staying focused on their child and working towards a common purpose. These emotion-based strategies are important for professionals to understand.

**Emotion.** Participants viewed their intimate knowledge of their children as a vital contribution that they made during meetings and through other modes of communication. Sometimes the information they shared tapped into the emotional side of what it means to be a parent of a child with a disability and reflected the sense of urgency as well as hope parents hold for positive long-term outcomes. At other times emotion was used in connection with strong advocacy. In contrast, participants recognized that the emotional nature of collaborating on behalf of their children took an emotional toll. So for some participants, choosing to take a step back to self-regulate and restore emotional balance was an intentional approach.

Andrew saw the act of expressing emotion as a unique perspective that he brought to the table when collaborating with his son's team. He expressed, "I find myself introducing compassion, empathy for the child, needs, strengths, and his tendencies. So I try as best I can to describe [my son] and what I think his needs are from my perspective as his dad." Lulu described this as making "them remember that my kid is a kid." She spoke about helping the team develop a whole child perspective. That being said, there were times when most of the parents I interviewed felt that they were not being heard or team members were not understanding their children's needs. At those times, parents adopted an advocacy posture. Katie described these moments:

*And as a mother you have to decide, I know the system is understaffed and underpaid and so am I going to be nice and be accepting of that or am I going to be like a witch and make sure that you take care of my child because I know that the squeaky wheel gets the grease and so I understand how systems work and I know that if you force them to do it, they will do it and maybe if enough parents come together but that's the thing.*

Will felt that being transparent about the steps a parent might take to advocate for something deemed necessary for one's child was an important part of the process of collaborating with schools and a strategy he openly employed when necessary. He felt that exercising due process rights and being clear about one's willingness to utilize that step was important to communicate to the teams he was working with. He provided this example:

*And I think too when you're dealing with somebody, a special educator, somebody who's knowledgeable about the system, I know it's a lot cheaper for them to get an air conditioner than it is for us to go to due process and so, and I know that they know that I'll say, yeah, I'm done talking about it, we'll just go to due process.*

That being said, adopting a strong advocacy stance was not always a comfortable position for parents.

Jane commented on watching other parents whom she described as "aggressive" in fighting for things they believed were important for their child. In her mind an aggressive approach was not conducive to collaboration, raising the question as to whether or not the use of strong advocacy was in fact an indication of a breakdown in collaboration. If parents value differing opinions and exchange of ideas, at what point does that process reach a tipping point where what the child's needs may get lost or consensus cannot be reached? Jane commented:

*And again, I come back to, and gosh, I think this all the time, that I'm actually probably pretty good at this and a lot of times it's the parents who don't really collaborate but they are very aggressive and a lot of times they get the services but I still don't think that that's the right way to go about things. I've had several times over the years that I think, well, look at so and so, their kid gets this and this and they're the kind of parent that goes to the meeting and just launches an attack. There's no collaboration but they're getting what they want and sometimes I think, well maybe I should do that, but it's just not my style. I keep fighting for that collaborative, the elusive collaboration.*

Collaboration is not always easy and participants identified that there were times when they felt they had to employ strategies to regulate their own emotion and frustrations as a form of self-preservation. Jane saw this as a stage in her own development moving from a reactive or defensive position to one in which she could employ different strategies to address areas of disagreement. She described that process:

*Well I think again a lot of it has to do with my improved confidence and in the beginning, I remember feeling...taking things very personally and feeling very defensive often and part of that might be because of some of the players on the teams but I think more than that it was just where I was at. It was all new to me. I felt at a disadvantage so I think that made me, nobody teaches you how this all works. You have to learn it as you're going as a parent and it's not easy. You're dealing with a lot while you're trying to learn this, all the relationships, the laws, and the rights. It's just very complicated and so I would often, because I felt at a disadvantage be defensive and take things personally. So as the years have gone on, I've learned not to do that and sometimes it's really hard actually...It doesn't come naturally to me, because it feels like it's potentially inviting conflict because you don't know how that person's going to take that feedback but I still make every effort to do that because I think it's important, if we're going to work together, that they understand how something feels to me if they say it. So that's one thing that I do. I also, if I don't understand something that they're saying to me, I will ask lots of questions and that's something I didn't do before but I do now. I don't really want to move on in a meeting until I feel like I completely understand what we've just gone through.*

Jane became more confident over time about her knowledge and her skills in navigating the process, which allowed her to not feel as emotionally charged in the process. Lindsay, on the other hand, recognized that at times she needed to take a step back to regroup, and self-regulate. She recalled how emotional the process of evaluating her son had been. When services finally fell into place and she felt confident that the team was functioning well, she chose to temporarily disengage from the process as a way to recover and resume a sense of balance in her life. She described this time:

*It's like let's have a meeting when we really need to have one. Otherwise I'm kind of operating under the no news is good news kind of, I just need, and I think my husband's the same, we just kind of needed a break from how intense that was and we fully expect that intensity will come back at some point with him getting older and social interactions becoming more and more complex and so we're kind of like, let's just enjoy this somewhat stable time for what it is. We have faith in his teacher. We have faith in his team. We love the school. We're happy. Like let's just enjoy that until it all blows up in our faces again...we're kind of stepping back basically.*

Perhaps the level of confidence parents feel with collaboration is influenced by the sense of resilience parents experience or around their level of self-efficacy. For example, Will and his wife both worked as educational professionals. His confidence in working the system was a resource for collaborating with the team because he does not feel hesitant to jump in and

question practices that, were he less informed, he might take for granted. He acknowledged, “If there’s something I don’t understand or know, I ask. I know when to ask a question too. A lot of parents sometimes don’t know when to ask a question.” While some parents relied on their experience in the system or their own self-confidence, others found themselves more at ease when the personalities of their team members meshed well. The level of parental engagement and comfort, then, was influenced by more than just the parents’ knowledge and experience; the dynamics between the individual team members played a part as well.

**Seeking information and support.** Finally, participants expended a significant amount of time and energy gathering information through their networks to arm them with the knowledge and skills to actively participate on their child’s teams. These actions of networking and information gathering were ways in which parents felt they garnered support and strength to collaborate with school professionals. Parents were resourceful and expressed that having information was critical. From staying up late at night googling information on the Internet, to reading books, talking with other parents and accessing other professionals in the field as allies, the participants I interviewed were actively engaged in building their knowledge base and personal connections. Holly acknowledged that she was not afraid to call on professional allies:

*I think also a big strategy is not being afraid to like calling [an ally] and saying, I don’t know what they’re talking about or you know, they’re talking about this testing or whatever and she’s like I don’t know why they are using that testing.*

Two-thirds of the participants initiated contacts with professionals outside their school team for purposes of evaluation or consultation. Will consulted with a former colleague who steered him to a University professional who might have special expertise to assist with his daughter’s language needs. Katie and Maggie accessed an evaluator from an organization that specialized in remediating learning disabilities. Lindsay and Kelly took advantage of behavioral consultants, and Andrew’s wife actively networked with her colleagues to provide advice on programming and IEP development. Jane and She’ Ra Monroe included their child’s pediatrician in meetings. In these situations the consultation helped move evaluations forward, informed programming or provided additional expertise that they felt was needed to reinforce a point they wanted to share.

### ***Discussion***

This research was designed to add to the literature by offering an in depth exploration of parents’ experiences with collaboration with schools. The study offered a deeper understanding of parent expertise and how parents construct collaborative relationships within the special education context.

### **Establishing Collaborative Relationships**

Whereas the research literature acknowledges the skills and behaviors professionals should engage in to foster collaboration (Blue-Banning et al., 2004; Sileo & Prater, 2012; Turnbull et al., 2011), parents in this study described ways in which they actively employed their own strategies to create a functional team approach. Strategies ranged from initiating meetings, sharing chocolate, and writing thank you-notes to more complex and obscure strategies such as employing emotion. The use of emotion as a strategy to foster collaboration was commonly

expressed by the majority of the participants and represented an approach to collaboration not described elsewhere in the literature. Parents described using emotion as a tool for engaging in advocacy and as a strategy for injecting a sense of hope and humanity into the process. They also described times when they refrained from showing emotion. This was done not to hide their feelings, but as a form of self-regulation, that served to help them disengage from conflict or to replenish their feelings and sense of stability. Some professionals may perceive that “disengagement” as a form of disinterest but several parents spoke of times where they intentionally disengaged to serve different purposes. This dynamic can be further explored through application of Kalyanpur and Harry’s (2012) work on culturally responsive practice.

**Applying principles of culturally responsive practice.** Kalyanpur and Harry contended that recognition of cultural differences is a critical factor in forming collaborative relationships. With specific regard to the perspectives of minority cultures, Kalyanpur and Harry asserted that special education policies and practices have been developed from dominant cultural values that sometimes do not align with the values and cultural orientations of families. Professionals are taught to implement special education procedures through the lens of dominant cultural values. Furthermore, they argued that through the teacher preparation process, “The knowledge you have received is highly specialized and is valued more highly than a layperson’s knowledge” (Kalyanpur & Harry, 2012, p. 24). The procedural qualities of meetings that often frame the conversation may inhibit parents’ abilities to feel comfortable in expressing or sharing their ideas and/or frustrations. Moreover, the emotional aspects of parents’ experiences may at times be overlooked or worse, de-valued by professionals who embrace a more “rational” approach. Kalyanpur & Harry described, “Parents’ silence can emerge as much from the professional imposition of the parameters for discourse as from differences in interpersonal communication styles” (p. 76). Although it may not always be comfortable for professionals to listen to and process the emotional contributions of parents, interpreting what they have to offer is important for strengthening trust and promoting collaborative relationships. Understanding and interpreting why parents might adopt an emotional posture and the intent behind it is a possible insight into another dimension of the cultural nuances of collaboration between parents and professionals. Although emotion is noted in the literature primarily as it relates to grief that parents of children with disabilities may experience (Turnbull et al., 2011), exploring broader applications of emotional dimensions and their relationship to culturally responsive practice, is perhaps a direction for future research.

## **Parent Knowledge**

Participants in this study spent a great deal of time describing the knowledge they bring to the table as the experts on their child and identifying the aspects of professional knowledge that they value. Key points to understand were that parents played a variety of roles in raising their children. When considering the statement “parent as expert” it is important to understand that a dimension of what makes parents experts on their children is the complexity of what it means to be the parent of a child with a disability. Sileo and Prater (2012) wrote:

*Parents make important contributions to their children’s education. They interact with their children in more settings than do educators, and they have the perspective of the “whole” person in mind when they participate in educational processes. (p. 144)*

Participants identified multiple roles including case management, interventionist, expert, medical care provider, advocate among others. Part of what makes parent knowledge so rich and compelling is the complexity of the roles that parents adopt to effectively care for their children. Additionally, the richness of parent knowledge stems from the dynamic process of how they develop the knowledge and skills required to parent their children and negotiate effective programs and services with professionals.

### *Limitations*

In reflecting on the potential contributions of this study, I acknowledge three primary limitations. First, this study is bounded within the stories shared by the 12 parents I interviewed. This study was conducted in one state with a relatively small sample size. While the participants offered their unique insights about the nature of collaboration, it is bounded within their experiences and therefore cannot be generalized to the experience of all parents. Additionally, the sample was primarily Caucasian and college-educated. The literature on collaboration with families in special education acknowledges the unique perspectives of families from diverse cultural backgrounds (Harry, 2008, Olivos, 2009, Sileo et. al, 1996); however, this study only included two parents who identified as non-Caucasian.

Another factor that may be seen as a limitation was that this study focused solely on the perspectives of parents. This was an intentional choice and reflected a desire to create an opportunity for parents to express their “truth.” Valle (2011) emphasized the importance of conducting more research that focused on gathering the stories of parents and warned that the heavy emphasis in the literature on “how-to” approaches mistakenly place the burden of fostering positive collaborative relationships in the hands of professionals (p. 187).

### *Implications for Research and Practice*

In summary, this study illuminates how parents play a central role in fostering collaborative relationships with school and community professionals. At the core of this process are the parents who very much “juggle” all the pieces to ensure that their children are adequately supported in all facets of their lives. This research suggests that parents can play equitable roles and that in order for true partnership to evolve, professionals need to reorient how they approach collaboration with families. This includes honoring and valuing the expertise that parents bring to the table and not underestimating the importance of parental knowledge. Moreover it suggests that understanding the role of emotion in how parents participate in the process is significant and worth attending to. Further exploration of how parents develop and understand their roles as “experts” is needed in order to more acutely address the barriers to collaboration that still exist. Additionally, participants identified that more time is needed for communication outside of the structure of IEP meetings. In the best case scenarios shared by participants, mechanisms for frequent communication were in place, which strengthened collaboration and participants’ sense of equity. More research is needed to understand not just the barriers parents face in participating equitably in special education processes but also why professionals struggle to meet the intent of the law despite all the guidance on effective collaborative practice. What are the structural and/or attitudinal barriers that limit professionals in fostering collaborative relationships with families and how can those be mitigated through effective teacher preparation as well as ongoing support and mentoring in the field? By creating more equitable relationships

between parent and professionals, ideally special education teams can collaboratively strive for the greater purpose expressed so eloquently by Andrew: “How do you optimize the life of [a] child? How can you make this journey as bump free for them as you possibly can?”

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