Parents' Experiences and Perceptions Navigating the Special Education Process Across Multiple School Years.

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ABSTRACT

Over seven million children in America receive special education services yearly, meaning millions of families participate in the special education process each school year (National Center for Education Statistics, 2021). The Individuals with Disabilities Education Act, or IDEA (2004), required that parents and educators collaborate within the special education process. Given that positive parent-school collaboration correlated with increased student achievement, researchers sought to identify components of a collaborative parent-school partnership in special education: an atmosphere of trust, mutual respect, empathy, cooperation, and a balance of power between the school and special education staff (Hampden-Thompson & Galindo, 2017; Henderson et al., 2020; MacLeod et al., 2017). Even with the collective understanding in the field of education regarding the characteristics of positive parent-school partnerships in special education and the benefits for student achievement, a disconnect between special education staff and parents persists (Fenton et al., 2017). Given the impact of parent-school collaboration on student achievement, the purpose of this basic interpretative study was to explore how parents of children who qualified for special education and have participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. Using in-depth interviews with six families representing different disabilities, researchers collected the stories the families shared of their experiences navigating a combined 59 years of special education with their children. The following themes emerged: The difference one educator can make; inequality in knowledge; parent to parent support; inequality in access; balancing and navigating the professionals; and the depth of a parents' unwavering love.

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Chapter I

INTRODUCTION

According to the Individuals with Disabilities Education Act, or IDEA (2004), parents of children with disabilities and school staff must collaborate to determine students' special education services and goals because researchers found that positive parent-school collaboration correlated with increased student achievement. Researchers sought to identify components of a collaborative parent-school partnership in special education: an atmosphere of trust, mutual respect, empathy, cooperation, and a balance of power between the parents and special education staff (Hampden-Thompson & Galindo, 2017; Henderson et al., 2020; MacLeod et al., 2017). Even with this collective understanding of positive parent-school partnerships in special education and the benefits for student achievement, a disconnect between special education staff and parents persists (Fenton et al., 2017). Given the impact of parent-school collaboration on student achievement, the purpose of this basic interpretative study was to explore how parents of children who qualify for special education and have participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. In this chapter, I addressed the background of this study, defined the problem, purpose, and significance of the study, and established the theoretical framework used.

Background

Almost 7.3 million students, or approximately 14% of public-school students ages 3-21, received special education services in 2020-2021 (National Center for Education Statistics, 2021). To protect the rights of these millions of families taking part in the special education process each year, Congress enacted laws empowering parents as necessary and equal participants in the special education process (ESSA, 2015; IDEA, 1997; IDEA, 2004; Reiman et al., 2010; U.S. Department of Education, 2020). As part of the special education process, parents and school staff collaborate each year as an individual education program (IEP) team to review, revise, and determine students' goals, services, and accommodations (Francis et al., 2016; Henderson et al., 2020). The IEP team drafts IEP goals to scaffold students to as near to grade-level expectancy as possible, positively impacting student achievement (Cohen & Mosek, 2019; Francis et al., 2016; Heller et al., 2019; Lalvani, 2012; McCoach et al., 2010; McGee, 2004; Reynolds & Howard, 2013; Sheldon & Epstein, 2005; Zhang et al., 2011). When studying this collaborative parent-school partnership in special education, researchers found that parents' involvement ranged from passive to active participation (Fish, 2006; Trainor, 2010; Turnbull et al., 2011). Many parents initially reported feeling lost, confused, or disempowered in the IEP process (Trainor, 2010; Turnbull et al., 2011). As parents learned more and became active advocates for their students, they more frequently questioned school staff's IEP recommendations or implementation (Turnbull et al., 2011). When disagreement occurred, parents perceived educators' reported values regarding parental participation as incongruent with educators' responses to authentic parental participation (Bezdek et al., 2010; Bodvin et al., 2018; Fenton et al., 2017; Lake

& Billingsley, 2000). Specifically, researchers found that when parents proactively advocated by challenging the school's recommendations for implementation of the IEP, educators described parents as a "squeaky wheel" or "an annoyance" (Bezdek et al., 2010; Lalvani, 2012; Rosetti et al., 2021).

In several studies, educators described parent-school communication as positive only when it aligned with educators' values and expectations (Bezdek et al., 2010; Burke et al., 2019; Henderson et al., 2020; Lake & Billingsley, 2000; More et al., 2013). Consequently, instead of collaborating, parents often perceived that school staff tended towards a one-way transmission of knowledge that undervalued parents' expertise and negated the concept of equal participation (Cavendish & Connor, 2018; Hodge & Runswick-Cole, 2008; Kluth et al., 2007; Kurth et al., 2020; Singh & Keese, 2020; Valle, 2011). When challenging this hierarchical structure within the IEP team, parents reported stress, isolation, and marginalization due to school staff limiting communication or negatively labeling them (Burke et al., 2019; Fenton et al., 2017; Reynolds & Howard, 2013).

Despite extensive research related to parents and special education, researchers over the last 20 years continued to report a disconnect between educators and parents (Adams et al., 2016; Baxter et al., 1995; Fish, 2006; Fish, 2008; Fu et al., 2020; Harry, 2008; Henderson et al., 2020; MacLeod et al., 2017; Valle, 2011; Wang et al., 2011; Zagona et al., 2019). This disconnect matters because researchers have found that positive communication and collaboration between parents, teachers, and staff critically impacted students' achievement, decreased disciplinary issues, and increased the graduation rate of students with disabilities (Cohen & Mosek, 2019; Francis et al., 2016;

Heller et al., 2019; Lalvani, 2012; McCoach et al., 2010; McGee, 2004; Reynolds & Howard, 2013; Sheldon & Epstein, 2005; Zhang et al., 2011). After years of participation in the special education process, parents most likely have varied experiences establishing relationships with multiple school staff. Researchers have yet to study how parents' perceptions and experiences of numerous years of involvement in the special education process impact parents’ interactions and collaboration with school staff each new school year. Parents' experiences navigating their children's special education over several years most likely include untapped insight or knowledge (Kurth et al., 2020). Exploring this untapped insight and expertise could help uncover ways to bridge the reported disconnect in special education, thus allowing parents and educators to move towards genuine collaboration in the spirit of IDEA (2004), ultimately impacting student achievement (Zagona et al., 2019).

Problem Statement

Researchers established that some parents report an adversarial relationship with special education or school staff despite the legal mandate for parent-school collaboration (Bezdek et al., 2010; Burke et al., 2019; Henderson et al., 2020; IDEA, 2004; Lake & Billingsley, 2000; More et al., 2013). To better understand parents' perspectives on the parent-school relationship, Kurth et al. (2020) surveyed parents regarding their experiences with the special education process. Kurth et al. found that the parents' sense of battling the schools for years was pervasive among the study's sample and appeared to take "a toll on the families" (p. 42). Because Kurth et al. collected data only through an online survey, the depth of information collected was limited. Researchers have yet to conduct in-depth analyses of how parents described their perceptions and experiences of navigating the special education process across multiple school years and how those experiences impact their ongoing interactions with current school staff. By researching parents' longitudinal experiences within the special education process, educators may more deeply understand how parents' perceptions and experiences led to their "watchdog" or "battle" stance. When parents approach the parent-school partnership with a defensive posture, positive collaboration may be affected, impacting student achievement (Collier et al., 2015; Tucker & Schwartz, 2013). With a deeper understanding of parents' perceptions of the special education process, teachers and administrators may better recognize and negotiate barriers to an authentically equal and collaborative special education parent-school partnership, which is both required by IDEA (2004) and correlated to increased student achievement (Collier et al., 2015; Tucker & Schwartz, 2013).

MacLeod et al. (2017) found that parents did not believe school staff purposefully perpetuated a hierarchical structure regarding the parent-school disconnect in the special education process. Nevertheless, parents' perceptions of the imbalance of power led both lower and higher socioeconomic status (SES) parents to describe the special education parent-school partnership as an ongoing battle (Czapanskiy, 2014; Lake & Billingsley, 2000; Lalvani, 2012; Love et al., 2017; Mazher, 2012; Rosetti et al., 2021). Furthermore, when parents perceived that school staff ignored or excluded them, they were more likely to contact the school because of a lack of trust and reciprocity or the perception that they must monitor special education services (Carlson et al., 2020; Lalvani, 2012). Researchers found that as parents increased their communication with school staff, teachers became uncomfortable due to perceived criticism or perceived legal risks, so they avoided or limited contact, creating an escalating cycle of misunderstanding between the parents and teachers (Lake & Billingsley, 2000; Mueller, 2015). In response to teachers' reactions to the strained parent-school partnership, parents reported that they had to be the "watchdog" that fought for their children (Lalvani, 2012). Lalvani (2012) found that some parents expected an ongoing contentious parent-school partnership throughout their children's education, creating a barrier for future teachers to overcome.

Additionally, when parents do not feel like equal or meaningful participants in their children's IEP development, parents may request due process hearings (Blackwell & Blackwell, 2015; Burke et al., 2019; Fenton et al., 2017; Rosetti et al., 2021). In one southeastern state, due process complaints going to court without resolution increased from 11% in 2010 to 28% in 2020 (The Center for Appropriate Dispute Resolution in Special Education, 2020). The Director of Special Education of a large southeastern urban school district reported spending more on special education litigation in 2019 than on the combined salaries of all the special education teachers in the district (B. McGaha., personal communication, September 28, 2021). In a zero-sum environment like a school, litigation costs divert funds away from other educational resources that could increase student achievement.

Purpose of Study

Given the impact of parent-school collaboration on student achievement, the purpose of this basic interpretative study was to explore how parents of children who qualified for special education and had participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. Using in-depth interviewing, I sought to give voice to parents' experiences of renegotiating the special education parent-school partnership across multiple school years to uncover parents' untapped knowledge and insight. This information may help educators empathize with how parents experience special education parent-school partnerships (Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Lo, 2008; Weiss et al., 2014). When parents perceived that educators treated them with empathy and as authentic equals in the parent-school partnership, they often shifted from a "soldier preparing for battle" mentality to an empowered participant (Lalvani, 2012; MacLeod et al., 2017; Mazher, 2012; Rosetti et al., 2021; Santamaria Graff et al., 2021). By gaining this more profound understanding of parents' experiences, school staff may better understand how to successfully negotiate the special education process, which ultimately benefits student achievement (Burke et al., 2019; Osborne & Russo, 2010). The population included in this study was parents whose children have received special education in a public-school setting for more than two school years. The parents' experiences included transitioning their children to middle or high school because these transitions required re-establishing the parent-school partnership with unfamiliar staff.

Significance of Study

More than seven million American families participate in the special education parent-school partnership each year, meaning a better understanding of the disconnect in the special education parent-school partnership may benefit many families (National Center for Education Statistics, 2021). The quality of the parent-school partnership is significant because of its correlation to increased student achievement (McCoach et al., 2010). While studying the parent-school collaboration, researchers found that teachers described communication with parents as positive when it aligned with their values and expectations and problematic when it challenged school recommendations (Bezdek et al., 2010; Burke et al., 2019; Lake & Billingsley, 2000; More et al., 2013). Goodall (2021) described the process of one individual or group attributing negative characteristics to an opposing group as "othering" (p. 100). The risk of educators "othering" parents involved in the special education process is that it perpetuates a deficit model of families and a hierarchical parent-school dynamic (Bodvin et al., 2018; Goodall, 2021; Harry, 2008; Kurth et al., 2020; Lalvani, 2012). When parents perceived a hierarchical power differential within the school relationship, parents' willingness to engage with the school decreased, which may negatively impact student achievement (Henderson et al., 2020). Researchers have yet to explore how parents' cumulative experiences impact present interactions with educators, especially if parents repeatedly encounter a hierarchical power differential. In addition, researchers found that parents of children with disabilities had a different perspective than educators regarding their children's disabilities, which could contribute to misunderstandings in the parent-school partnership (Koch, 2016; Ray et al., 2009). The original contribution of this study was to research the gap in the literature regarding how parents' longitudinal experiences within the special education process impacted their interactions with their current school staff to understand better the complex dynamics of the parent-school partnership in special education.

Collier et al. (2015) documented that when educators listened to parents' stories of navigating their children's disabilities and school relationships, they realized how significantly their role impacted families, positively or negatively. In contrast, when teachers lacked firsthand experiences with disabilities, they often lacked understanding of the parents' points of view, leading to strain on the parent-school partnership (Hampden-

Thompson & Galindo, 2017; Heller et al., 2019; Weiss et al., 2014). Marshall and Rossman (2006) described the value of in-depth interviewing:

> Human actions cannot be understood unless the meaning that humans assign to them is understood. Because thoughts, feelings, beliefs, values, and assumptive worlds are involved, the researcher needs to understand the deeper perspectives that can be captured through face-to-face interaction (p. 53).

Understanding the special education parent-school partnership from the parent's point of view may reduce the disconnect parents experience by increasing educators' critical consciousness of the need for genuinely equitable parent-school partnerships in special education (Freire, 1970/2000; Gibbs et al., 2021).

In addition, a deeper understanding of parents' perspectives and experiences helps educators avoid a fundamental attribution error regarding parents in the special education process. Instead of attributing parents' behaviors as internally caused by parents' negative personality traits, educators may consider parents' interactions within the special education parent-school partnership to be reactive responses to their cumulative experiences of the special education process (Ungvarsky, 2022). Avoiding this error prevents educators from seeing special education families through a deficit model that perpetuates "othering" and encourages the empathy and mutual understanding needed for effective parent-school partnerships (Goodall, 2021). Sharing the stories of parents navigating special education for multiple years may help to prevent families who may already experience isolation related to their children's disabilities from experiencing further marginalization in a context that is supposed to support their participation.

Research Questions

A deeper understanding of how parents' perceptions shifted in response to historical experiences may identify and uncover barriers to collaboration, which educators can then identify and work to more effectively address when establishing the parent-school partnerships required in special education each year. To better understand these experiences, the following research questions guided this basic interpretative study:

RQ 1: How do parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences?

RQ 2: How do parents of children who have participated for two or more years in the public-school special education process describe the impact of previous experiences and perceptions in the special education process on how they currently interact and collaborate with school staff?

Theoretical or Conceptual Framework

Several theorists have described the parent-school partnership using a systemic lens. In his ecological systems theory, Bronfenbrenner (1979) theorized that the interactions of multiple systems within children's lives impacted their development. In their model of parental involvement, Hoover-Dempsey and Sandler (1995) used the ideas of systems from Bronfenbrenner's ecological systems theory to describe how those systems interacted to produce varying levels of parental involvement with the school. In her theory of overlapping spheres of influence, Joyce Epstein (1987) also applied Bronfenbrenner's idea of interacting and overlapping systems to describe the systemic interplay within the community-parent-school relationship. The concepts of these three theories help to understand the dynamics of the parent-school partnership in special education.

Bronfenbrenner's Ecological Systems Theory

As part of his theory, Bronfenbrenner (1979) stated that the interaction of a child's microsystem, mesosystem, exosystem, and macrosystem facilitated child development. The microsystem included teachers, parents, students, and peers, but their interactions and relationships with each other were part of the mesosystem. Within the mesosystem, parents, teachers, doctors, and therapists interact to provide support and services for children, especially those with disabilities. The parent-school partnership in special education developed as the microsystems worked together or in conflict. The quality of microsystem interactions creates the mesosystem and may influence the exosystem. The exosystem included power settings, such as social policy, laws, courts, or school boards (Bronfenbrenner, 1979). Power settings included special education law, school board decisions, and school district expectations for the special education process. The macrosystem component related to special education included social norms about inclusive education and the treatment of people with disabilities. The systemic concept of this theory applied to the development of the special education parent-school partnership, given that the interaction of multiple systems affected its relational dynamic.

Epstein's Overlapping Spheres of Influence

Building on the ideas of Bronfenbrenner's ecological systems theory (1979), Epstein (1987) proposed a model for understanding the family-school partnership, which she called overlapping spheres of influence, based on the assumption that schools and families shared responsibility for the education of the child given their ecologically nested interactions. Epstein stated that four forces predicated the degree of overlap: time, community experience, family experience, and school experience. Epstein described time as Force A and included developmental and historical timelines for students, families, and schools. Force B included families' experiences and perceived pressures regarding school organizations. Force C included school experiences, like teachers' attitudes towards parents in conferences or staff flexibility in scheduling IEPs. Force D included the community, which could extend beyond physical borders (Epstein, 2011). How parents and school staff related shifted the level of overlap (Epstein, 2011). Maximum overlap occurred when parents and schools were collaborative partners (Epstein, 2011). When school staff and parents became adversarial, the spheres had minimal overlap. Epstein's model visually represented the level of positive collaboration between the parents and the school.

The Hoover-Dempsey and Sandler Model of Parental Involvement

The Hoover-Dempsey and Sandler model (Hoover-Dempsey & Sandler, 1995) of the parental involvement process provided a way to interpret the interactions between the microsystem, mesosystem, exosystem, and macrosystem described by Bronfenbrenner (1979). This model proposes a temporal merging of parents' past experiences regarding schools, their perceived life contexts, and their beliefs and values (Green et al., 2007; Hoover-Dempsey & Sandler, 1995). Parents' perceived life contexts included their knowledge, skills, time, and energy, all components of the parents' microsystem. Parents were more likely to be engaged with the school when they perceived they had more knowledge, skills, time, and energy. When interacting with special education school staff in the mesosystem, parents may have been intimidated by the complexity of special education jargon and IEP procedures and, consequently, limited their interactions (Mueller & Buckley, 2014). Surprisingly, parents who were strong and informed advocates often found that their knowledge negatively affected the parent-school partnership as school staff perceived the parents as a legal threat and thus limited communication (Burke et al., 2019). Mesosystem interactions with school staff encouraged or discouraged parental involvement (Epstein, 2011). The exosystem and parents' motivational beliefs impacted parents' role perceptions regarding their children's education (Hoover-Dempsey et al., 2005). Their role perceptions also shifted in response to experiences in the mesosystem with school staff and other service providers for their children (Green et al., 2007; Shelton, 2019). Some parents defined their role as managing the school, while others saw their role as a support for the school with deference to educators' expertise (Gibbs et al., 2021). Parents' experiences in the mesosystem affected their beliefs about how effectively they could help their child to succeed in school (Green et al., 2007). For example, when parents perceived a hierarchical power structure with the school in the expert role, parents became adversarial or disengaged (Cohen & Mosek, 2019; Henderson et al., 2020; Kluth et al., 2007; Kurth et al., 2020; Lalvani, 2012). Multiple systems, both past and present, impacted the parent-school partnership and student achievement (Epstein, 2011).

Researcher's Assumptions and Delimitations

Assumptions

1. Throughout the interview series, participants were open and honest in their self-reports of their experiences with their children's special education.

2. Parents were sincerely interested in the study's purpose.
3. Parents possessed expertise regarding their children that may differ from educators.
4. Most educators strive to make the special education process a positive experience for parents.
5. Parents and teachers have distinct roles in the special education process, which may lead to tension in their relationship.
6. Collaboration efforts impact IEP team decision-making and the potential of students' academic success.
7. Participation in the research occurred on a volunteer basis, and participants may withdraw at any point during the study.
8. Participants were not inclined to answer questions based on my relationship with them.
9. I monitored researcher bias and positionality to minimize the impact on data collection and analysis.
10. As a researcher, I assumed that the qualitative data gathered through interviews and analyses will provide in-depth information about parents' experiences.

Delimitations

The following delimitations bound the scope of the study:

1. The research location and the sample were limited to parents with children receiving public-school special education in a southeastern state in the United States.

2. The scope of the study sample included only parents whose children participated in special education for two or more years to provide the year-to-year perspective referenced in the research questions of this study.
3. Participants included only fluent English speakers.
4. The researcher's interview guides provided the data collection instrument for this study.
5. The timeframe was limited to a few months during the summer between the 2022-2023 school year and 2023-2024 school year.
6. The research findings will only generalize to some special education parents.

Definitions of Terms

Advocate. A person who seeks to ensure that students receive the most appropriate special education services available to meet specific and measurable goals addressing the student's academic deficits (Blackwell & Blackwell, 2015).

Collaboration. A mutual effort between school staff and parents to plan, implement, and evaluate the educational program for a given student (Carrea et al., 2005).

Disability. A disability under IDEA (2004) includes an intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities.

Due Process. Parents have the right to remediation or a due process hearing to resolve conflicts with their local school system regarding the educational program for their children with disabilities (IDEA, 2004).

IEP. The Individualized Education Program provides specially designed instruction for students with disabilities eligible for services through IDEA (2004). IDEA (2004) regulations defined a child who is eligible for an IEP as a child aged 3-9 experiencing developmental delays or a child aged 3-21 whose educational performance is adversely affected due to the presence of one or more of the following disabilities: autism, deaf-blindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment (including blindness).

IEP meeting. A meeting where the school staff and parents discuss, develop, and review a student's IEP and progress monitoring (IDEA, 2004).

IEP team. The minimally required participants for an IEP meeting include the parent, one special education teacher, and one general education teacher. Other participants may include the student, other classroom teachers, school psychologists, therapists, other supportive family members or friends, advocates, attorneys, and other service providers (Blackwell & Blackwell, 2015; IDEA, 2004).

Parent Involvement. Attendance at the IEP meeting, participation in the IEP development, progress monitoring of services and goals, and academically supporting students in the home setting (Gibbs et al., 2021; McNeal, 2012).

Parents. A biological or adoptive parent of a child; a foster parent of a child; a guardian authorized to act or make decisions on behalf of the child; or an individual acting in the place of a natural or adoptive parent with whom the child lives or an individual legally responsible for the child's welfare (IDEA, 2004).

Parent-school partnership. A collaboration between the parents and teachers in the student's educational interest that emphasizes shared responsibility between these two parties (Epstein, 2011).

Resource. Small group, individualized instruction by a special education teacher in a separate classroom from the general education classroom (Bateman & Cline, 2015).

Special Education. Specially designed instruction to meet the unique needs of a child with a disability (IDEA, 2004).

Special Education Process. The process includes the following steps: identification, evaluation, eligibility, placement, IEP development, and progress monitoring (IDEA, 2004).

Team-taught. Another term for co-taught. Co-teaching is a collaborative approach to instruction in which two teachers, typically a general education teacher and a special education teacher, work together to plan and implement instruction for a class that includes students with disabilities and general education students (Bateman & Cline, 2015).

Summary

Using a basic interpretative study design, I conducted in-depth interviews to explore parents' perceptions and experiences of renegotiating the special education parent-school partnership across multiple school years to gain empathy for how parents experience the special education parent-school partnerships (Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Lo, 2008; Weiss et al., 2014). Parents of children with disabilities who have participated in special education for two or more years were included and chosen through purposive sampling. By gaining this more profound understanding of parents' experiences, educators may better understand how to successfully negotiate the special education process, which ultimately benefits student achievement (Burke et al., 2019; Osborne & Russo, 2010). The literature review in the next chapter examines the history of special education law, pertinent theories for evaluating parent-school partnerships, and research related to the special education process from both the parents' and educators' points of view.

Chapter II

REVIEW OF THE LITERATURE

When IDEA (2004) became law, the intent of the law was to actively include parents in their children's special education program planning. Despite legal mandates for parent-school collaboration in special education, parents have continued to report an adversarial relationship with the school. (Bezdek et al., 2010; Burke et al., 2019; Henderson et al., 2020; IDEA, 2004; Lake & Billingsley, 2000; More et al., 2013). Bray and Russell (2016) found that even when schools proactively sought parent involvement, the legal requirements and implications of the IEP process created an unrecognized barrier to improved parent-school relationships because parents and teachers perceived vulnerability in the IEP process. Teachers perceived parents as a legal threat, while parents feared schools' retaliation in response to being challenged (Bray & Russell, 2016; Henderson et al., 2020; Love et al., 2017). Consequently, parents and teachers adopted a wary stance when entering the parent-school relationship, resulting in the parent-school partnership being overly focused on compliance with the law (Cavendish & Connor, 2018; Love et al., 2017). As a result, special education meetings often proceeded with a school-oriented agenda giving limited attention to parental concerns (Blue-Banning et al., 2004; Santamaria Graff et al., 2021). When parents did not feel like their concerns were acknowledged or addressed, a disconnect in the parent-school collaborative relationship often occurred (Adams et al., 2016; Baxter et al., 1995; Fish, 2008; Fu et al., 2020; Harry, 2008; Henderson et al., 2020; MacLeod et al., 2017; Valle, 2011; Wang et al., 2011;

Zagona et al., 2019). This disconnect is significant because researchers have found that positive communication and collaboration between parents, teachers, and staff critically impacted students' achievement, decreased disciplinary issues, and increased the graduation rate of students with disabilities (Cohen & Mosek, 2019; Francis et al., 2016; Heller et al., 2019; Lalvani, 2012; McCoach et al., 2010; McGee, 2004; Reynolds & Howard, 2013; Sheldon & Epstein, 2005; Zhang et al., 2011).

Given the impact of parent-school collaboration on student achievement, the purpose of this basic interpretative study is to explore how parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences in the special education parent-school partnership. A deeper understanding of how parents' perceptions shifted in response to historical experiences may identify and uncover barriers to collaboration, which educators can then identify and work to more effectively address when establishing the parent-school partnerships required in special education each year. To better understand these experiences, the following research questions guided this basic interpretative study:

RQ 1: How do parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences?

RQ 2: How do parents of children who have participated for two or more years in the public-school special education process describe the impact of previous experiences and perceptions in the special education process on how they currently interact and collaborate with school staff?

In the following sections of this literature review, I discuss three theories used to view parent-school relationships: Bronfenbrenner's Ecological Systems Theory, Epstein's Overlapping Spheres of Influence Theory, and the Hoover-Dempsey and Sandler Model of Parental Involvement. To better understand parents' perspectives, I also included a brief history of special education law in how it relates to parental involvement, a description of the role of parents' previous life experiences with schools, their perceived life context, and the effect of parental stress on school partnerships. To better understand the school staff's perspective, I described the impact of the staff's previous experiences with parents, personal life experiences, and beliefs on the parent-school partnership. By exploring parents' and school staff's experiences, I sought to understand more deeply what led to the disconnect between parents and school staff in the special education partnership.

Theoretical Framework

In this theoretical framework section, I discussed three theories used to view parent-school relationships. The first is Bronfenbrenner's Ecological Systems Theory (1979), which he updated in 1993 to include a biological component. I referenced Bronfenbrenner's theory throughout this review as ecological systems theory and, where warranted, the more recent bioecological systems theory. The second theory included in this framework is Joyce Epstein's Overlapping Spheres of Influence Theory (1987), referenced in this review as overlapping spheres of influence theory. The third is the Hoover-Dempsey and Sandler Model of Parental Involvement (1995), referenced as the Hoover-Dempsey and Sandler Model in this review. The three theories are connected because the overlapping spheres of influence theory and the Hoover-Dempsey and

Sandler Model developed from the concepts described in Bronfenbrenner's original ecological systems theory.

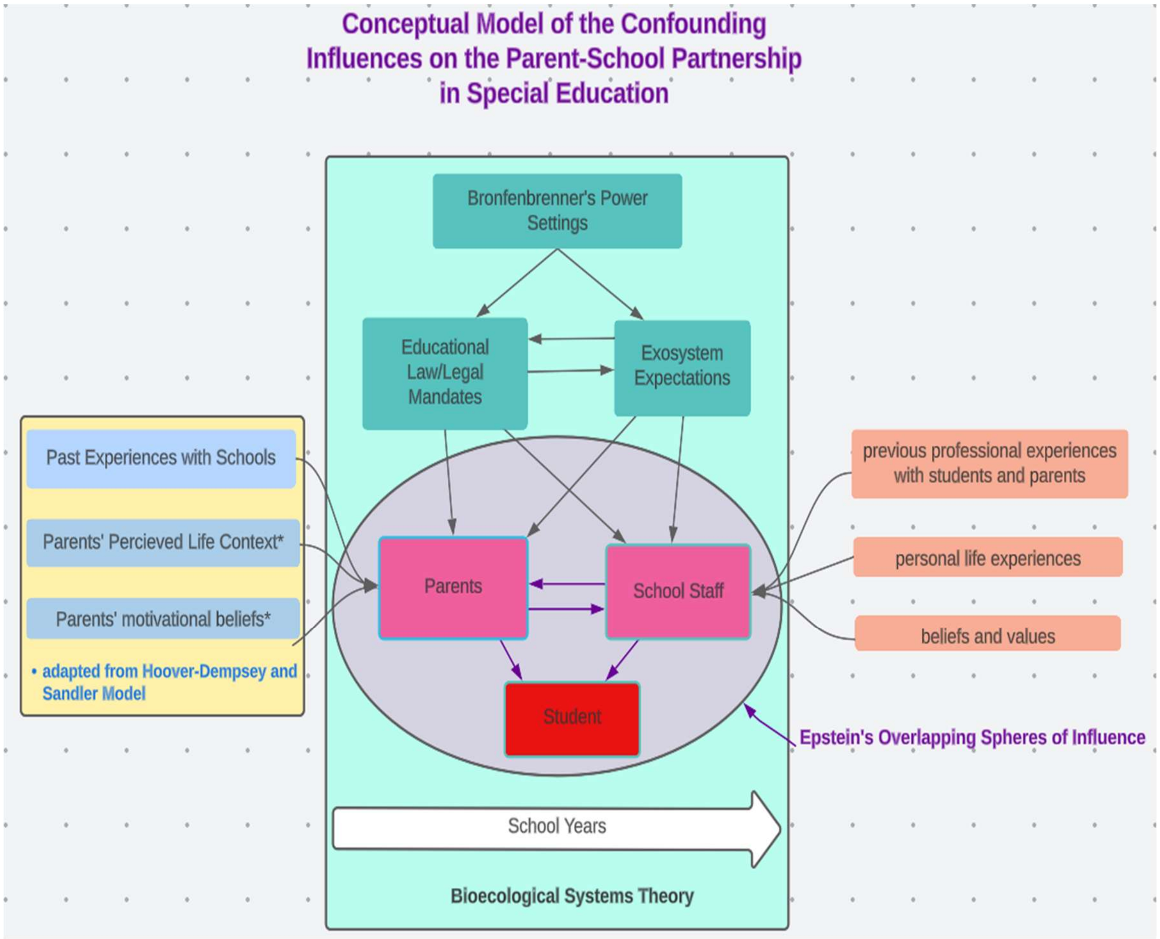
In the original ecological systems theory, Urie Bronfenbrenner (1979) pioneered a systemic view of how children and their environment interacted to impact a person's development. Within his systemic contextual perspective, Bronfenbrenner (1979) viewed students, parents, community, school staff, and societal structures not as isolated units but as interconnected systems adjusting to ongoing interactions with each other. The interactions of these different systems created a relationship dynamic or outcome that continually adapted to ongoing interactions. Joyce Epstein took Bronfenbrenner's ecological systemic perspective and narrowed the view to the interactions between family, school, and community (Epstein, 1987). She developed a theory to understand better how those three systems overlapped and affected each other and students (Epstein, 1987). Building on Bronfenbrenner's (1979) and Epstein's (1987) theories, Hoover-Dempsey and Sandler (1995) used the ideas of systems from the original ecological systems theory to describe how Epstein's three overlapping spheres of influence interacted to produce varying levels of parental involvement with the school. I combined the concepts of these three theories to understand the dynamics of the parent-school partnership in special education and to develop the concept map shown in Figure 1.

From an Ecological to a Bioecological Systems Theory

In this section, I described the five systemic levels included in ecological systems theory. Bronfenbrenner (1979) initially included only four systemic levels, but later, he added the chronosystem, the fifth systemic level, to his ecological systems theory (Bronfenbrenner, 1986). In 1994, Bronfenbrenner and Ceci (1994) updated the theory and renamed it bioecological systems theory to encompass the influence of the child's biological characteristics on interactions with their ecosystem. At the end of this section, I address the addition of the biological component and how it provides a context to view the impact of a child’s disability on systemic interactions.

Figure 1

Conceptual Model of Confounding Influences on the Parent-School Partnership in Special Education

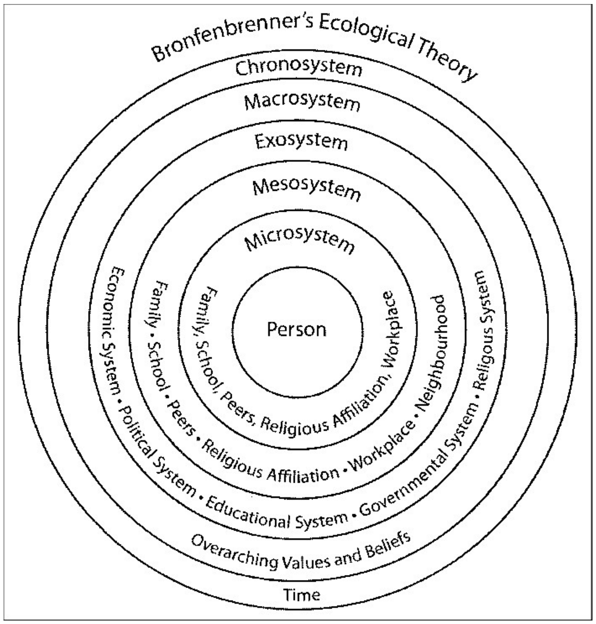


Note. Concept map illustrating parent-school partnership dynamics in special education.

In developing the original ecological systems theory, Urie Bronfenbrenner (1979), a psychologist, created a conceptual language for understanding the interactions of human ecosystems within a person’s environment. His ideas resulted from frustration at the field for not having a way to conceptualize how systems or influences within a child's life interacted and affected each other (Kirksey et al., 2022). Bronfenbrenner used a constructivist approach to view how a person experienced interactions in a system and made sense of those experiences (Shelton, 2019). His theory described child development as the interaction of different systems, specifically the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, as shown in Figure 2 (Bronfenbrenner, 1986; Shelton, 2019). In the following five sections, I briefly describe each system level.

Figure 2

Bronfenbrenner's Ecological Systems Theory Model



Note. Representation of the Ecological Systems Theory. Reprinted from “Moving ‘eco’ Back into Socio-Ecological Models: A Proposal to Reorient Ecological Literacy into Human Developmental Models and School Systems,” by N. R. G. Stanger, 2011, *Human Ecology Review, 18*(2), p. 169. Copyright 2011 by Society for Human Ecology. Reprinted with permission.

Microsystem

In the original ecological system theory, the level nearest to the individual is the microsystem. By processing and adapting to experiences with each system, Bronfenbrenner (1979) suggested that a person developed an understanding of their environment. The child's microsystem included teachers, peers, neighbors, parents, and siblings, yet their interactions occurred in the mesosystem (Bronfenbrenner, 1979). For a child with a disability, the microsystem may have also included doctors, therapists, and other service providers (Kirksey et al., 2022). Additionally, when the child receives special education, additional school staff may have entered the child's and parents' microsystems (Kirksey et al., 2022). Consequently, Kirksey et al. found that the microsystem of a child with a disability often included more people and settings than a child without a disability.

Mesosystem

While the microsystem included specific people and settings, Bronfenbrenner (1979) described the mesosystem in ecological systems theory as interactional and dynamic. This system represented relational dynamics between the microsystems, such as the relationship between the teacher and the parent (Kirksey et al., 2022). Bronfenbrenner (1986) suggested that people's experiences in different environments do not exist in isolation. For example, the dynamics in an individual's home may impact the individual's dynamics at school (Bronfenbrenner, 1986). While this connection may seem obvious, ecological systems theory provides a framework for describing the different systems and interactions that influence a person in the environment or ecosystem. These interactions between systems comprise the mesosystem (Bronfenbrenner, 1986). Researchers used ecological systems theory to develop research designs that could better measure or describe the influence of each setting on the other setting (Ahmed et al., 2017; Chun & Duvall, 2019; Kirksey et al., 2022; Masten, 2018; Smith & Sheridan, 2019). For example, the relationships in the mesosystem may change after a child begins in special education because additional school staff enter the dynamic and pose different expectations than teachers in general education (Kirksey et al., 2022). According to ecological systems theory, the mesosystem includes the connections between these crucial systems in a child's environment (Blandin, 2017).

Exosystem

As the systemic levels described in ecological systems theory progress outward from the individual, the individual has less direct contact with the system. For this reason, Bronfenbrenner (1979) used the prefix “Exo” for this system level because the settings in this level are external settings that indirectly impact the person in their environment. Bronfenbrenner described this level as containing the processes between two or more settings, one of which does not directly involve the person but does indirectly impact the person. In addition, the exosystem included power settings, which Bronfenbrenner described as settings in which the participants control resources or decisions affecting society. Power settings included laws, courts, and school boards, whose actions impacted the mesosystem (Bronfenbrenner, 1979). Power settings most likely affecting families with children in special education included special education law, school board policy, and school district expectations for the special education process (Kirksey et al., 2022). In addition, the exosystem included the parents' work schedules and job demands because they indirectly impacted the time a parent interacted with the child or the school

(Bronfenbrenner, 1986). One or two connections, such as a parent, teacher, principal, or boss, usually remove the exosystem level from the individual. Understanding this level helps to understand how a family's life context impacts interactions related to their child.

Macrosystem

While the first three systemic levels have easily identified connections to the individual, the macrosystem connections are more global and include cultural influences such as socioeconomic, political, and religious influences (Bronfenbrenner, 1986). In the early 1950s, children with disabilities did not always attend school (Yell, 2019). As laws and social policies changed, children with disabilities began to have more guaranteed access to public-school education (Yell, 2019). IDEA (1997) stipulated that students were guaranteed education in the least restrictive setting and preferably with their general education peers. The historical shifts in educational philosophy and services for children with disabilities reflected shifts in the culture's belief system towards more equality and inclusion (Low et al., 2020; Yell, 2019). Changing cultural beliefs led to enacting new laws and educational policies at the macrosystem level, indirectly impacting the parent and school microsystems and their interactions (ESSA, 2015; IDEA, 2004). Educational policy and laws have significantly impacted how parents and children have experienced the special education process at the mesosystemic and microsystemic levels (Low et al., 2020; Yell, 2019).

Chronosystem

In his later writings, Bronfenbrenner (1986) added the chronosystem to his ecological systems theory to account for the impact of time and life transitions on a person's development. The chronosystem encompasses changes to a person's life, like moving to college, high school graduation, or other major life events (Kirksey et al., 2022). For example, when a child first transitions to special education, the child and parents' microsystems and mesosystems may change, impacting interactions within and between microsystems (Kirksey et al., 2022; Low et al., 2020). Under IDEA (2004), a child receiving special education necessitated more parental involvement at the school level, which shifted the mesosystem interactions between parents and school staff (Kirksey et al., 2022). Bronfenbrenner suggested that the environment shifted in response to changes in other systems over time, which he proposed occurred in the chronosystem. According to ecological systems theory, the chronosystem encompasses the parents' historical experiences and perceptions of the special education process across time. At the same time, current interactions with school staff would occur in the mesosystem (Bronfenbrenner, 1986).

Model Evolution

Bronfenbrenner and Ceci (1994) updated the theory from an ecological to a bioecological model to encompass the influence of the child's biological characteristics on interactions with their ecosystem. For children with disabilities, this updated model captured the impact of a disability on a child's development (Kirksey et al., 2022). For example, children with autism, attention-deficit/ hyperactivity disorder, or depression may perceive the environment differently as their biological processes impact their experiences and perceptions of their environment (Kirksey et al., 2022; Low et al., 2020). A child with a reading disability may interact and perceive the school setting differently due to academic difficulties related to the disability, which this updated model captured (Bronfenbrenner & Ceci, 1994). Adding the biological system to the ecological systems model incorporated the individual’s biology and social interactions and provided a more comprehensive view of the relational dynamics impacting a person in their environment (Bronfenbrenner & Ceci, 1994).

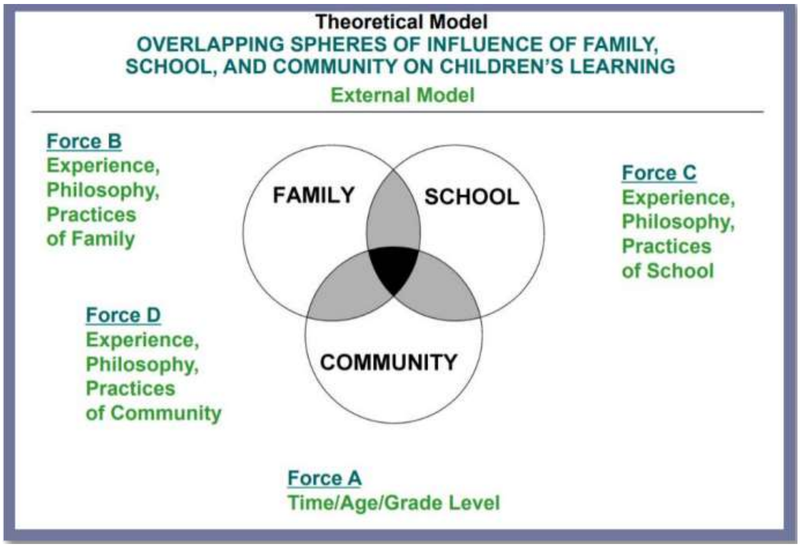
According to Clandinin and Connelly (2000), the collected stories of lived experiences should include the social, cultural, and historical context of the experiences and how the participants made meaning of those experiences. In Bronfenbrenner and Ceci’s (1994) updated bioecological model, the chronosystem included the historical context of experiences, while the macrosystem included the social and cultural context. In addition, while the mesosystem continued to reflect relational dynamics between microsystems, the microsystem now included the child’s biological characteristics. Bronfenbrenner and Ceci's bioecological perspective provided the language to discuss the impact of varied influences on the child and the family.

Epstein's Overlapping Spheres of Influence Theory

Building on the ideas of Bronfenbrenner's original ecological systems theory, Epstein (1987) suggested a model for understanding the family-school partnership, which she called overlapping spheres of influence, as shown in Figure 3. The theory included the assumption that schools and families shared responsibility for the child's education, given their ecologically nested interactions (Epstein, 1987). Epstein stated that four forces predicated the degree of overlap: time, family experience, school experience, and community experience.

Figure 3

Theoretical Model of Overlapping Spheres of Influence



Note. Illustration of the spheres of influence. Reprinted from *School, Family, and Community Partnerships: Preparing Educators and Improving Schools*, by J. L. Epstein, 2011, p. 32. Copyright 2011 by Taylor & Francis. Reprinted with permission.

Epstein (1987) described time as Force A and included developmental and historical timelines for students, families, and schools. Force B included families' experiences and perceived pressures regarding school organizations. Force C included school experiences, like teachers' attitudes towards parents in conferences or staff flexibility in scheduling IEPs. Force D included the community, which could extend beyond the physical borders of a community (Epstein, 2011). At the center of these forces were the students' learning and development. Epstein stated that when the forces of school, family, and home interacted more frequently, students were more likely to perceive the importance of school, hard work, and helping others. In developing home-school programming, Epstein suggested that program developers design activities to increase communication between the forces to impact student success positively.

The level of overlap between spheres varied for each family depending on how well the school and the family worked together (Epstein, 1987). Maximum overlap occurred when parents and schools were collaborative partners (Epstein, 1987). When school staff and parents became adversarial, the spheres had minimal overlap (Epstein, 1987).

The internal structure of this model described how these forces might interact at the individual or institutional level (Epstein, 1987). For example, at the institutional level, schools may have invited parents to be involved in school or community events (Epstein, 1992). At the individual level, teachers may have developed a strong partnership with their classroom parents (Epstein, 2011). Epstein (2011) proposed that educators consider how to draw these forces together when planning for improved parent-school partnerships, given their impact on parental involvement with the school.

In addition to developing the overlapping spheres of influence theory, Epstein (1987) also developed a framework describing six types of parental involvement found in comprehensive home-school partnership programs. Epstein created the framework to assist educators in developing effective home-school partnership programming. With the enactment of ESSA (2015), school personnel often referenced Epstein’s model as a working framework for building home-school-community partnerships as they sought to support parental involvement and school improvement (Fenton et al., 2017; Mayger & Provinzano, 2022).

The first type of involvement is called parenting, which may be misleading because it specifically includes school staff assisting families in supporting their children's education at home (Epstein, 1987). This level may have also included special education training programs and advocacy training to help parents understand the special education process (Burke et al., 2019). Epstein (1987) argued that when school staff worked to understand families, a stronger and more trusting relationship developed, especially in special education.

The second level of involvement was the parent and school-initiated communications (Epstein et al., 2018). Epstein et al. (2018) suggested ways to facilitate communication and address barriers to effective communication, like language and literacy. IDEA (2004) regulations required parent-school communication, creating an ongoing area of involvement for school staff to manage. By better understanding parents' perceptions of school communication, school staff may better navigate the parent-school relationship in special education (Epstein, 2011).

The third level of parental involvement was volunteering, which may or may not have impacted the special education parent-school partnership (Epstein et al., 2018). The fourth area of involvement was learning support at home (Epstein et al., 2018). Parents of special education students varied in the level of at-home support due to exosystem demands or parents' knowledge and skills (Bronfenbrenner & Ceci, 1994; Epstein, 2011). The fifth level of involvement was decision-making, which meant parents participated in school-wide decision-making, such as being part of the parent-teacher association or governance council (Epstein et al., 2018). The fifth level impacted parent-school involvement but had less connection to special education unless decisions included inclusivity issues (Epstein et al., 2018). The sixth level included collaborating with the community to provide resources and services to support learning (Epstein et al., 2018). This level affected special education transitional planning and planning for parental support, like parent advocacy groups (Mitchell et al., 2010; Rios et al., 2020). Because federal law required schools' staff to improve parent-school collaboration, educators designing home-school partnership programs often incorporated Epstein's six dimensions of parental involvement into their partnership plan (Auerbach, 2007; ESSA, 2015; Harry, 2008; IDEA, 2004; Love et al., 2017; Smith & Sheridan, 2019). Like Bronfenbrenner, Epstein's theory provided language to describe relational dynamics in and between settings (Epstein, 2011).

Hoover-Dempsey and Sandler Model of Parental Involvement

Bronfenbrenner's (1979) ecological systems theory focused on the interrelatedness of all settings in a person's environment. Using Bronfenbrenner's systemic conceptualization, Epstein (1987) narrowed the focus of her theory to the interrelatedness of the family, school, and community, but she called the systems spheres of influence. Using the ideas of both ecological systems theory and overlapping spheres of influence theory, Hoover-Dempsey and Sandler (1995) focused their model on the family and school spheres of influence to specifically explain parental involvement with the school and its impact on student achievement. The Hoover-Dempsey and Sandler model of the parental involvement process demonstrated that the role of the parents' perceived life contexts and their motivational beliefs influenced their choices regarding involvement with the school (Hoover-Dempsey & Sandler, 1995).

Parents' perceived life contexts included their knowledge, skills, time, and energy (Hoover-Dempsey & Sandler, 1995). When parents perceived that they had more knowledge, skills, time, and energy, they were likelier to be engaged with the school (Hoover-Dempsey et al., 2005). For example, when school staff's use of educational jargon related to special education or the complexity of the IEP process intimidated parents, parents reacted by limiting their participation (Mueller & Buckley, 2014). However, parents who were informed advocates remained highly involved in the IEP process (Burke et al., 2019). Unfortunately, Burke et al. (2019) found that when parents had much knowledge, skills, and time, their involvement negatively affected the parent-school partnership because school staff perceived the parents as a legal threat and thus limited communication (Burke et al., 2019). Regarding the self-efficacy component of the Hoover-Dempsey and Sandler (1995) model, even highly knowledgeable and skilled parents experienced lower self-efficacy when these adverse reactions occurred because they perceived that the school resisted their involvement and isolated them (Burke et al., 2019; Henderson et al., 2020). Thus, parents at both ends of the knowledge continuum experienced less self-efficacy in their ability to impact their children's special education experiences, resulting in less overlapping spheres of influence (Epstein, 2011).

According to the Hoover-Dempsey and Sandler (1995) model of parental involvement, parental motivational beliefs included parents' beliefs about their role in their child's education. Parents' beliefs about their role may shift in response to experiences in the mesosystem or the perceived level of overlap in the spheres of influence (Epstein, 1987; Green et al., 2007; Shelton, 2019). Some parents defined their role as managing the school, while others saw their role as a support for the school with deference to educators' expertise (Gibbs et al., 2021). These differences may be related to parents' historical experiences or life context (Green et al., 2007; Hoover-Dempsey et al., 2005). For example, when parents perceived a hierarchical power structure with the school in the expert role, parents became adversarial or disengaged, depending on the knowledge, time, skills, and energy that they could devote to the parent-school partnership (Cohen & Mosek, 2019; Henderson et al., 2020; Kluth et al., 2007; Kurth et al., 2020; Lalvani, 2012). In another instance, a single, working parent may not have had the time or flexibility to miss work to attend the meetings required to challenge school recommendations or be more involved (Henderson et al., 2020; Kurth et al., 2020). However, the parent's motivational beliefs prioritized her child's education, so she overcame the barriers to attending (Chun & Duvall, 2019). Life context and parental motivational beliefs impacted the special education parent-school partnership and parents' level of interaction (Hoover-Dempsey et al., 2005).

Model Evolution

In an update to the Hoover-Dempsey and Sandler Model (2005), Ice and Hoover-Dempsey (2011) added another piece to the parents' reasons for involvement, specifically parents' perceptions of invitations. Ice and Hoover-Dempsey (2011) recognized that the social context of invitations and parents' support systems influenced parental involvement and their role construction concerning the school. Ice and Hoover-Dempsey (2011) surveyed 64 parent-child dyads from both home-schooled and public-school settings. Participants completed the surveys in the spring and six months later in the fall, so students were in grades 4-7 in the spring and 5-8 in the fall. Using a five-point Likert scale, the authors created a Social Networks and Social Support Report to assess social support (Ice & Hoover-Dempsey, 2011). The authors concluded that a correlation between social support and role construction existed, but in-depth interviewing was needed to explore this relationship further (Ice & Hoover-Dempsey, 2011).

Summary of Theoretical Framework Section

In summary, the authors of all three theories continued developing their theories and considered additional influencing components. Bronfenbrenner expanded his ecological systems theory twice. First, in 1986, he included the chronosystem to account for the impact of accumulated historical experiences. Second, in 1994, he added the person's biology to the theory, which was pertinent to the discussion of special education as the child's disability was often a part of their biology. Hence, the theory now incorporates how disability impacts students' systemic interactions. Epstein has not changed her theory significantly, but she has further explained the impact of the spheres of influence and how schools can work to build positive parent-school relationships. Lastly, Kathleen Hoover-Dempsey partnered with her colleague, Christa Ice, to add a component to the model: social support. They found that social support often increased parental involvement in and out of the home (Ice & Hoover-Dempsey, 2011). Theorists, as well as researchers, continue to seek to understand better how a person's systemic environment interacts to create their experience and influence the parent-school partnership (Cohen & Mosek, 2019; Henderson et al., 2020; Kluth et al., 2007; Kurth et al., 2020; Lalvani, 2012).

History of Special Education Law Concerning Parents' Roles

To create a historical context of the parent-school relationship in special education, I included this section to review how the laws and policies regarding the education of children with disabilities have shifted over time, impacting both students and their parents. This perspective provided a context for understanding why parents may distrust the school as a system and why an inherently hierarchical relationship between the family and the school system often persisted.

For over seventy years, parents of children with disabilities have been fighting for access to equal education for their children (Rotatori et al., 2011; Yell, 2019). In *Brown vs. Board of Education* (1954), Chief Justice Warren wrote the following:

> In these days, it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. Such an opportunity, where the state has undertaken to provide it, is a right that must be available to all on equal terms. (p. 493)

Brown vs. the Board of Education (1954) was a victory for African American students' access to equal education. However, it paved the way for systemic change in America's public schools for more than just African Americans (Chopp, 2012; Klarman, 2007). The ruling brought education and equality to the forefront of America's discourse and inspired parents of children with disabilities to also pursue access to equal education for their children (Klarman, 2007; Rotatori et al., 2011; Yell, 2019). The language of Justice Warren in the 1954 ruling inspired parent advocacy groups for children with disabilities to file lawsuits to gain access to the equal education Justice Warren described (Chopp, 2012; Yell, 2019). By 1972, one of these lawsuits reached the Supreme Court, *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1972). In this ruling, the Supreme Court ruled that all children, no matter how severe the disability, had a protected legal right to access a free and appropriate education (The Public Interest Law Center, 2019; Rotatori et al., 2011). By 1975, Congress responded to both a parental outcry and shifting societal norms regarding equality by passing the Education for All Handicapped Children Act (EAHCA), or Public Law 94-142 (1975), which guaranteed students aged 3-21 years the right to a "free public education" (The Public Interest Law Center, 2019, para. 1). At the time of enactment, only half of the eight million children who required special education received such services (University of Kansas, 2021). Even if the students received services, school policies often segregated students with disabilities from their peers, or staff removed students from or placed them in programs without their parents' knowledge (Rotatori et al., 2011; University of Kansas, 2021). While EAHCA (1975) codified the educational rights of children with disabilities, parents' rights to be involved in the special education process remained less established (Yell, 2019).

By 1986, not only were students' educational rights ensured under the law, but The Handicapped Children's Protection Act of 1986 amended EACHA and granted parents the right to be more involved in developing their children’s IEP (Rotatori et al., 2011). Congress reauthorized EACHA in 1990 and renamed it the Individuals with Disabilities Education Act (IDEA) (Yell, 2019). IDEA's regulations gave parents a legally protected voice regarding their children's educational programming (Santamaria Graff et al., 2021). From 1975 to 2006, Congress passed additional laws that granted parents more rights regarding their children with disabilities' education and empowered parents as necessary and equal contributors to their children's IEP (Reiman et al., 2010; U.S. Department of Education, 2020). Today, not only are children with disabilities guaranteed a free and appropriate education, but schools must include parents as equal participants in the special education process, an enormous shift from seventy years ago (ESSA, 2015; U.S. Department of Education, 2020).

The Special Education Process Today

From 1975 to today, special education services have changed dramatically (EACHA, 1975; IDEA, 2004). In the 1970s and 1980s, children with disabilities were often segregated from their general education peers (Rotatori et al., 2011). However, IDEA (Education of the Handicapped Act Amendments, 1990; IDEA, 1997) regulations swung the pendulum from isolation to inclusion in the least restrictive setting (Rotatori et al., 2011). In this section, I reviewed the special education process used by schools today per current law (ESSA, 2015; IDEA, 2004). This context is necessary to understand the extent of interaction parents and school staff have had as they navigated the special education process together.

In contrast to parents of the 1970s suing to gain access to special education services, the Child Find mandate in IDEA (2004) required that all school districts actively strive to identify, locate, and evaluate all children with disabilities, regardless of the severity of the disabilities. To ensure accurate identification of disabilities, the 2004 amendment to IDEA also included the development of the concept of response to intervention (RTI). Before IDEA (2004), school districts required a discrepancy between a student's tested IQ and performance scores to qualify a student for special education services (IDEA, 1997). Concern arose because this discrepancy model had an inherent bias, given the understanding that IQ tests had cultural bias and that poor instruction could create a performance discrepancy (Buffum et al., 2010). RTI grew from the goal of providing quality instruction to remediate learning needs before assuming a disability existed (Musgrove, 2011). According to the U.S. Department of Education, the core characteristics of RTI included identifying struggling learners, providing needed support to improve academic performance, and collecting data to inform decision-making regarding students' educational needs (Musgrove, 2011). As a result, RTI intervention and data collection for a student often continued for several months, with their parents attending multiple meetings to review progress (Musgrove, 2011). If a student did not improve with interventions, the student support team (SST) could move to consider special education eligibility (Musgrove, 2011). When ESSA (2015) passed, RTI moved under the Multi-Tiered System of Supports (MTSS) umbrella. ESSA (2015) regulations defined MTSS as "a comprehensive continuum of evidence-based, systemic practices to support a rapid response to students' needs, with regular observation to facilitate data-based instructional decision-making" (Title IX, Sec. 8002(33)). Within MTSS, parents and school staff often meet every four to six weeks as a team to evaluate data and student progress, as shown in Figure 4 (ESSA, 2015).

Since the passing of IDEA (2004) and ESSA (2015), school districts have continued to explore effective ways to implement the response-to-intervention model (Florida Problem Solving & Response to Intervention Project, 2021). As part of MTSS, students receive services at tiered levels of intensity (Florida Problem Solving & Response to Intervention Project, 2021). Tier 1 is what all students get as instruction and includes approximately 80% of students (Florida Problem Solving & Response to Intervention Project, 2021; Georgia Department of Education, 2021). Tier 2 services focus on academic or behavioral interventions for students not meeting grade-level performance expectations and include approximately 15% of students (Florida Problem Solving & Response to Intervention Project, 2021; Georgia Department of Education, 2021).

Figure 4

Multi-Tiered Systems of Support Cycle

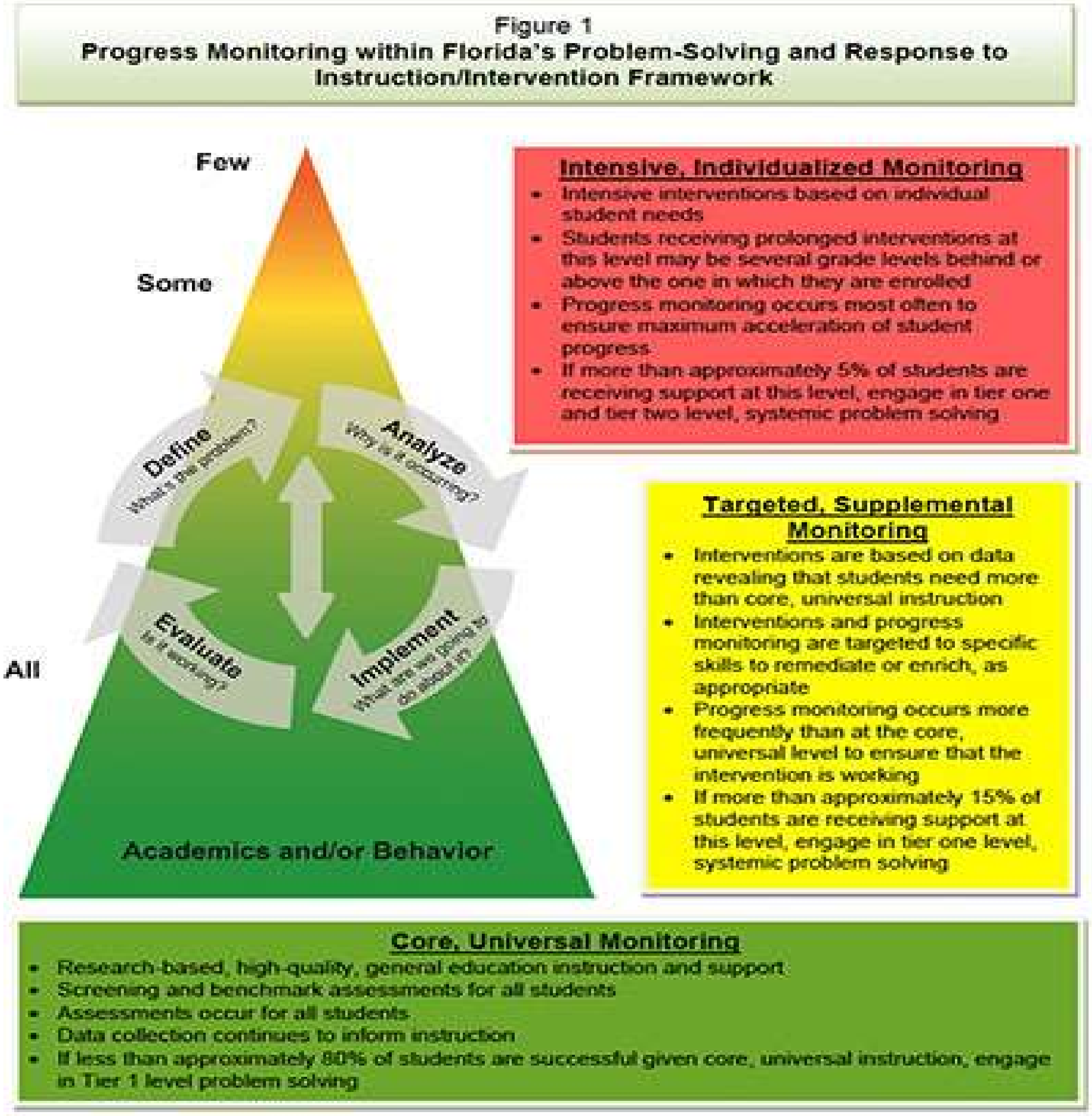


Figure 1

Progress Monitoring within Florida's Problem-Solving and Response to Instruction/Intervention Framework

Intensive, Individualized Monitoring

- Intensive interventions based on individual student needs
- Students receiving prolonged interventions at this level may be several grade levels behind or above the one in which they are enrolled
- Progress monitoring occurs most often to ensure maximum acceleration of student progress
- If more than approximately 5% of students are receiving support at this level, engage in tier one and tier two level, systemic problem solving

Targeted, Supplemental Monitoring

- Interventions are based on data revealing that students need more than core, universal instruction
- Interventions and progress monitoring are targeted to specific skills to remediate or enrich, as appropriate
- Progress monitoring occurs more frequently than at the core, universal level to ensure that the intervention is working
- If more than approximately 15% of students are receiving support at this level, engage in tier one level, systemic problem solving

Core, Universal Monitoring

- Research-based, high-quality, general education instruction and support
- Screening and benchmark assessments for all students
- Assessments occur for all students
- Data collection continues to inform instruction
- If less than approximately 80% of students are successful given core, universal instruction, engage in Tier 1 level problem solving

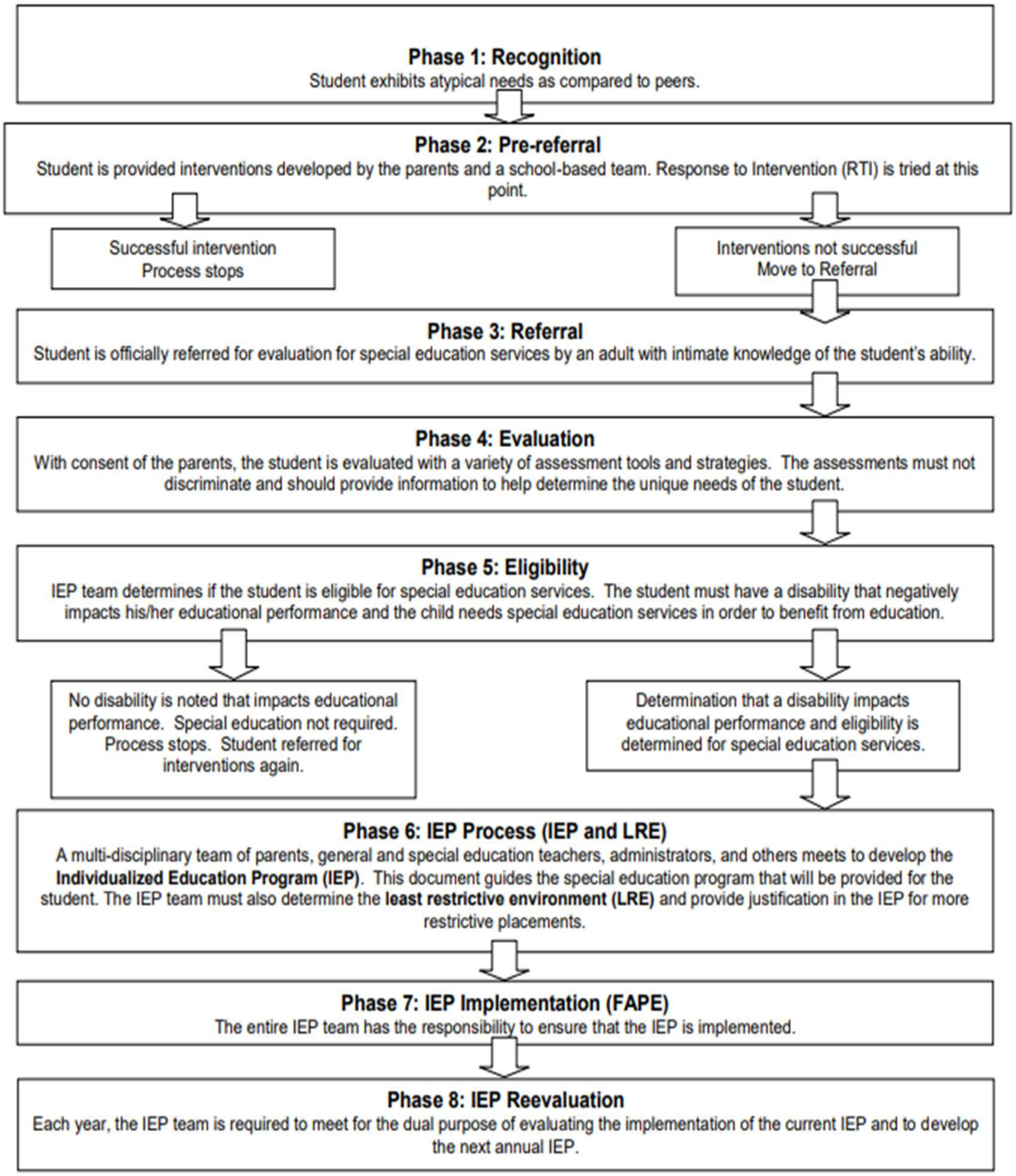
Note. Depiction of the MTSS Cycle. Reprinted from *MTSS Implementation Components: Ensuring Common Language and Understanding*, by the Problem Solving & Response to Intervention Project, 2021, https://floridarti.usf.edu/resources/index.html. Copyright 2021 by the Florida Department of Education and the University of South Florida. Reprinted with permission.

Tier 3 intervention is narrowly focused instruction to remediate barriers to the acceleration of students learning, which may include special education services and approximately 3-5% of students (Florida Problem Solving & Response to Intervention Project, 2021; Georgia Department of Education, 2021). When a student in Tier 3 does not progress toward mastery, the MTSS team may refer the student for a special education evaluation (IDEA, 2004). The Office of Special Education Programs (OSEP) at the U.S. Department of Education worked with community college early childhood programs in North Carolina to develop an IEP process flowchart, as shown in Figure 5 (Supporting Change and Reform in Preservice Teaching in North Carolina [SCRIPT-NC], 2022). Given that federal law defined the special education process, this chart applies to all states.

The evaluation may include the following components: vision, hearing, gross and fine motor testing, speech and language, achievement testing, intelligence testing, classroom observation, teacher reports, behavioral reports, socio-emotional testing, and other tests that the school psychologist may need to gain a better understanding of the student's learning strengths and needs (Fulton County Schools, 2015; IDEA, 2004). School staff and parents will then meet to review assessment results and determine if the child is eligible for special education services.

Figure 5

Special Education Flow Chart



Phase 1: Recognition
Student exhibits atypical needs as compared to peers.

Phase 2: Pre-referral
Student is provided interventions developed by the parents and a school-based team. Response to Intervention (RTI) is tried at this point.

Successful intervention
Process stops

Interventions not successful
Move to Referral

Phase 3: Referral
Student is officially referred for evaluation for special education services by an adult with intimate knowledge of the student's ability.

Phase 4: Evaluation
With consent of the parents, the student is evaluated with a variety of assessment tools and strategies. The assessments must not discriminate and should provide information to help determine the unique needs of the student.

Phase 5: Eligibility
IEP team determines if the student is eligible for special education services. The student must have a disability that negatively impacts his/her educational performance and the child needs special education services in order to benefit from education.

No disability is noted that impacts educational performance. Special education not required. Process stops. Student referred for interventions again.

Determination that a disability impacts educational performance and eligibility is determined for special education services.

Phase 6: IEP Process (IEP and LRE)
A multi-disciplinary team of parents, general and special education teachers, administrators, and others meets to develop the **Individualized Education Program (IEP)**. This document guides the special education program that will be provided for the student. The IEP team must also determine the **least restrictive environment (LRE)** and provide justification in the IEP for more restrictive placements.

Phase 7: IEP Implementation (FAPE)
The entire IEP team has the responsibility to ensure that the IEP is implemented.

Phase 8: IEP Reevaluation
Each year, the IEP team is required to meet for the dual purpose of evaluating the implementation of the current IEP and to develop the next annual IEP.

Note. Illustration of the process for special education services and IEPs. Reprinted from *IEP Process Flowchart*, by Supporting Change and Reform in Preservice Teaching in North Carolina (SCRIPT-NC), 2022, https://scriptnc.fpg.unc.edu/sites/scriptnc.fpg.unc.edu/files/resources/IEP-Process-Flowchart_0.pdf. Copyright 2022 by SCRIPT-NC. Reprinted with permission.

Areas of disability that make a student eligible for special education include the following (IDEA, 2004):

- Autism Spectrum Disorder
- Deaf-Blindness
- Deafness
- Emotional or Behavioral Disturbance
- Hearing Impairment
- Intellectual Disability
- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impairment
- Specific Learning Disability
- Speech or Language Impairment
- Traumatic Brain Injury
- Visual Impairment, including Blindness

In qualifying for special education services, the student must be determined to have one of these disabilities, and the IEP team must agree that the disability negatively impacted the student's academic performance (IDEA, 2004). If both criteria exist, the student qualifies for special education, and the parents and IEP team will meet to develop the IEP and determine goals and services (IDEA, 2004). Once services begin, progress toward goals must be reported to parents regularly as determined by the IEP team (IDEA, 2004). In addition, the team will meet at least once a year to renew the IEP (IDEA, 2004).

Parents of a child receiving special education experienced all of these steps and interactions with the school (ESSA, 2015; IDEA, 2004). For a child to qualify for special education services, school staff collected data for months. Parents most likely participated in numerous meetings with the MTSS team, often every six weeks (Rotarori et al., 2011). Once a student received special education services, the special education process included staff reporting frequent data to parents and parents participating in more meetings with the IEP team (IDEA, 2004). When viewed through ecological systems theory, the parents and child in the special education process experienced more interactions in the mesosystem regarding the school in that the school psychologist, counselor, special education teacher, and other specialists are now more regularly involved in their child’s education (Bronfenbrenner, 1986). When viewed through the overlapping spheres of influence theory, if this process went smoothly, the spheres now overlap more as the school staff and parents work closely together to develop the IEP. If disagreement and conflict arose throughout the special education process, the spheres might overlap less as the IEP is negotiated (Epstein, 2011). Given the length of time and ongoing meetings related to special education, parents participating in the special education process accumulated years of experience interacting with school staff, adding to chronosystem experiences (Bodvin et al., 2018). When viewed systemically, the special education process shifts the interactions between the family and school because the needs of each system change, as do the people included in the systems.

The Parents' Perspective on the Special Education Process

As students moved through the MTSS levels, their parents interacted with teachers, school counselors, administrators, school psychologists, and various special education staff, possibly including speech, occupational or physical therapists (Georgia Department of Education, 2021). These professionals had extensive knowledge of educational jargon and special education (Mueller et al., 2019). In contrast, parents of a child with a disability often reported that they entered the special education process with limited knowledge of the established procedures and protocols for special education, along with some hesitation about what services would look like for their children (Lake & Billingsley, 2000; Mueller et al., 2019). In this section, I explored the parents' perspectives and experiences of the special education process. This information may help educators collaboratively navigate the special education process with parents.

To better understand a parent's perspective and experience of their child's special education process, educators should consider three components: the parent's previous experiences with school staff, the parents' perceived life context, and the parents' motivational beliefs and values (Hoover-Dempsey et al., 2005; Macleod et al., 2017). According to the Hoover-Dempsey and Sandler (1995) model, these components are important because they impact parents' level of school involvement, which correlates with increased student achievement (Cohen & Mosek, 2019; Francis et al., 2016; Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Lalvani, 2012; McCoach et al., 2010; McGee, 2004; Reynolds & Howard, 2013; Sheldon & Epstein, 2005; Zhang et al., 2011). With a better understanding of parents' perspectives, educators may more effectively build strong, positive parent-school partnerships in special education and improve student achievement (Zagona et al., 2019).

Parents' Previous Experiences With Their Children's Schools

Bronfenbrenner’s (1986) ecological systems theory incorporated a chronosystem because systemic interactions across time interconnected and lead to shifts in the person’s current interactions with other systems. Based on this theoretical assumption, parents’ collective experiences with educators across time would consequently shift parents’ interaction with current educators (Bronfenbrenner, 1986). In this section, I reviewed what researchers, who have spent decades striving to understand better the legally mandated collaborative parent-school partnership in special education, determined led to positive parent-school partnerships (Baxter et al., 1995; Broomhead, 2018; Fish, 2006; Fish, 2008; Friedman et al., 2007; Heller et al., 2019; Hodge & Runswick-Cole, 2008).

For more than fifteen years, researchers have repeatedly found that when parents perceived the teacher as welcoming and willing to openly communicate with them, the resulting positive interactions created a sense of trust between the teacher and the parents (Broomhead, 2018; Friedman et al., 2007; Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Hodge & Runswick-Cole, 2008; IDEA, 2004; MacLeod et al., 2017). With a sense of trust, parents and teachers cooperatively navigated the special education process (Baum & Swick, 2008; Carlson et al., 2020; MacLeod et al., 2017). Trust, empathy, and mutual respect were essential to effective parent-school collaboration (Harry, 2008). Collier et al. (2015) paired 28 teacher candidates with 14 families of children with disabilities for a semester class. They had them conduct home visits with their paired families, then reflect upon the visit in a paper and complete a pre- and post-visit questionnaire. After the home visits, the teacher candidates described professional realizations of the complexities and stress of the families' lives, and the candidates explained that school was just one part of parents' experiences with their children. The teacher candidates also acknowledged that the parents possessed unique and valuable expertise related to their children (Collier et al., 2015). When educators listened to parents to learn more about their experiences parenting a child with a disability, they responded by becoming more empathetic, respectful, flexible, and responsive in the parent-school partnership (Collier et al., 2015; Jackson & Andipatin, 2021). When their interactions included mutual respect and reciprocity, parents and teachers developed a collective responsibility for students' success, which Cohen and Mosek (2019) termed collusive power because the parents and teachers had joined together for the child's good. If viewed through Epstein's overlapping spheres of influence theory, collusive power is similar to the maximum overlap between the family and school spheres of influence.

On the other hand, when professionals protected their identity as experts, the parents perceived a relational hierarchy with the school as an expert (Lalvani, 2012). Not only did parents feel disempowered as a result, Valle (2009) found in a longitudinal study of 15 mothers of children with disabilities that the mothers also experienced shame, guilt, and failure related to their children's need for special education, leading to minimal overlap in the spheres of influence. In her study, Valle conducted individual interviews with 15 mothers of children with learning disabilities, of whom 13 resided in the southeastern United States and two lived in the northeastern United States. Out of the 15 participants, there were 13 who were white, identified as middle class, and had children born between 1960-1990. Five mothers' parenting experiences were from the 1960s-1980s, five were from the mid-1980s to the mid-1990s, and five were from the mid-1990s to 2004. Due to the varied timeframes, Valle's narrative captured shifts in the exosystem and the macrosystem. Specifically, school recommendations shifted from exclusion in the 1960s to more inclusion with the passage of IDEA in 1997 (Valle, 2009). In her analysis, Valle utilized Foucault's critical discourse analysis (Machin & Mayr, 2012) and Labov and Waletzky's (1997) narrative structure to identify significant narrative passages in the transcripts. Her choice of quotes and participants' phrases highlighted the pain and angst mothers experienced as their relationships with the schools or mesosystem changed. In her narrative storytelling, Valle effectively conveyed how deeply mothers experienced the authoritative nature of the school staff and the labels given to their children. The power of Valle's narrative storytelling made the mothers' emotions palpable because it magnified the judgment, pressure, and labeling that mothers fought against to have their children seen not only for their strengths but for their entirety as a person. Her narrative described the emotional impact of spheres of influence shifting towards minimal overlap and conflict in the mesosystem.

In another study of parents' experiences of the special education process, Macleod et al. (2017) used a Facebook survey to gather over 50 responses from 35 parents and guardians who were members of a closed parent-advocacy Facebook group. Given the nature of the data collection, the researchers only explored the stories of those parents who actively engaged in an electronic exchange with the researchers, which meant the researchers were unable to view parents' nonverbal language or to use the interview process to follow participants' stories to gain greater understanding. In addition, the participants most likely filtered their responses due to the public nature of Facebook. Despite these limitations, Macleod et al. used parents' narratives to portray their intense frustration with not being heard in the special education process and having their expertise regarding their children discounted by school staff. One couple, who collaborated with the researchers in collecting the Facebook responses, summarized the study's findings by stating that "if educators would take the time to reflect on why parents feel anxiety and fear, it may be easier to practice patience and compassion and to address the power imbalance" (Macleod et al., 2017, p. 391). Managing the mesosystem to maintain positive and supportive communication appeared to be a vital concern for parents (Burke et al., 2019; Henderson et al., 2020; Macleod et al., 2017).

Considering the deficit-based special education model written into IDEA (2004), it is not surprising that parents often reported experiencing the special education process as anxiety-producing and overwhelming (Karande et al., 2009). In response to parents' emotions around the special education process, researchers studied how parents' stress, anxiety, behaviors, education level, and socioeconomic status (SES) were related to their children's disabilities (Karande et al., 2009; Lalvani, 2012; Zhou et al., 2022). In doing so, researchers may have inadvertently perpetuated the deficit model view of families that underlies the school as an expert approach (Bonifacci et al., 2016; Goodall, 2021; Hodge & Runswick-Cole, 2008). For example, if school staff perceived themselves as operating in the best interest of students and families, they had more difficulty acknowledging parents' perspectives and expertise by relinquishing professional power (Lee & Park, 2016). After documenting parents' experiences in the special education process over a forty-year timeframe, Valle (2009) found that even with the implementation of IDEA (1997), parents' experiences of professional power in the special education process remained. This study explored the decades since Valle's research to discover if parents' experiences have changed since IDEA (2004) and ESSA (2015) passed, given that the language of both laws emphasized the importance of the least restrictive environment and parents' equal participation and collaboration in the special education process.

Even though MacLeod et al. (2017) found that parents did not believe school staff purposefully perpetuated a hierarchical structure, parents still perceived an imbalance of power in the parent-school partnership. Consequently, lower and higher SES parents have sometimes described the family-school partnership as an ongoing battle (Mazher, 2012; Rosetti et al., 2021). In an in-depth analysis of five IEP meetings, Bray and Russell (2016) found that most IEP team participants' feedback did not significantly change the drafted IEP, meaning that school staff disregarded parents' knowledge and skills. Given these experiences, many parents developed a watchdog stance to ensure their children received the most appropriate services (Lalvani, 2012). With a deeper understanding of parents' perceptions of the special education process, teachers and administrators may better recognize and negotiate barriers to an authentically equal and collaborative special education parent-school partnership, required by IDEA (2004) and correlated to increased student achievement (Collier et al., 2015; Tucker & Schwartz, 2013).

After analyzing data from a 34-item online survey of 73 parents of children with autism living in the Midwest and Southwest regions of the United States, Kurth et al. (2020) found that parents' sense of battling the schools for years was pervasive among the sample and appeared to take "a toll on the families" (p. 42). Given that the data thematically analyzed was only four short-answer responses, Kurth et al. provided limited evidence to describe the toll mentioned in their findings. Kurth et al. did find that parents described the quality of the parent-school partnership as in flux because school staff often changed, especially each new school year, which led to a sense of "foreboding about what the next year may bring" (p. 43). Due to the online survey method, Kurth et al. did not further explore how parents experienced the described flux in the parent-school partnership. To more deeply understand the connection between families' past experiences and their current interactions with school staff, this study's design methods include in-depth interviews to explore these experiences.

Understanding parents’ experiences matters because when parents perceived that school staff ignored or excluded them, the parents were more inclined to frequently contact the school because of a lack of trust and reciprocity (Carlson et al., 2020). As parents increased their communication with school staff, teachers became uncomfortable due to perceived criticism, so they avoided or limited contact, creating an escalating cycle of misunderstanding between the parents and teachers (Lake & Billingsley, 2000; Mueller, 2015). As a result, higher SES parents often adopted a systemic approach where all teachers comprised a larger system to battle (Lalvani, 2012; Wingate et al., 2018). Theoretically, the family perceived that the family and school spheres of influence remained separated with minimal overlap. According to the Hoover-Dempsey and Sandler (1995) model, this perception of lower self-efficacy negatively impacts the parent-school partnership.

Parents' Perceived Life Context

Along with parents’ previous experiences with school staff, researchers found that parents’ perceptions of their own knowledge and skills also impacted the parent-school partnership (Hoover-Dempsey et al., 2005; Lake & Billingsley, 2000; Mueller et al., 2019; Reiman et al., 2010). The Hoover-Dempsey and Sandler (1995) model included parents’ perceptions, the parents’ knowledge of special education jargon, academic instruction, academic skills, and an understanding of how to help their child. Skills included not only parents' academic skills but also advocacy, job, and communications skills (Hoover-Dempsey et al., 2005). Hoover-Dempsey and Sandler included parents' perceptions of their knowledge and skills as one component of parents' perceived life context that impacted interactions with school staff. In this section, I explored how parents' perceived life context impacted their interactions with the school to provide more context for understanding parents' perceptions of the parent-school partnership.

Researchers found that parents' perceived life context was vital because it impacted parents' perceptions of the special education process (Hoover-Dempsey et al., 2005; Mueller et al., 2019; Reiman et al., 2010). Understanding the special education process and legalities was often a huge learning curve for parents as they entered the special education journey (Reiman et al., 2010). Parents reported that they realized they had insufficient knowledge when challenging school recommendations or decisions because they did not know the educational jargon and special education law like the educators did (Lake & Billingsley, 2000; Mueller et al., 2019). When parents doubted their knowledge and skill, they were less willing to advocate for their children, perpetuating the view of school as the authority (Lee & Bowen, 2006; Murtadha-Watts & Stoughton, 2004).

In addition to a lack of knowledge of the special education jargon, language barriers also impacted parents' participation (Salas, 2004). Salas (2004) interviewed 10 Mexican American women who spoke primarily Spanish about their experiences during IEP meetings for their children. These mothers experienced marginalization and isolation during the IEP meetings when school personnel engaged in disrespectful behavior, such as not showing up for a scheduled meeting or repeatedly looking at the clock during the conference. As a result, the women perceived that their knowledge, skills, and participation were not valued (Salas, 2004). Even when schools used family liaisons to bridge cultural, racial, and class differences, Ishimaru et al. (2016) found that the school staff rarely created opportunities for the school to learn from the parents. Instead, Ishimaru et al. found that school staff's attempts at cultural brokering most often appeared to be more like socializing families to school-centric norms. While parents requested help to improve their knowledge and skills about their children's education, they also wanted respect for their unique expertise regarding their children (MacLeod et al., 2017).

The second component of the Hoover-Dempsey and Sandler Model (2005) was parents' perceptions of time and energy. Helping with homework, communicating with the school, participating in the Parent Teacher Association, or volunteering were types of parental involvement (Auerbach, 2007; Epstein, 2011). School staff sometimes misjudged parents' involvement when defining parent involvement by only these components (Gibbs et al., 2021). Gibbs et al. (2021) found that parents wanted to be more involved with their children's education but work or family demands restricted their ability to volunteer. Instead, these parents offered behind-the-scenes support that typical measurements of school involvement did not capture (Auerbach, 2007; Santamaria Graff et al., 2021; Wanat, 2010). Researchers found that only in-depth interviewing captured the extent of the varied ways parents engaged with their children's education because the interview uncovered unknown parental involvement aspects (Carlson et al., 2020; Gibbs et al., 2021).

In a qualitative study of 33 diverse parents of children with disabilities living in New York and New Jersey, Lalvani (2012) conducted one extended interview with open-ended questions with each parent in the study to determine parents' perceptions of the IEP process and their children's current educational program. Lalvani found that school staff placed the children of the nine parents labeled low SES in more restrictive settings, which correlated to the parents' self-reports of limited knowledge of the least restrictive setting expectations in special education. Higher SES parents also reported limited success advocating for effective and inclusive education despite ample time, energy, and resource access (Lalvani, 2012). While low SES parents also advocated for their children's needs during the special education process, work demands, limited financial resources, language barriers, and limited knowledge of special education may have inhibited their effectiveness (Lalvani, 2012). In the Hoover-Dempsey and Sandler (1995) model of parental involvement, these challenges are defined as "perceived life context."

Having a child with a disability often taxed parents' time and energy (Murphy & Risser, 2022). Specifically, parental stress increased when siblings perceived that their parents devoted more time to their sibling with a disability than to them (Kassa, 2019; Wang et al., 2011). Along with time demands, Coetzee et al. (2018) suggested that parents may experience deep-rooted feelings of despair, fear, and helplessness depending on their children's disabilities and behavioral needs and the effect on family life, depleting parents' energy resources. Hsiao et al. (2017) had 236 parents of children with autism spectrum disorder complete three scales*:* the Beach Center Family Quality of Life Scale*,* the Parental Stress Scale*,* and the Beach Center Family-Professional Partnerships Scale. After quantitative analysis, results suggested that positive parent-school partnerships reduced parental stress and improved family quality of life, indicating a positive impact on parents' "energy" resources, one component of the Hoover-Dempsey and Sandler (1995) model's life context component. However, the study's use of scaled measures as the methodology limited the gathering of more in-depth information regarding parental responses. In another study of mothers of children with autism, Benson (2015) found that positive home-school communication reduced maternal distress and led to higher parental self-efficacy. While Benson conducted his study over multiple years, he focused only on mothers of children with autism spectrum disorder, and he only used questionnaires to collect data, which, like Hsaio et al., limited the depth of information gathered.

Similarly, Baxter et al. (1995) found that parental anxiety decreased when parents believed that they were well-supported by teachers and that the teachers valued and cared for their children. Even though they used interviews to collect data, Baxter et al. structured the interviews with Likert scale questions, limiting collected information to a scaled 1-5 response. Parenting a child with a disability often requires more educational, physical, psychological, and economic resources, all components of life context that increase parental stress (Murphy & Risser, 2022). For this reason, Burke and Hodapp (2014) suggested further research on the effects of parent-school relationships on parental stress. With more in-depth interviewing to learn about parents' life context, educators may have more insight into ways to improve the parent-school partnership and decrease parental stress (Burke & Hodapp, 2014).

Educators must better understand the effects of parent-school relationships on parental stress because higher parental stress correlates to more behavioral problems in students with developmental disabilities (Neece et al., 2012). Neece et al. (2012) included 237 families of children with developmental delays and followed the children from ages 3-9 to capture the transactional relationship between parental stress and child behaviors. The researchers used quantitative analysis to determine that parental stress was both an antecedent and consequence of children's behavioral problems. Neece et al. found that parents of children with disabilities experienced increasing stress as their child aged, partially related to navigating the special education process. In contrast, parents of children without disabilities experienced decreased stress over time. Summers et al. (2005) proposed that one source of increased parental stress was parents being less satisfied with their children’s education as they acquired more knowledge about their rights and expectations for special education. Summers et al. had 147 families of children with disabilities complete The Beach Center Family-Professional Scale and then quantitatively analyzed the data. Their findings suggested that parents of younger children tended to be more satisfied than parents of older children and called for future research to understand better why this pattern emerged. In addition, Bailey et al. (2004) found that higher SES parents were unsatisfied with the amount of service, while lower SES families were more unsatisfied with both the quality of services and the parent-school partnership, suggesting the need for a deeper understanding of the variation in parents' satisfaction. As noted, much of the research around parental stress was quantitative, so the use of in-depth interviewing as a methodology in a basic interpretative study allowed me to gain a deeper understanding of how parents described and experienced the parental stress related to both having children with disabilities and navigating the special education process (Bailey et al., 2004; Baxter et al., 1995; Hsaio et al., 2017; Neece, 2012; Summers et al., 2005).

Parents' Motivational Beliefs

In the previous two sections, I have described the impact of parents’ previous school experiences and perceived life context, as defined in the Hoover-Dempsey and Sandler (1995) model of parental involvement, on their perceptions and experiences of the special education partnership. The Hoover-Dempsey and Sandler model also included parents' motivational beliefs as a component of their partnership with the school, which I described in this section.

Hoover-Dempsey and Sandler’s model included two components of parents’ motivational beliefs: the parent’s role construction concerning the support of their child’s education and the parent’s sense of self-efficacy in helping their child to learn (Hoover-Dempsey & Sandler, 1995; Lilly & Hoover-Dempsey, 2011). Parental role construction incorporated the parents’ beliefs about what they should do concerning their children’s education, which varied based on parents’ child-rearing beliefs, their understanding of child development, and their social schemas regarding education (Auerbach, 2007; Green et al., 2007; Sheldon & Epstein, 2005). Regarding special education, parents' role construction varied depending on their schema, beliefs, and culture (Kurth et al., 2020; Reiman et al., 2010; Santamaria Graff et al., 2021). For example, the culture of some parents viewed school staff as having more authority, which limited parents' willingness to challenge the schools' recommendations (Bodvin et al., 2018; Harry, 2008; Lo, 2008). In contrast, other parents saw their role as monitoring and managing their children's education, which conflicted with the school as authority paradigm (Gibbs et al., 2021).

Hill & Taylor (2004) attributed this difference to parents' childhood experiences of school, or schemas, influencing their perceptions of the school staff. Similar to Valle (2009) and Hodge & Runswick-Cole (2008), Lalvani (2012) found that parents fought to have their children seen as more than a label or category in an IEP.

Nevertheless, IDEA (1997) regulations led to the expectation that parents’ roles would include advocating for their children as part of equal participation in the IEP. However, when parents adopted the role of advocate, their role conflicted with the professional status underlying the hierarchical structure of the parent-school partnership (Kalyanpur et al., 2000). In an analysis of a 34-item online survey of 73 parents of children with autism living in the Midwest and Southwest regions of the United States, Kurth et al. (2020) found two significant predictors of parents' satisfaction with schools: input in their children's IEP and teachers' knowledge regarding their child’s disability. Kalyanpur et al. (2000) suggested that professional knowledge was more objective than parents' subjective knowledge of their child, creating a contextual barrier to the reality of parents' equal participation. As a result, parents may have felt forced to sacrifice a positive relationship with school staff to fulfill their role as advocates to get the services their children need (Kalyanpur et al., 2000; Kluth et al., 2007; Kurth et al., 2020). In addition, Chopp (2012) noted that the IEP team usually consisted entirely of school staff besides the parent, making the parent feel like the lone voice of dissent. As a result, parents’ role construction may have shifted in response to their perception of a power imbalance in the parent-school partnership (Kurth et al., 2020).

According to the Hoover-Dempsey and Sandler model (1995), parents’ perceptions of a power imbalance in the special education parent-school partnership may have affected their parental self-efficacy, the second component of motivational beliefs described in the model. Lilly and Hoover-Dempsey (2011) defined self-efficacy concerning parental involvement as parents making involvement decisions based on desired outcomes. Benson (2015) found that positive home-school communication led to higher parental self-efficacy, possibly perpetuating increased involvement and, thus, increased student achievement. Macleod et al. (2017) noted that parents' self-efficacy diminished when parents experienced frustration about school staff acknowledging their concerns. While Lalvani (2012) found that all parents advocated for their children, higher SES parents experienced more self-efficacy than lower SES parents partly because lower SES parents doubted their knowledge and decided to defer to a professional's expertise. Lalvani described how some parents reported that school staff treated them as equals where their input was valued. In contrast, other parents in the study reported that school staff's labels of them included terms like annoyance, nuisance, or squeaky wheel. Those parents described the parent-school partnership as exhausting and predicted an ongoing adversarial relationship with the school (Lalvani, 2012). By researching parents' longitudinal experiences of the special education process, educators may develop a deeper understanding of the parent's beliefs and values that motivate their battle stance (Collier et al., 2015; Lalvani, 2012). With this understanding, teachers may be better prepared to facilitate the complex special education parent-school partnership required each school year (Collier et al., 2015; Tucker & Schwartz, 2013).

The School Staff's Perspectives

In special education, parents and educators ideally work together to best meet students' needs (Kurth et al., 2020). Unfortunately, parents and school staff sometimes develop adversarial relationships (Henderson et al., 2020). To understand the parent-school partnership, I reviewed the research regarding school staff's perspectives, experiences, and beliefs in the following sections to create a context for educators' perspectives of the parent-school relational dynamic. To better understand the parent-school collaboration in special education, researchers explored the viewpoint of school staff in the special education relational dynamic, including staff's previous interactions with parents, personal experiences with disability, and staff's beliefs (Bezdek et al., 2010; Bodvin et al., 2018; Collier et al., 2015; Henderson et al., 2020; Koch, 2016).

School Staff's Previous Experiences With Students and Parents

I included this section because teachers' previous experiences may impact their current interactions with parents, impacting both the mesosystem and the level of overlap between spheres of influence (Fox et al., 2020). Given the impact of parent-school collaboration on student achievement, researchers have explored both parents' and staff's perceptions of the special education process (Bezdek et al., 2010; Burke et al., 2019; Henderson et al., 2020; IDEA, 2004; Lake & Billingsley, 2000; More et al., 2013). When describing parent-school communication, teachers reported that a significant source of stress was administrators' responses to highly involved or upset parents (Fox et al., 2020). In a longitudinal mixed methods study conducted from 2018-2019, Fox et al. (2020) surveyed and interviewed 29 secondary teachers in a small, K–12 private school with 385 students with learning difficulties to determine how teachers defined their well-being and how that definition shifted over time. A key finding was that teachers experienced administrators' responses to upset or highly involved parents as "extreme pressure." Often, administrators responded to parents' demands by micromanaging the teacher, resulting in teachers losing a sense of autonomy and trust as professionals, negatively affecting their well-being and willingness to engage with parents (Fox et al., 2020). Balancing the demands of parents with teachers' professional autonomy challenged school administrators (Fox et al., 2020).

Given teachers' negative experiences with upset or highly involved parents, some teachers may have developed implicit bias in their response to parents (Collier et al., 2015; Goodall, 2021; Hodge & Runswick-Cole, 2008). Bezdek et al. (2010) found in interviews with 20 educators that special education teachers often labeled the parents as involved too much or too little despite parents' legal status as equal participants in the special education process. However, when parents supported the educators' guidance, educators deemed parental involvement as just right (Bezdek et al., 2010). Bezdek et al. described this view of parents as the "Goldilocks perception" and suggested that educators perceived parents as threatening when parents acquired expertise about special education. Instead, educators in this study preferred that the parents let the professionals lead recommendations while parents provided in-home support and assistance (Bezdek et al., 2010). Theoretically, this educator preference forces the spheres of influence apart and shifts systemic interactions between microsystems based on chronosystem experiences (Epstein, 1987; Hoover-Dempsey & Sandler, 1995). For parents, the disconnect between the legal mandate of equal participation and educators' perceptions and behaviors in the IEP meeting may have eroded trust, impacting their systemic interactions (Carlson et al., 2020; Salas, 2004).

This dichotomy between educators' reported values and actions also appeared in findings by Bodvin et al. (2018). In a study conducted in Belgium, Bodvin et al. used eight semi-structured focus group interviews that included 50 school counselors and special educators to explore how educators viewed collaboration with special education families. For example, all the educators recognized that a positive and collaborative parent-school partnership required trust and respect for the parents. Nevertheless, when parents asserted their opinions, educators often labeled them difficult (Bodvin et al., 2018). More specifically, the school counselors in the study reported that they and the parents frequently viewed students' problems differently, which the school counselors described as "annoying" and "obstructive" (Bodvin et al., 2018, p. 426). Henderson et al. (2020) found that teachers often viewed parental communication as positive only when it aligned with the teachers' values and expectations, which Blue-Banning et al. (2004) described as turfism. Some educators even expressed frustration when parents challenged decisions instead of "rubber stamping" school recommendations, while others welcomed parents' input (Ross, 2019). These conflicts may represent a battle over how much overlap the spheres of influence may have, with school staff preferring more power (Epstein, 2011).

In addition, most educators in the Bodvin et al. (2018) study and the study by Bezdek et al. (2010) attributed problems collaborating with parents to deficits in the family, such as unstable home situations and problematic parenting. However, a minority of educators identified problems in the special education process (Bodvin et al., 2018). One barrier Bodvin et al. noted was the gap between the norms of communication and parental involvement of educators in Western culture and those of ethnic minority families. For example, parents of some ethnic minority groups preferred to manage their children's difficulties at home and not involve school staff, which educators perceived as resistant (Bodvin et al., 2018). Both parents and school staff's past experiences with each other impacted their perceptions of their current parent-school interactions, which is an example of the chronosystem impacting mesosystemic interactions (Bodvin et al., 2018).

School Staff's Personal Life Experiences

In the previous section, I described the impact of school staff's prior professional experiences with parents on their perceptions and behaviors of the parent-school partnership. In addition to educators' professional past experiences, educators' personal life experiences with people with disabilities also impacted their perceptions and experiences in the parent-school partnership (Bezdek et al., 2010; Cavendish & Connor, 2018; Koch, 2016). In this section, I review the research regarding the impact of educators' personal experiences on their attitudes and behaviors toward the special education process and parents because of the implications for the parent-school partnership (Bezdek et al., 2010; Cavendish & Connor, 2018; Koch, 2016).

Due to personal experiences, some teachers were more open to parental involvement and communication because they had experienced the IEP process or had similar issues with their children (Bezdek et al., 2010). When viewed systemically, these teachers' microsystems included the special education experience and the experiences of their children's disabilities. As a result, they may have had a deeper understanding of the emotional impact of the mesosystemic interactions required in the special education process on parents (Bronfenbrenner & Ceci, 1994). For this reason, these educators may have looked beyond the parent-school partnership to empathize with the challenges faced by families, both inside and outside of school (Cavendish & Connor, 2018). In interviews with 11 special education teachers who also were parents of children, Koch (2016) found that special educators with personal experiences with disabilities in their families reported being strong advocates for families because they operated from the perspective of "What if this was my child?" In Koch's study, special education teachers reported that sharing their personal experiences as parents of children with disabilities helped them build trust with their students' parents (Burke et al., 2019; Cohen & Mosek, 2019). Koch found that the special education teachers who were also parents of children with disabilities had more success bridging the gap between school and parent expectations, which the teachers attributed to parents trusting them more because the teachers had walked in the parents' shoes. In addition, Bezdek et al. (2010) found that more experienced teachers reported a better understanding of the parents' challenges and displayed more compassion in their responses to parents (Bezdek et al., 2010). Bezdek et al. questioned whether teachers were more open to sharing the role of expert and power with parents when their own developed sense of competence, expertise, or similar life experience reduced their perception of parents as a threat and instead shifted the teacher towards establishing more equality in the partnership. By valuing a parent's expertise on their child's disability, educators positively impacted parent-school communication in special education (Olivos et al., 2010).

School Staff's Beliefs

While educators' previous professional and personal experiences impacted their interactions in the parent-school partnership, educators' beliefs regarding the role of parents and special education also influenced their perception of the parent-school partnership (Broomhead, 2018; Cook & Friend, 2010). Most educators reported a desire for positive and collaborative parent-school partnerships while recognizing the value of trust in strengthening relationships with parents (Anthony & Campbell, 2020; Broomhead, 2018). Teachers recognized that building collaborative relationships included parents feeling supported and valued (Sears et al., 2021). Unfortunately, despite teachers' reports of being overwhelmed facilitating the special education parent-school partnership, pre-service teachers have not consistently received training on establishing positive and supportive two-way communication with families (Santamaria Graff et al., 2021; Ratcliff & Hunt, 2009; Rosetti et al., 2021). Consequently, teachers often reported feeling unprepared to collaborate with families in the complex special education partnership (Koch, 2016; Smith & Sheridan, 2019).

Regarding special education, teachers with supportive beliefs towards inclusion believed that all individuals were welcome and valued in the school community (Cook & Friend, 2010). Mueller and Piantoni (2013) conducted 30-minute phone interviews with 10 experienced special education directors from 10 western United States school districts to garner educators' perspectives. The directors reported that communication, supporting parents, and leveling the playing field for parents helped to reduce conflict in the special education process (Mueller & Piantoni, 2013). Leveling the playing field meant balancing the power in the IEP dynamic by helping parents understand the educational jargon and their rights in the special education process (Mueller & Piantoni, 2013). Unfortunately, teachers reported feeling stuck in the mesosystem, balancing the microsystem of the family with the exosystem power settings of the district and school expectations (Cavendish et al., 2020).

Even though educators understood the components of a collaborative parent-school partnership in special education, researchers found a disconnect between educators' expressed values and actions (Carlson et al., 2020). In an attempt to create a shared perception of the special education process, Mereoiu et al. (2016) conducted training with 15 educators and 18 parents of children with disabilities to determine if participants' views of the IEP process shifted after attending a training on parent-school collaboration in the special education process. In the study, only three of the 15 educators reported some personal experiences with a child or person with disabilities, substantiating Ratcliff and Hunt's (2009) findings that teachers' life experiences often did not include persons with disabilities. Mereoiu et al. used an ANOVA analysis of the participants' pre- and post-intervention questionnaire responses. They found that parents had more negative views of collaboration in the IEP process after the training and that teachers reported the IEP process being more team-based, similar to Bodvin et al. (2018) and Kurth et al. (2020). Mereoiu et al. surmised that parents increased negative perceptions corresponded to the parents gaining more knowledge and, thus, having more questions about their children's special education services. Mereoiu et al. suggested that future research should explore parents' experiences throughout each stage of the special education process as parents possessed critical insights that more in-depth interviewing could access.

Summary

The special education parent-school partnership is complex at multiple systemic levels. At the macrosystemic level, United States culture has shifted away from the exclusion of special education students in the 1960s to the full inclusion of special education students today (IDEA, 2004; Valle, 2009). Exosystem power settings, like federal and state education departments, created policies and expectations for how schools and parents should collaborate and interact (ESSA, 2015; IDEA, 2004; U.S.

Department of Education, 2022). Consequently, the exosystem influences the parents' and teachers’ mesosystemic interactions. As a result, some teachers and parents have adopted a wary stance when entering the parent-school relationship, given the legal expectations and consequences (Cavendish & Connor, 2018; Love et al., 2017). The quality of the mesosystemic interactions remained vital as researchers established that parental involvement correlated with increased student achievement, making it an essential educational component (Cohen & Mosek, 2019; Francis et al., 2016; Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Lalvani, 2012; McCoach et al., 2010; McGee, 2004; Reynolds & Howard, 2013; Sheldon & Epstein, 2005; Zhang et al., 2011). With a better understanding of parents' perspectives, educators may more effectively build strong, positive parent-school partnerships in special education and improve student achievement (Zagona et al., 2019).

Chapter III

METHODOLOGY

In this chapter, I described the methodology for this study, including my reasoning for choosing a basic interpretative study design. In addition, I defined my sampling technique and data collection procedures and outlined my data analysis. I concluded this chapter by discussing the study's trustworthiness. This research protocol was exempt from Institutional Review Board oversight under 45 CFR 46.101(b) of the federal regulations, Category 2 (see Appendix A).

Purpose and Research Questions

The focus of this basic interpretative study was to use in-depth interviewing to explore how parents of children who qualify for special education and have participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. With a deeper understanding of how parents experience the special education process, educators may more effectively navigate the parent-school partnerships required in special education each year. To better understand these parents' experiences, the following research questions guided this basic interpretative study:

RQ 1: How do parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences?

RQ 2: How do parents of children who have participated for two or more years in the public-school special education process describe the impact of previous experiences and perceptions in the special education process on how they currently interact and collaborate with school staff?

Research Design: Basic Interpretative Study

A basic interpretative study design provided the opportunity to understand participants' perceptions and interpretations of their experiences, the context of their experience, and the meaning they attribute to their experiences (Merriam, 2002). As part of the spheres of influence model, Epstein (2011) stated that the family's historical experiences with one school affected the family's knowledge and attitudes in future school interactions. Expanding on the idea that historical context influenced current experience, Polkinghorne (1995) defined the interaction of a person's previous learning and experiences with their present experiences, proposed goals, and purposes as human action. Within the process of a basic interpretative study, participants' human actions can be framed in both historical and current contexts to create a deeper understanding of how parents of children with disabilities described the meaning and impact of their past perceptions and experiences in special education on their current perceptions and experiences of the special education parent-school partnership. In-depth interviews provided a context for more detailed information (Maxwell, 2013). According to Merriam and Tisdell (2016), phenomenology often informs interpretative research and propounds that people interpret experiences based on the meaning it has for them. In addition, interpretative research emphasizes seeing experiences from the perspectives of others (Crotty, 1998; Merriam & Tisdell, 2016). Through in-depth interviewing and utilizing the underlying constructs of a basic interpretative design, I sought to give voice to parents' experiences and the meaning it had for them so that the reader may understand the journey of special education from these six families' perspectives (Merriam & Tisdell, 2016).

Sampling Technique

In Georgia, 204,004 public-school students, or 12% of Georgia's students, received special education in 2021-2022 (Georgia Department of Education, 2022). Considering that families may have more than one child receiving special education and not all families have two parents or guardians, this statistic suggests that at least 200,000 parents or guardians in Georgia experience the special education process each year. In this section, I described the selection process and criteria for selecting the sample for the study.

To answer the research questions, I explored parents' previous experiences in the special education process and how those experiences impact their current interactions with school staff. I chose two or more years as a sampling criterion to ensure parents had historical and current special education involvement. Weiss et al. (2014) found that continuity in parental engagement was critical during the transition from elementary to middle school and middle to high school because families had to build new relationships at each level. Because these transitions capture parents' experiences establishing new relationships with school staff, transition experiences most likely provide information-rich cases. For this reason, I drew the sample from families who transitioned their children receiving special education to either middle or high school.

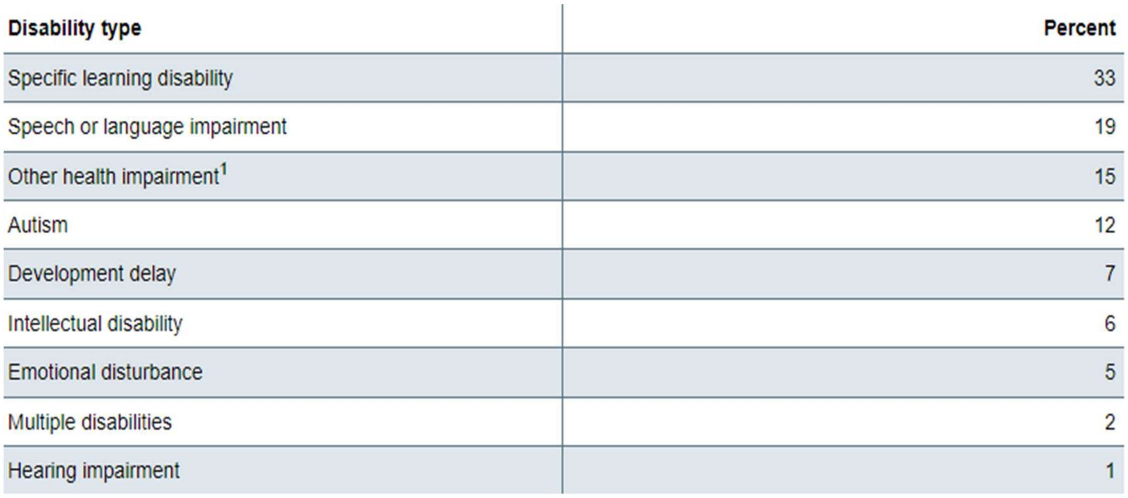
When considering additional criteria, I included all 14 disabilities listed in IDEA (2004) in the sampling criteria since parents and school staff must collaborate to finalize the IEP regardless of the disability type. Areas of disability that make a student eligible for special education include the following (IDEA, 2004):

- Autism Spectrum Disorder (AU)
- Deaf-Blindness
- Deafness
- Emotional or Behavioral Disturbance or Disorder (EBD)
- Hearing Impairment
- Intellectual Disability (MOID for mild to moderate intellectual disability)
- Multiple Disabilities
- Orthopedic Impairment
- Other Health Impairment (OHI)
- Specific Learning Disability (SLD)
- Speech or Language Impairment if they receive more than just speech services
- Traumatic Brain Injury
- Visual Impairment, including Blindness

According to the National Center for Education Statistics (2021), disabilities were distributed in 2020-2021, as shown in Table 1.

Table 1

Percentage Distribution of Students Ages 3-21 Served Under the IDEA for School Year 2020-2021



Disability type	Percent
Specific learning disability	33
Speech or language impairment	19
Other health impairment[1]	15
Autism	12
Development delay	7
Intellectual disability	6
Emotional disturbance	5
Multiple disabilities	2
Hearing impairment	1

Note. Illustration of students covered under IDEA for 2020-2021. Reprinted from *Students with disabilities*, by National Center for Education Statistics, 2021, https://nces.ed.gov/programs/coe/indicator/cgg. Copyright 2021 by Condition of Education. Reprinted with permission.

High-incidence disabilities include autism, speech or language impairment, intellectual disabilities, specific learning disabilities, and emotional and behavioral disorders (The University of Kansas, 2021). Students who receive only speech and language impairment services have a different special education experience than other students with disabilities. “Speech-only” students receive special education services from a speech pathologist once or twice weekly for 30-60 minutes. However, they receive no support from a special education teacher in their academic placement (S. Bloom, personal communication, February 22, 2023). Since “speech-only” students do not receive academic support from a special education teacher, the sample did not include students receiving only speech services. Maxwell (2013) suggested a purposeful selection of cases representing the typicality of settings and individuals when selecting participants. To follow Maxwell’s suggestion, I used the percentage distribution chart in Table 1 to determine the typicality of students.

Based on the percentage distributions, I selected two families whose children have an SLD, as this disability represents 33% of the population. The students included a female, an eighth grader in the 2023-2024 school year, and a male, a ninth grader in the 2023-2024 school year. For my third family, I selected a family whose son is a sophomore in the 2023-2024 school year and who has an OHI disability related to his health conditions from being born premature, as this disability represents 15% of the population and who also has a learning disability. For my fourth family, I selected a family whose son has AU, as this disability represents 12% of the population. In the 2023-2024 school year, he is a high-school senior served through the modified curriculum autism program because he has minimal verbal skills.

Low-incidence disabilities include visual and hearing impairments, developmental delays, intellectual disabilities, and multiple disabilities combined. They represent 16% of the population. To remain balanced with the percentage distribution, my fifth participant is a family with a child with one of these disabilities. In the 2023-2024 school year, this family’s son is a high-school senior with Down’s Syndrome.

Students with EBD, also known as emotional or behavioral disorders instead of disturbance, occur with low incidence but present very differently than the other low-incidence disabilities. A child with an EBD often has difficulty with interpersonal relationships, consistent or chronic inappropriate behaviors or feelings, a pervasive mood of unhappiness or depression, and anxiety or somatic symptoms (IDEA, 2004). The sixth family selected has a child with an EBD. In the 2023-2024 school year, he is a ninth grader with a secondary disability of OHI for his attention deficit disorder. Using these distribution criteria, I chose these six families for the study. The parents were willing to participate in the interview process and had at least one child in grades 6-12 who had participated in public-school special education for at least two years within school years 2018-2023 in a Georgia public-school setting. All the families spoke English well enough to facilitate communication.

After identifying each volunteer, I collected and recorded the information in my research journal. I collected this information to ensure that I included students with different disabilities from various schools and districts to provide a more representative sample (Maxwell, 2013). The families in this study attended three local school systems and six different local schools. The general information I collected was as follows:

1. Name of parent and their contact phone number and email
2. The child's age, grade, and primary disability and, if applicable, secondary disability listed on the IEP according to the parent's self-report
3. Name of the local school district
4. Name of child's school

Despite posting recruitment flyers (see Appendix B) in local school Facebook groups, local county Facebook groups, and my personal Facebook group, only five people volunteered, so they were selected due to limited access to additional volunteers. I still was missing one disability category, so I attempted to use snowball sampling to find additional participants to reach the desired six participants (Patton, 2015). Referrals given had the same disability, so the referrals were not compatible. I found my last volunteer through a referral from a friend whose son has a physical disability but is only five years old, making their experience in special education too limited for this study. She is active in a group for children with special needs and referred me to a family whose son had autism and was 17 years old. His mother agreed to participate, bringing me to the required six families and needed categories. Once I chose the families, I emailed the consent form (see Appendix C) and spoke to them on the phone to answer any questions they may have had before agreeing to the study.

Data Collection Procedures

In qualitative research, data is often collected through interviewing, allowing the researcher's biases and assumptions to unknowingly impact the data collection process. To increase the study's trustworthiness, I used a systematic method for collecting data (Patton, 2015). In this section, I described the data collection process.

To obtain detailed and thorough data, I conducted and recorded three 90-minute semi-structured interviews with each participant in person (Siedman, 2013). Grinyer and Thomas (2012) noted that the first interview with a participant tended to be the public account of their personal stories because the researcher and participant were establishing rapport. Grinyer and Thomas found that the second interview often included more meaningful and in-depth accounts if the researcher effectively established rapport and trust during the first interview. Rubin and Rubin (2011) described the qualitative interview as a conversation in which the interviewer intently listened to the participants, noticed nonverbal cues, and then determined the next question. I balanced the topics of the interview guide with staying present with the participants' stories to allow more in-depth or unexpected information to emerge (Kim, 2016; Mishler, 1986).

Additionally, using the semi-structured interview guide allowed the flexibility to follow the participants' ideas while counteracting the suppression of stories that can occur in the structured interview's stimulus-response paradigm (Mishler, 1986; Wilkinson & Birmingham, 2003). Using a strict order of questions may have stunted rapport if the participants had perceived that I was ready to move to the next question, leaving the story unfinished or unexplored by the participant (Mishler, 1986). According to Mishler (1986), how the interviewer listens, attends, encourages, interrupts, digresses, and starts or ends topics in the interview context impacts the participants' storytelling. Using an interview guide approach, I balanced gathering the topic information with honoring the participants' stories and experiences (Johnson-Bailey, 2002; Mishler, 1986; Patton, 2015). At the end of each interview, I reviewed the guide and found that the participants naturally answered the questions while sharing their stories and experiences. If they did not, I marked those questions to follow up in the next session or asked them at the end of the interview if time allowed.

Regarding honoring the participants' stories, Mishler (1986) cautioned the interviewer to ensure that both the interviewer and the participants had a similar shared meaning of the questions so that a disconnect in understanding did not occur. To address this risk of misunderstanding, Wilkinson and Birmingham (2003) recommended sharing the main points I noted during the interview with the interviewee at the end of each interview to allow the interviewee to clarify or make additional comments. At several points during the interview, I noted in the transcripts that I said, "So what I hear you saying is" to ensure I understood their concerns. In addition, I would read each interview before the next and bring follow-up questions regarding any unclear areas or check in with my interpretation. This step helped me strengthen credibility and create a shared meaning (Clandinin & Connelly, 2000).

I spaced interviews on average three to ten days apart to maintain an established rapport. However, the schedule depended on the participants’ summer vacation plans and was at the participants’ convenience (Seidman, 2013). To respect the participants’ time and the methodology, I kept each interview to 90 minutes (Seidman, 2013). All participant interviews overlapped in a series between June 7, 2023, and July 26, 2023. The final interview for the second family, Kathy and her son, John, was on August 26, 2023, as she asked to meet after school had started to see how the transition to ninth grade transpired.

I used my interview guide (see Appendix D) to begin the first interview with a question about participants' histories related to their children's disabilities and the special education process (Seidman, 2013). Specifically, I asked the participants to describe how they and their children first became involved in the special education process. Throughout the interview, the goal was to gather the stories of the parents’ experiences by asking questions that explored the presented stories instead of redirecting the parents’ narrative with too much questioning (Patton, 2015). Merriam and Tisdell (2016) stated that rich, thick descriptions provided a better context for the study and promoted credibility, so questioning should encourage rich data and stay present with the parents’ story.

Before the second interview, I reviewed the first interview and made notes of any questions or areas to clarify. I held these questions to not skew the participants’ stories at the start of the second interview. In the second interview, I explored parents' present experiences of the special education parent-school partnership, including experiences with the IEP meeting, current classroom teachers, and the case manager (Seidman, 2013). I used the second interview guide in Appendix D for the interview. Often, questions I had noted were clarified naturally during the second interview as the participant told their story. As part of the third interview, I explored the parents' reflections on their experience of their children's educational experience and the parent-school partnership in special education and what it has meant for them (Seidman, 2013). In addition, during the third interview, Merriam and Tisdell (2016) recommended member checking the information and tentative interpretations by asking follow-up questions and clarifying with the participants, which I did. In this interview, I asked any outstanding questions from my review of the interview transcripts.

As part of developing the interview process, Wilkinson and Birmingham (2003) recommended piloting the interview questions before conducting all the interviews. Before conducting my research interviews, I piloted the questions to determine if a question was too ambiguous and to evaluate the structure and flow of the questions. I had an acquaintance whose child was a high school senior and had received special education in grades 1-12. I conducted the pilot interview with her and her husband. During the pilot interview, the participants naturally answered many of the interview guide questions if I simply stayed present to their story and asked questions to expand their story. For this reason, I did not change the interview guide after the pilot.

I began the first interview for each family by recording my reading of the consent form to them while they also had a paper copy in front of them. I ensured the interviewees agreed to be recorded via the consent form (see Appendix C). I recorded all interviews using the Trint app on my iPhone. I also took brief notes during each interview to prevent slowing down or skewing the interview dynamic (Kim, 2016; Patton, 2015; Wilkinson & Birmingham, 2003). Patton (2015) explained that too much or minimal notetaking could encourage or discourage the participant's storytelling and create an unspoken influence on the interview process. My field notes concentrated on body language that the recording would not capture. I focused my energy on remaining present to the story and asking questions that would expand the story. I also strove to stay aware of my assumptions and biases to not skew the story with my own agenda or biases. After each interview, I would review the transcript to determine if my assumptions skewed the interviews as a form of improving trustworthiness.

To expand my field notes, after each interview, I immediately completed the interview summary form (see Appendix E), which I adapted from an example provided by Miles et al. (2014) on p. 125 of their text. Kim (2016) described "narrative competence of listening" as observing the non-verbal components of the interview, like body language, emotions, sighs, or pauses. By elaborating on interview notes immediately after each interview on my interview summary form, I captured more of the non-verbal context and understanding of the discussion than a brief field note provided and increased data trustworthiness through data triangulation (Patton, 2015).

After completing the interview and case summary form (see Appendix E), I had the interview recording transcribed via Trint.com. Then, I listened to the audio recording and corrected the transcripts for wording accuracy. To capture nonverbal components of the interview, I listened to the recordings a second time and added the following transcription conventions for the transcription of non-syntax occurrences:

- (?) = talk too obscure to transcribe
- *Hhhhh* = audible outbreath
- *hhh* = in-breath
- [= overlapping talk begins
-] = overlapping talk ends
- (.) = silence, with the number of … or a number representing the length of time
- :::: = lengthening of a sound
- becau- = cut off, interruption of a sound
- <u>he</u> says = underlined words indicate emphasis
- *LOUD* sounds are capitalized to show the intensity
- [notes, comments] = researcher notes on tone or rate noted during transcription (Bailey, 2008).

A pseudonym identified participants and their school or any agency to protect their anonymity and responses. All audio recordings and transcribed data are kept on a password-protected external hard drive and maintained for five years before being destroyed.

Moreover, I maintained a research journal, which I stored in a binder and included data collection and analysis information. For each participant, I incorporated the following information in the data collection section of the research journal:

- Each participant's contact log (see Appendix F) is physical evidence of the data collection timeframe, including phone contacts, emails to study participants, and a calendar of scheduled interviews.

- Transcriptions of each interview recording.
- I completed the interview summary (Appendix E) form immediately after each interview as a form of field notes and placed it with the corresponding interview transcript.
- I placed field notes taken during each interview with the corresponding transcript.

I kept the research journal in my home in a locked filing cabinet, to which only I have the key. I will destroy this journal at the same time that the raw data is destroyed.

Data Analysis Procedures

According to Creswell (2014), the first step in analyzing the data is preparing the data collected, which I did in organizing the data collection section of my research journal. The second analytical step is to reread the data after accurate transcription. To promote credibility, Merriam and Tisdell (2016) recommended creating an audit trail, which I did in my research journal. The data analysis section of the research journal includes the following:

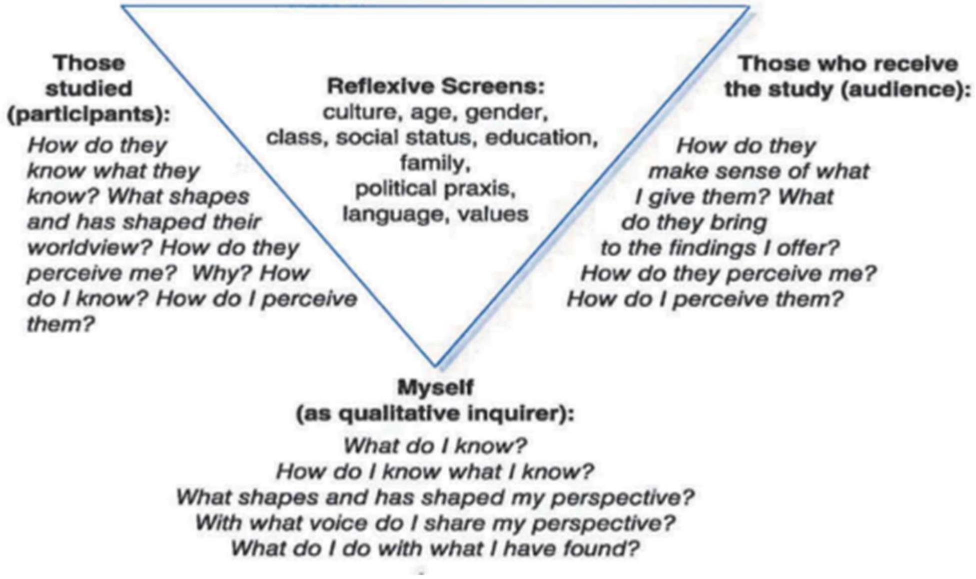
- Post-interview notes in the form of jottings or written observations about the content of each interview as I reread them.
- Analytic memos, which I used to capture possible categories or to document connections between stories I noticed while reading and rereading the transcripts (Miles et al., 2014).
- Coding methods used to evaluate the data, creating an audit trail. I maintain all coding drafts and categorizing attempts in the research journal.

- After each interview, I entered a reflexivity memo into the reflexivity log in the research journal after I reflected on the questions Patton (2015) described in Figure 6, shown below, to raise my awareness of my implicit assumptions and biases. AERA (2009) standards for humanities research stated that participants' perspectives should be respected and honored. By examining my implicit bias, I attempted to mitigate any unforeseen impact my beliefs had on the participant's perspective.
- After each interview, I recorded a memo about how these biases may have impacted the interview process and steps to reduce this influence in subsequent interviews.

Regarding coding methods, Mishler (1986) stated that by focusing on discourse and coding techniques inherent in categorizing data, researchers had moved away from the original purpose of interviewing, which was to understand better what respondents meant by what they said. By breaking participants' stories into small phrases and words, I risked decontextualizing participants' stories (Polkinghorne, 1995). To avoid decontextualizing and biasing participants' stories, Polkinghorne (1995) proposed narrative analysis in contrast to the analysis of narrative. Narrative analysis is like what Maxwell and Miller (2008) described as connecting, which is making meaning between reported information. Stories result from the participants recalling, describing, and framing stories within the context of their lives (Riessman, 1993). How participants choose, arrange, and express their experiences provides insight into how participants view themselves and others (Clandinin & Connelly, 2000). To better capture participants' experiences and stories, I used holistic coding, coding the more prominent stories and then the smaller stories within the more notable stories. I manually coded on a copy of each transcript. As I holistically coded, I focused on insightful passages relevant to the research question and connected to the literature and stories that might not immediately appear connected (Seidman, 2013). Polkinghorne (1995) described the goal of narrative analysis as creating a standalone story that represents how or why an outcome occurred by using rich descriptive detail and three-dimensional representation. However, other researchers proposed leaving the reader with unanswered, thought-provoking questions that the narratives suggest (Saldana, 2016). Based on my findings, Polkinghorne's approach would best give the participant's stories voice.

Figure 6

Patton's Description of Reflexive Questions: Triangulated Inquiry



Note. Diagram outlining reflexivity within the context of triangulated inquiry. Reprinted from *Qualitative Research & Evaluation Methods* (4th ed., p. 72), by M. Q. Patton, 2015, Sage Publications, Inc. Copyright 2015 by Sage Publications, Inc. Reprinted with permission.

In addition to holistic coding, I also chose narrative coding with Labov and Waletsky's (1997) model of narrative structure to consider the meanings more deeply within the narrative. Reissman (2008) and Saldana (2016) suggested using Labov and Waletsky’s model of narrative structure for narrative structural analysis. Labov and Waletsky outlined the structure of a fully formed narrative as the following:

1. Abstract (point of the story)
2. Orientation (time, place, people, situation)
3. Complicating action (then what happened?)
4. Evaluation (why did the participant tell the story and their desired point)
5. Result or resolution (what finally occurred)
6. Coda (signals the end)

Not all stories have all these elements, nor does the order always occur sequentially. Each part is not necessarily a sentence, as people often do not speak in complete sentences when they shift their thoughts. Instead, Labov and Waletsky (1997) used clauses as units. I manually coded each transcript. I found the evaluation component of this coding to provide valuable insight as to why participants were telling me the stories they chose and in the order they did.

After coding stories, or what Labov and Waletsky (1997) described as narratives, I used emotions and values coding for the narratives as part of thematic analysis (Miles et al., 2014; Reissman, 2008). Miles et al. (2014) described two affective coding methods that help uncover more subjective experiences: emotion and values coding. Because parents often have intense emotions related to the needs of their children with disabilities, I chose emotion coding to explore the feelings connected to parents' perceptions and experiences because feelings often drive actions and responses (Clandinin & Connelly, 2000).

While emotion coding helped discover emotions connected to parents' experiences and the stories they chose to share, many of these parents had moved through an emotional reaction to their child’s special education experience as they had been navigating the journey for many years. While emotions were still present, I found that values coding highlighted participants' values, attitudes, and beliefs that had developed through the years, contributed to their perceptions, and motivated their behaviors (Miles et al., 2014). Combining values and emotion coding uncovered connections between participants' experiences and perceptions and suggested why these stories were shared or had meaning.

Instead of manually coding for emotions, I used Quirkos. I listened to each transcript once, just coding for emotions to focus on the participant’s tone of voice and the emotions under the described behaviors and values. I recorded purposefully significant coding decisions about words used to label emotions as an analytic memo in the coding decision section of the research journal. After I had coded all transcripts for emotions, I coded for values in Quirkos. Miles et al. (2014) stated that values coding consists of three related codes: values, beliefs, and attitudes. Value was how we see the importance of ourselves and others, while attitude was how we think and feel about ourselves and others. Beliefs included values, attitudes, knowledge, experience, prejudices, and morals. Values coding was well-suited to exploring interpersonal participant experiences such as the parent and school staff mesosystem interactions (Miles et al., 2014). I noted purposefully significant decisions about how to code values in the research journal coding section. Once values coding was complete, I merged the two files in Quirkos.

Once holistic, narrative, emotions, and values coding were complete, Roberts and Hyatt (2019) suggested reducing the overlap and redundancy of codes. Before doing this, I returned to the research question. In allowing participants to tell their stories, they often included their challenges outside of school. I did not want to create a master list of codes until I thought about the emerging data. I reread my literature review, and what I saw missing in the literature based on my interviews was the complexity of the parents' pain, anxiety, and desire to protect and do their best for their child, which was more extensive than just school. I stepped back and looked at these codes and the families more holistically, outside of simply the parent-school partnership, because the holistic experience appeared to underlie how that parent interacted in the parent-school partnership. I did not want to condense codes and inadvertently minimize the complexity of the parents' experiences. I tried to keep an open mind to the connections between codes before consolidating them. I loaded all the coded documents into MAXQDA, which has more visual features than Quirkos. I used code patterns and visual mapping to look at document trends.

I looked for a coding pattern suggesting emerging issues, categories or connections, causes/explanations, relationships, or themes (Miles et al., 2014; Wilkinson & Birmingham, 2003). As part of the conceptual stage, I used analytic memoing and recorded in the coding decision section of the research journal (Creswell, 2014). I displayed the coding data in a network display using Quirkos software to visually compare the data to the concept map as a form of theory triangulation (Miles et al., 2014). I clustered the data into categories related to the components of the three theories noted in the theoretical framework to display the data and determine if additional categories emerged from the data. I analyzed the relationship between the concept map in Figure 1 and the network display of the data. After reflecting on the categories, I recorded tentative themes in the research journal (Roberts & Hyatt, 2019). This part of the analysis correlated to what Reissman (2008) called thematic analysis.

Saldana (2016) also suggested memoing about routines, rituals, roles, rules, and relationships to look for connections. In the case of parent-school partnerships, rituals and rules may apply to the IEP process. At the same time, roles may relate to the parents' and educators' perceptions of their role, life context, and status in the special education process (Saldana, 2016). While these noted connections are apparent, looking beyond the concrete representations of roles, rules, and relationships as part of the analysis was imperative to gaining a deeper understanding of the parents' perceptions and experiences. In the research journal, I recorded analytic memos about routines, rituals, roles, rules, and relationships, as Saldana suggested, to reduce how my biases may have blinded me to connections I may have missed through previous coding methods.

Trustworthiness

In qualitative research, the terms validity and reliability are often replaced with the term credibility, a component of trustworthiness. Patton (2015) described trustworthiness as a combination of credibility, transferability, and dependability. Credibility means the research findings are plausible and truthful (Patton, 2015). Transferability relates to the researcher providing enough information that the reader of the study can determine how similar cases may or may not relate to the study's cases (Patton, 2015). Dependability was determined using a systematic process to collect and analyze qualitative data to create an audit trail (Patton, 2015). I described these components in this section.

Regarding credibility, I maintained a participant contact log in the research journal (see Appendix F) as physical evidence of the data collection timeframe, in which I documented phone contacts, emails to study participants, and a calendar of scheduled interviews (Miles et al., 2014). Detailed record-keeping that reflected coding, categorizing, connecting, and theming decisions was recorded in the coding section of the research journal to create an audit trail and provided evidence of the plausibility of the findings (Maxwell, 2013). To provide a timeline of research activities, I maintained each section of the research journal with dated entries for contacts with participants, jottings, memos, and coding attempts and decisions.

Regarding transferability, I provided a rich, thick, detailed description of the participants' stories to create the depth of context that allows readers to connect to situations in their lives. For the reader to assess the relatedness of the study to their own situation, I included the following details:

1. The type of disability each of the participants' children had and how it was identified.
2. The type of special education services the child received (e.g., co-taught, resource, self-contained, or program classes), grades in which the services were received, and the timeframe.
3. Description of how the parents described their understanding of special education processes and services.

4. Parents' descriptions of additional resources or services accessed outside of the public school on behalf of their children.
5. The school's setting, such as urban, suburban, or rural.
6. Demographic information that the parents shared, such as education level or socioeconomic status.
7. Parents' personal school experiences as a child or young person that they were willing to share.

By including this information, the readers may more accurately determine if parts of this study apply to their own situations (Universal Teacher, n.d.). A study participant's experiences will never precisely match a reader's situation. However, with a detailed, thick description of the participants' experiences, the readers of this study may gain new insight or make connections related to their situation.

Regarding dependability, I used the research journal to maintain an audit trail of the systematic process of data collection and analysis. I recorded my initial reactions to the interviews and my thoughts and questions on the interview summary form (see Appendix E), which I included in my research journal. I engaged in ongoing jottings and analytic memoing during data collection and analysis, and I recorded these jottings and analytic memos in the corresponding section of my research journal (Miles et al., 2014).

Reflexivity

In qualitative research, the researcher often has direct contact with the participants. As a result, the interactions and behaviors of the researcher may influence the participants' behaviors and responses. My assumptions and biases may have also influenced their perceptions and analysis. In this section, I addressed my plan to remain aware of the impact of my assumptions and beliefs on data collection and analysis.

When conducting a basic interpretative study, the researcher is a joint participant in making meaning of participants' stories (Creswell, 2014). For this reason, I remained aware of my own experiences, attitudes, beliefs, and values as I listened to participants' stories (Creswell, 2014). To improve credibility and dependability, I documented my biases or personal connections after each interview on my interview summary form (see Appendix E) to heighten my awareness of my biases so that I can better bracket them during subsequent interviews (Maxwell, 2013). After each interview, I reflected on the questions Patton (2015) described in Figure 6 to bracket my biases better. After reflection, I wrote a memo about how to improve my neutrality for the following interview.

Not only might my assumptions and biases have impacted the interview process, but my implicit assumptions and biases may have also impacted my coding decisions. After coding the data, I reflected using Patton’s (2015) questions and re-evaluated whether my biases, attitudes, and beliefs impacted my coding choices. After re-evaluating the coding data, I wrote a reflective memo in the reflexivity section of my research journal regarding the impact my assumptions or biases may have had on the coding process (Patton, 2015). I took notes and wrote follow-up questions if I was unclear on the participants’ beliefs or attitudes so that I could clarify them in the following interview. In this reflexive memo, I also evaluated my interpretations for cultural awareness, political consciousness, beliefs, values, and attitudes that may affected my interpretation (Patton, 2015). As Patton states, “To excel in qualitative inquiry requires keen and astute self-awareness” (p. 71). Taking steps to write reflexive memos in the research journal after interviews and coding attempts encouraged deeper self-awareness as I attempted to bracket my bias and perspective. This step was valuable because being more aware of my biases and assumptions helped me recognize if they skewed my coding decisions. By remaining cognizant of how my subjective I impacted the analytical process, I sought to honor and respect the voices of my participants while minimizing my own to add credibility to the findings (Maxwell, 2013).

Triangulation

Analytical triangulation provides both credibility and dependability to research findings (Patton, 2015). Patton (2015) described one form of analytical triangulation as having the participants review findings and offer reflections on the possible themes. Another form of analyst triangulation is having an expert audit review the findings (Patton, 2015). Patton stated that a doctoral committee often performs this step to assess the quality of the analysis. Patton also stated that a critical friend, such as a fellow doctoral student, could review my findings. I had two of the participants who were available review the findings. I also asked a colleague to review my findings, and my doctoral committee reviewed the findings.

Another form of triangulation is theory triangulation (Patton, 2015). I clustered the data into categories related to the three theories noted in the theoretical framework. I analyzed the relationship between the concept map and how each theory impacted categorizing the data. Using three different theories to view the data, I analyzed different ways to categorize the data to see if different themes emerged, which provided dependability to the findings. I proposed that the theories were interrelated in the concept map, so looking at the data through each theory's lens helped to determine if this overlap was found in the data (Patton, 2015).

Summary

In this basic interpretative study, I explored how parents of children who qualified for special education and participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. I hoped to use their feedback and stories to learn about how parents experience the special education process to increase educators' empathy for the parents' experience and possibly uncover barriers to collaboration. Using the results of this study, educators may more effectively establish the positive parent-school partnerships required in special education each year, which ultimately benefits student achievement (Burke et al., 2019; Osborne & Russo, 2010). Participants were parents with at least one child in grades 6-12 who had participated in public-school special education for at least two years within school years 2018-2023, with a preference for those parents with more than two years of experience with the special education process. I conducted three semi-structured interviews and recorded and transcribed the interviews. After transcription, I analyzed the transcripts using holistic, narrative, emotions, and values coding. In evaluating my choice in coding, I recorded my answers to the questions shown in Figure 6 in the research journal to become more self-aware of possible biases and assumptions skewing my coding choices. In addition, my research journal contained documentation of analytic memos, interview summary data, jottings, and coding decision points to provide an audit trail. By creating a context for reflexivity and triangulation, I sought to strengthen the trustworthiness of my study.

Chapter IV

THE FAMILIES' EXPERIENCES

The participants in this study included six families of children who qualified for special education and participated for two or more years in the public-school special education process. At the time of this study, the children discussed attended three different public-school systems in one southeastern state. Based on the percentage distributions in Table 1, I selected two families whose children had a specific learning disability (SLD), as this disability represents 33% of the population. Pseudonyms were used for names and places to respect the participants' privacy. The first family included Iris and Mark and their two daughters, Laura and Lisa, who both had dyslexia, an SLD. Laura qualified for special education in fourth grade and was a rising eighth grader at the time of the interviews. Laura's little sister, Lisa, was a rising fifth grader and qualified for special education in second grade. Only Iris participated in our first interview, but then her husband, Mark, asked to join the interview process when he became interested in our conversation during the first interview. I read him the consent form. At the end of the first interview, Iris and Mark requested that I interview them together for the second and third interviews. The second family I chose was Kathy and her son, John, who was diagnosed with an SLD in second grade and was a rising ninth grader at the time of the interviews. Kathy participated in her three interviews alone.

Students with an "other health impairment" (OHI) disability represented 15% of the population, so the third family I chose was Sheila and Don and their son, Evan, who had an OHI related to his prematurity, as well as an SLD. He qualified for special education in second grade and was a rising high school sophomore at the time of the interviews. During our first interview, Sheila asked Don to join the interview to get his perspective. She was a teacher, and his viewpoint differed significantly from hers since he was not a teacher. I did ensure that he was read the consent form when he joined. Don stayed for the rest of the first interview, and then Sheila and Don participated in the second and third interviews together.

Autism (AU) represented 12% of the population, so the fourth family I selected was Ann and her son, Kevin, a rising high school senior who had AU. Kevin qualified for special education at the age of three and had received services in two states and three public-school districts over the past fifteen years. Kevin participated in the modified curriculum autism program because he had “limited verbal skills,” as Ann described. Kevin’s class was a self-contained special education class that taught both academic and functional life skills. Ann participated in the three interviews by herself.

Low-incidence disabilities represented 16% of the population and included visual and hearing impairments, developmental delays, intellectual disabilities, and multiple disabilities combined. To remain balanced with the percentage distribution in Table 1, my fifth participant was Victoria and her son, Randy, a rising high school senior with Down’s Syndrome. Randy participated in what their district called a “program class,” a self-contained special education class designed to teach academic and functional life skills. Victoria participated in the three interviews alone, but her husband stopped by to say hello during our third interview.

Students with emotional or behavioral disorders represented 5% of the population. While included with low-incidence disabilities, these students present very differently than students with other low-incidence disabilities. A child with an emotional or behavioral disorder (EBD) often has difficulties with interpersonal relationships, consistent or chronic inappropriate behaviors or feelings, a pervasive mood of unhappiness or depression, and anxiety or somatic symptoms (IDEA, 2004). My sixth participant was Leah and her son, Andre, who had an EBD and was currently a rising ninth grader with a secondary disability of OHI for his attention deficit disorder. Leah participated in the three interviews by herself.

Using the distribution criteria in Table 1, I chose these six participants for the study. The parents were willing to participate in the interview process and had at least one child in grades 6-12 who had participated in public-school special education for at least two years within school years 2018-2023 in a public-school setting. The participants' profiles are represented in Table 2.

The following profiles share the story of each family's journey in special education while describing the larger context or mesosystem, including the parent-school partnership for these parents, and convey a process and time (Seidman, 2013). In writing each profile, I highlighted the participants' voices in sharing their experiences with the reader. I used pseudonyms for names and places to respect the participants' privacy. The profile of each participant revealed that parent-school partnerships did not exist in isolation but as part of a dynamic mesosystem that the parents continuously navigated in their pursuit to best meet their children's needs. What struck me about each parent in this study was the deep, underlying, driving motivation to ensure they had done everything they could for their child, often questioning even into their child's adulthood whether there was more to do or if they should have done something differently. One participant succinctly encapsulated the parents' depth of love when she said, "Of course, I keep trying to figure out the best path. That is my baby." Each of their stories was unique and complex, revealing the depth of emotions and experiences each family brings to the special education parent-school partnership at the start of each school year. To assist with ease of transferability, I have outlined the families' demographics in Table 3.

Table 2

Participants and Children's Profiles

Parent(s)	Child(ren)	Grade Level	Disability	Years in Special Education	School Size	School District
Iris and Mark	Laura	8th	SLD	6	Suburban middle school, more than 800 students	District A*
	Lisa	5th	SLD	3	Suburban elementary school, more than 800 students	
Kathy	John	9th	SLD	9	Suburban high school, more than 2500 students	District B*
Sheila and Don	Evan	10th	OHI, SLD	9	Suburban high school, more than 1900 students	District C*
Ann	Kevin	12th	AU	13	Suburban high school, more than 1800 students	District B*
Victoria	Randy	12th	Intellectual Disability (MOID)	13	Suburban high school, more than 1900 students	District A*
Leah	Andre	9th	EBD, OHI	6	Suburban high school, more than 1800 students	District A*

Note. Table summarizing study-related profiles.
*Districts A, B, and C are pseudonyms representing three different school districts in the same Metropolitan area of the same Southeastern state.

Table 3

Parents' Demographics

Family	Ages	Length of Marriage	Ethnicity	Education Level	Occupation	Children Name, Grade
Iris and Mark	Mid-40s Mid-40s	>17 years	White White	Masters High School	Marketing Project Manager Informational technology professional	**Laura, 8th grade** **Lisa, 5th grade**
Kathy and John	Both early 40s	>16 years	White	Masters Bachelors	Middle school teacher Informational technology professional	**John, 9th grade** Tim, 1st grade
Sheila and Don	Early 50s Early 60s	>20 years	White	Masters High School	Elementary school teacher Retired electrical lineman	**Evan, 10th grade**
Ann and Scott	Both late 50s	>37 years	White	Masters	Homemaker, now part-time at autism day treatment program for adults Business executive	Four adult children ages 22-36 **Kevin, 12th grade**
Victoria and Bill	Early 50s Late 50s	>25 years	White	Masters College-level unknown	School counselor until first child, then homemaker. Paraprofessional in elementary school for the past 10 years Business executive	Shannon, 24, is a teacher Makayla, college freshman Roger, 12th grade **Randy, 12th grade**
Leah and Curtis	Early 40s	>15 years	White, but children are of mixed race: White and African American	College-level unknown	Business (unknown), now homemaker Informational technology professional.	Nadia, 12th grade **Andre, 9th grade** Isaac, 7th grade

Note: Table summarizing demographic data for the parents. The child(ren) in bold has the disability discussed in the parents' interviews.

Family 1’s Experience: Iris, Mark, and Their Daughters

Iris and Mark were white, middle-class professionals in their mid-40s living in a suburb of a metropolitan city in a southern state. Their local schools were part of a large metropolitan school district. Iris was a marketing project manager, and Mark was an informational technology professional. They had been married for more than seventeen years. They had two daughters, both of whom had dyslexia and qualified for special education services. Neither parent had a Southern accent, so it did not appear they grew up in the South, but they had resided in the area for several years.

Iris and Mark believed that Mark likely also had dyslexia because he was “terrible at school and spelling.” When I asked Mark about having dyslexia, he said he had done okay and had a career, so everything worked out. This attitude of resilience characterized this family. Iris started her story with Laura’s preschool years:

> Laura went to Montessori school. She was incredibly bright. She was doing really well. And her Montessori teachers kind of brought up, and they’re not trained ... dyslexia, but they kind of brought up a little bit of concerns about, like, reversals ... because she didn’t learn letter names, she learned letter sounds first … but ... they’re like, but she’s so smart. And then when she had kindergarten, she had this fabulous teacher ... she did really great, she had great grades. And the teacher wrote on her very end of year report card, like, hey, maybe there’s something here we need to investigate with, like, letters and, you know, with reading and stuff like that. I, you know, just ... she was an older teacher, like, tons of experience. And so, there was just something, I think, like her Spidey senses were tingling, but that was a handwritten note on a report card at the end of the year, where she

> gave her a lower grade and said, hey, maybe something needs to be investigated. But there was no ... there was no channel. So, we're kind of like; oh, okay, maybe, you know, the school, clearly, if there's something wrong, the school's going to, like ... they're the education experts. They're going to sit me down, and they're going to tell me, like, hey, your kid's got a problem. We're going to do X, Y, Z because we're the educational *experts* [sarcasm and exaggeration in the tone]. Like, this is what we do all day. You're a parent, and you don't ... you never learned phonics yourself [sarcasm towards her naïve expectations at that point in her life]. So ... um … (long sigh) so, she wrote that. And then the following year, we had a very, what I'll call quite a nice teacher [sarcasm and using air quotes with her hands]. And Laura did not like this teacher at all, but this was the teacher that subscribed to the; *oh, they'll just ... they'll just pop* [emphasis added], and reading will just all of a sudden flourish. It'll all make sense. And by first grade, we were like, something's not right.

As first grade progressed, Iris said the following to herself:

> Yeah. Okay. So, I'm very analytically minded, right? And you get the piece of paper, the numbers really don't mean anything, but you have a graph, and the graph has, here's the green area, and here's where you're supposed to be for average. And Laura was outside of that consistently. Like, and it didn't matter what test it was. She was consistently below average. But they're like, oh, but she's not that far. She just hasn't *popped* [emphasis added] yet. Like, it'll just ... suddenly it'll click, and they'll flourish [mom has a sarcastic tone mimicking the staff] And now, years later, I'm like, that's BS, that doesn't happen.

When I asked Iris what she thought the school's motivation was for waiting to see if Laura "popped," she said this:

> The administration at that time was against special education and trying to get kids into the special education system. So, when we get further along in the story (sigh) … we had active detractors for Laura's special ed. We had people actively trying to prevent her from getting into special ed and getting the help that she needed.

Iris noted that her daughter had severe dyslexia and required assistive technology for most of her work in class now. To her, the disability was "cut and dry" and should not have been something that she had to fight the school to recognize. Iris, joined by Mark, described second grade as follows:

> So, then we got into second grade and had an actual teacher who was an advocate. Now, I could tell from talking with her … I get this so often with teachers, so often, where you have to, like, read their body language, and they're kind of like giving you, like, these big eyes, where they're like; please say the right words, because I can't tell you the right words. I'm not allowed to … she was very good at conveying the body language and speaking without speaking and saying, like, just on the edge of what she could say and really walking that line. And the amount of, like, just ... I see teachers ... (sigh) ... in our current environment, so handicapped in their ability to help kids. It's disgusting. Because you ... you see these, like, super passionate people that, like, want children to succeed and want to help. And there's all these, and I don't know what it is with the administration

> or laws or budgets or ... it’s just, there’s this endless sea of paperwork and testing and conforming … [Iris is very expressive in her tone and frustrated] … and rules.

Even though Iris expressed distrust and frustration with the school system, it did appear that the second-grade teacher started the paperwork for the multi-tiered system of interventions, which began the process toward special education. The parents reported that they did not understand the process:

> They do that automatic, like, Tier 2 intervention, and then we call the teacher, and we’re like, what’s this Tier 2 intervention thing? ... like what WTF is this, right? [sarcastic] Because we don’t know the system. (sigh) And so, then she gets through whatever tiers, and it’s basically not till the end of the year that she gets all the way to whatever tier it is where you can get, like ... they’re like three. And so, she gets all the way to Tier 3, and it’s ... it’s within like so many weeks to the end of the school year. Like, we’re at the end, like, it’s like February, March, April.

When I asked Iris what the intervention graph looked like that year regarding making progress with interventions throughout the year in Tier 3, her response was this:

> It didn’t do shit. Pardon my language. She was getting farther behind. Because what I’ve ... what I’ve come to find out, the current environment in the state’s laws for the special education system, you basically have to prove that you’re failing before you get tested and get intervention … (sigh) … So, basically, you have to take a seven-year-old child ... (deep breath) … cause them to fail horribly, which negatively impacts their self-esteem, and then you can intervene. And then they’re like, well, I think they have test anxiety … you have to keep repeatedly

> testing them and showing them extra how bad they are at reading to get the data [Iris is laughing but her tone is sarcastic, angry, and frustrated]. Rather than them being allowed to be like; hey, I'm an educational professional. In my professional opinion, something is going on with this child. I want to reach out to my service support person to have this individual tested because we could intervene early so, they wouldn't have this problem.

Given that there was a family history of dyslexia on Mark's side, Iris realized that her daughter might have dyslexia. She stated that she began to educate herself:

> I was like; oh shoot, this is dyslexia. And so, I started researching it and getting all of the information off the Internet. And that's when I finally got to the Ideas [IDEA] Act and read it diligently. I found that if the team agreed with six weeks of data, you can go directly to special education testing without 12 weeks of data.

Iris described the meeting to see if Laura could qualify for special education as sitting at a table with eight people she did not know. She referenced a "psycho-ed person, a speech person, the teacher, and some special education lady with clout." She described the meeting like this:

> And so, we get in the room, and we start talking about it, and there's this whole push for six more weeks of Tier 3. So, she'll begin next year at Tier 3 ... we walked in, we're like, she needs to be tested. Clearly, there is a problem. She needs her evaluation so that she can start with special ed next year. I figured out that if I got every person in that room to agree to test her at six weeks (sigh) intervention, they would test her at six weeks intervention. I spouted off the Ideas [IDEA] act about how if I had six weeks ... how if we had six weeks and we

> agreed to it, they would test her. And they're like, no, no, no, no [mocking] … and then I said; well, my husband and I are advocating for her to be tested for special education, to ... to screen her for dyslexia. Oh, and they wouldn't say dyslexia at this point. I wasn't allowed to say dyslexia (sigh) ... I don't think that they thought six more weeks would do something. I think it was a roadblock. And so, specifically, that ... that woman that was in there was trying not to move forward with special ed services. I don't know why she was trying to deny services, but I got that impression. And to the point of, I ... you know, we were in the meeting, and I started challenging her, right? And so, I had to be a challenging adult. I had to, like, you know, you hear all these horror stories of parents, but like, you have to be that way. Otherwise, you get rolled over. And I was like; "Do you even know my daughter? Have you met her? She is so clearly dyslexic. Flip over that piece of paper. What's my daughter's name? Huh." She didn't know. She ... she had never met my daughter before. [intense emotion of frustration and anger] Then everybody was really ... then everybody was, all of a sudden, on board for testing. [laughing sarcastically] And I noticed it. I ... I said, I'm on board for testing. Mark, are you on board for testing? [She went around the table] Are you on board for testing? Are you on board for testing? Are you on board for testing? Yeah, we got testing signed. They did the testing, and, of course, you know ... [looking at me] you know how much I love my baby, right?

After the meeting Iris described above, the school initiated the psychological evaluation required to determine special education eligibility. Based on the evaluation, Iris reported that Laura qualified for special education with a specific learning disability (SLD) with "orthographic processing disorder with dysgraphia or a lot of fancy words to say dyslexia because they can't just say that." Schools cannot diagnose dyslexia but only identify a specific learning disability. Before initiating the evaluation process, the parents had heard of a private reading intervention program to address Laura's reading deficits. However, they had waited to start the program to ensure that she qualified for help in school, which meant they had to temporarily watch Laura be anxious and fail to get her long-term assistance in the classroom. Iris and Mark worried that if she began to improve, the school would have credited the Tier 3 reading interventions for the improvement that the outside program caused, thereby negating the need for further evaluation. Iris said, "We delayed help for her outside of school to make sure that she could get the help inside of school first." Iris anticipated a better year as third grade began but was disappointed:

> So, she started the intervention in third grade. And holy hell, that was tough, that first year of intervention, because she did the private reading intervention program all summer, and then she was doing it twice a week, all through the school year, as well as we're now ... we're now learning to navigate the special ed system. And unfortunately, her third-grade teacher, her primary third-grade teacher, and her IEP teacher seemed okay. Right? But her primary teacher was a whole word teacher. Yep. [sharp yep], which is all working memory, a significant weakness for Laura. Yep. Yep. So, the interventions were not ... the school interventions were not incredibly helpful in third grade. [yeps show frustration and disbelief].

The family moved to a new elementary school for Laura's fourth-grade year. As Laura progressed through school, the parents continued to educate themselves:

> So, what happened in fourth grade is, I started learning about assistive technology. So, I started advocating for assistive technology. And Mark and I started ... which I have to say, having ... I think having both parents show up and having Mark there because he's ... he's intimidating, right? ... I think when you've got two parents showing up in force, from ... I would imagine from the educators' point of view, they're like, oh man, these parents are going to just keep pushing me until we do the thing [sarcastic educator voice].

Iris and Mark reported working well as a team and while participating in the IEP meetings, with Mark being more reserved than his wife. The parents talked about how hard it was to educate themselves and learn about the process; Mark said, "It [information] wasn't easy to find." Iris responded.

> We did a lot of … a lot of research … and just talking to every parent you can find to find out what they knew. And there's Facebook groups … some of it was Google searching, but a lot of it was that Facebook community and then posting, like, oh yeah, here's the trick you need to know. Oh, yeah, here's the piece of paper you need to ask for. Oh, yeah, here's this thing or that thing. Or here, go look at this. Here's where it talks about the laws … Networking and the Internet, the power of the Internet.

The district's assistive technology specialist evaluated Laura in fourth grade and provided the needed technology resources. Iris and Mark discussed the considerable difference the assistive technology (AT) specialist made for their daughter. The AT specialist became a point of contact they used whenever trouble in the classroom arose. Iris described the specialist as "She is magical. She shows up, brings assistive technology, and makes everybody’s life amazing. And then leaves.” Mark added, “She was good at her job.” I asked Iris how she got the assistive technology referral, as the school usually initiated that from the special education department. Iris requested it after completing her research and learning about how assistive technology could help with dyslexia. When asked if Laura’s teachers participated in understanding the technology, Iris replied, “Laura taught her teachers, and she has consistently been teaching most of her teachers for years.” Iris reported that the difference was that now they had the AT specialist as a contact anytime they needed help, so they felt supported.

Laura’s fifth-grade teacher knew assistive technology well, so the year went smoothly. At this time, the couple’s other daughter, Lisa, was in second grade. First grade for Lisa was the COVID year, so Iris referred to that year as a “dumpster fire” as this school system was virtual for an extended period. When Lisa returned to in-person school full-time, Iris reported that the classroom teacher noted concerns. Iris described how Lisa’s support for qualifying for special education was significantly different from Laura’s experience:

> [The process at the new school] was so much simpler with Lisa because we just had all this support from the school. They did an intervention. They were much more willing to look at just, how do we solve the problem creatively. How do we do what works for our students? How do we meet them where they’re at? Like I didn’t have to do hardly anything … it was like just the resource teacher and her primary classroom teacher, and us on the call. And she’s like, yeah, let’s go ahead and refer her for testing. And that was it. She had a great advocate for a teacher. And then, she was in a co-taught classroom and got the intervention she needed.

> It's not really a big deal. There's all the AT that just comes. And so, this year, Lisa’s actually scaling back on co-taught for fifth grade because she just doesn’t need it.

I asked Iris what she thought would have happened with Laura if the process had been that easy to qualify her for special education. Iris’s response was as follows:

> Laura wouldn’t have dropped so far. She would have … She would have kept up, (sigh), and she wouldn’t have the level of anxiety that she has. She wouldn’t have the level of test anxiety that she does. You know, … so Lisa only needed about two years of the private reading intervention program. Laura needed like four years. We stopped at the end of sixth grade. And now … now we do therapy, to make sure that everybody can cope with all of the anxiety that’s built up. Nothing severe. It was so hard because she is smart …, so she really saw that she was struggling and didn’t understand why. (sigh and deep breath) … And to this day, rumination is still a really big challenge that she has because she’s just still gnawing on that. Like, why is this happening? Because it doesn’t make any damn sense. So, anyways, so yeah, so night and day experiences. So, in fourth grade, we pushed for the use of assistive technologies. By fifth grade, we had everything in place for her [Lisa].

As the parents reflected on their special education experience, they made additional statements. Iris began, “From a parent perspective, [it] is very much … it’s like there’s this wall or gatekeeping, and once you get past it, you’re in. And like, once you get in …” Mark finished her sentence, “It becomes easy.” Iris picked up from there, “Because then everybody wants to help you. But trying to get in is so hard, and there’s like, it’s – it’s –

it’s like Fight Club. The first thing about Fight Club is, you don’t talk about Fight Club.” After years of participating in the IEP process, Iris said she now understood it and had begun prioritizing her concerns in the meeting:

> I feel like I understand every section of the IEP now because I’ve spent a lot of time with it, but I don’t really care about half of it, because there’s … (sigh) … okay, so when you get into the IEP, there’s the, “what brings us here together” summation of what the initial findings were. Well, okay, we review that every time, but, well, I’ve heard that now every year, for many years. So, I think we get into, like, present levels and what the teachers are saying. That’s where I pay attention and ask many questions … Once we got past the initial gatekeepers, the IEP meetings went well. Now, IEP meetings with Laura are going through the motions. So, we just go through the IEP meeting and the motions. We get to the part that I care about, like, what are we doing for the plan and services? I just want to make sure that she has the right mix of support … And talking through any challenges she’s having in class, and what supports or things we need to change to ensure that she can get those supports. And the other thing that I always ask in the meetings is if the teachers have the support that they need to support my daughter or if there’s something I need to advocate for them. They’ve never actually asked for anything. But I always put it out there, like, if I need to, like, if I need to go raise hell with somebody, you just let me know. If you need me to ask for assistive technology for you guys to have in the school for my daughter, I will do that.

Iris said the transition to middle school had gone relatively well because her daughter, Laura, was good at advocating for herself. Iris and Mark strived to raise strong, independent daughters who could stand up for themselves. Iris described Laura like this:

> Laura is so good at advocating for herself, and she's got a team at middle school. She's got a team of caseworkers, right? So, she's got her primary caseworker. She's just like, hey, I need blah, blah, blah, blah. And they're just like, okay, here you go. Right. So, she doesn't seem to have many barriers when she's asking for the support she needs.

Iris and Mark described how they have coached her over the years to talk to her teachers and ask for the support she needs. While her parents stated that the support from the school for Laura's disability had been good, they reported frustration with the classroom dynamic. Iris stated the following:

> Yeah. So, Laura, in general, likes her teachers and likes her coursework. I would say she really enjoys five out of the seven or eight classes. The challenge is that she's in the co-taught classrooms, which have not only the kids that have educational IEP support but also behavioral IEP support. And so, she's with a pack of animals, right? And so, like, the behavior of the middle schoolers is just…

Mark finished, "Awful." Iris reported, "So when we had our IEP meeting this year, we talked about the rough group of kids she travels with [in the co-taught classes.] And so, what we've decided to do for next year is, she's actually going to just go to check-ins." Students in co-taught classes often have been together for several years, which was the case in this instance. Because Laura was using assistive technology well, her parents moved her to consult, meaning a special education teacher checks in with her weekly but does not directly teach her. The IEP team and parents made this placement decision to get her away from the other co-taught-served students and their behavior problems. Her parents stated:

> So, that'll hopefully get her out of that crew of rougher kids because when we really looked at what services she needs, what services does she utilize? In those classrooms, Laura was one of the most independent kids. She really doesn't need as much support because she's figured out what she needs … She does need extended time. But there are so many kids now that need extended time or small group testing that she can get that in a gen ed classroom because of how they built the middle school. Every classroom has a small group test area.

Iris and Mark described how they have learned to communicate in the IEP process. Iris stated that first, she says the following in the meeting:

> Help me understand this thing. And then they explain it to me, and then you look for weaknesses in the logic. And then you come back. So, what you're saying is, and then that's where you put your spin and interpretation on it.

Mark added, "You can tell the teachers that want to work with you versus the ones that don't or disengage." Iris also added later in the interview:

> I will say when I do talk to other parents, one thing I do coach them on is, I say; "Listen, the thing that you want to do is you want to get to the meeting; you want to be really polite and really respectful with the teachers, and let them know that you're on the same page with them and that we're all here to support the child" … And like, putting them on that … level playing field with the teachers. Because it's like somebody's got to cross – like, somebody's got to hold up the hand and

> cross the aisle. So, if new teachers, if they could, when they sit down with a parent to tell them something, be like; hey … like a therapist. “Hey, we’re here to work on this together and do what’s best for little Bobby. Let’s figure it out together.” Because when the school holds its power, we think, “Why won’t you help me? Why won’t you help my baby? There is something wrong here. I don’t understand. I’m not an educational professional.” We tell other parents to go in positive and work the system. You just have to be patient with the system and all of its rules and the ways you have to go about things because it is what it is. It’s the government.

When I asked Iris and Mark to reflect on how they would describe trust concerning the school, they said this:

> So, if it is a classroom teacher or a classroom special ed teacher, then I will generally trust that individual. If it is an administrator or a school-level support or something like that, they have to prove they’re trustworthy.

The parents discussed understanding that the staff had rules and procedures to follow. The parents reported being patient with the procedures and forms as long as they felt their children’s best interests remained at the forefront:

> What we found has worked successfully is that we … uhm … come in as the savvy parents. We know the system. You're not going to pull one over on us. We are going to, you know, we always try and say [the] right words or we always ... It's knowledgeable and wanting to work with, instead of, we're doing this. We ask a lot of leading questions to get them to think about it the same way we do so that

> they're saying what we want them to say. The other thing that we do is that we've worked really hard with both Laura and Lisa to be advocates for themselves.

Iris and Mark have been fortunate that their daughters have successfully used technology to scaffold to less special education services. As their daughters began their fifth and eighth-grade years, both required minimal support outside of assistive technology, which has changed the parents' relationship with the school. Every school year seemed to bring more independence for Iris and Mark's daughters as they scaffolded away from needing as much special education support. Most likely, Laura's teachers entered the parent-school partnership this school year, unaware of the history of distrust between the school and the parents. Listening to the parents' stories at the beginning of the year might help the school staff to establish a positive and trust-filled relationship.

Family 2's Experience: Kathy and Her Son, John

Kathy and her husband, John Sr., were white, middle-class, college-educated professionals in their early 40s living in a suburb of a metropolitan city in a southern state. Their local school was part of a suburban school district. They had been married for over 15 years. She was a middle school teacher, and John was an information technology professional. They had two sons: Tim, who was in first grade, and John, who was in ninth grade and was diagnosed with a learning disability in second grade. Kathy grew up in the area as the oldest of four girls and graduated from high school in the same school district where she currently teaches. Her husband also grew up in the area, but they met at college, which they attended in the same state in a city a few hours away. They both have family members who live nearby. Kathy began her story like this:

> His [John], like, … teacher at pre-school, kind of like, just blindsided us at the end of the year with, like, "Hey, he's not doing X, Y, and Z" … And so, mama bear is like, "Well, why are you just now telling me this now? If he's not hitting these milestones that you're supposed to be seeing in class, why haven't we been having conferences?" She really didn't have any answer for that.

Kathy had been concerned about the possibility of her children having a learning disability, given her family history. Kathy had an IEP growing up but no longer needed it after fifth grade. Her two younger twin sisters also had IEPs all through school for their learning disabilities. Kathy had many memories of her mother "fighting" with the school and crying in frustration as she fought to ensure Kathy's little sisters received a regular high school diploma. In reflecting on her concerns, Kathy stated, "Like, [I] watched both of my kids because learning disabilities run in our family. And so, that was one of the reasons why I had gone into special education, was because of our family background." Once the preschool teacher raised concerns, Kathy spoke to her pediatrician and sought an evaluation:

> Well, I talked to my pediatrician because his, you know, three-year appointment was coming up anyway. But then also having taught special ed and having that background knowledge of saying, but at age three, like, if we're still seeing these things, then I can request, you know, an evaluation through the school district. So, uhm, I did. And they had … you know, early childhood special educators come out and do the evaluation. The OT [occupational therapy], PT [physical therapy], we had hearing, vision, the whole thing ... And he had discrepancies at age three, but not enough to qualify for services. [So], they called it a developmental delay.

Kathy remained concerned and did her own progress monitoring at home:

> Okay. So, pre-k comes around, kindergarten comes around … I began to notice that his early, like written language skills weren’t progressing. He struggled a lot with reading, understanding sounds, processing what he hears, and even retelling what was going on in the day … uhm … and that … that was something that I kind of kept an eye on with him. To help with that, I had, you know, like, picked up at the dollar spot at Target, you know, the little notebooks that have, like, a character on top. And we split the page, you know, like an early reader, and, you know, draw a picture every day, and then, you know, let's work on trying to write a sentence or things like that. We did that every day, and there wasn't like any progress being made … So, kindergarten finished, he was fine. In first grade, he did well; he was growing in his reading, but it really wasn't … like, we could not get through a picture book. Like, he could not read like a level one reader. He definitely was struggling with that … uhm … and then it was right around the start of grade two, so second grade. And we had here, in October, we had his parent-teacher conferences, and his teacher brought up, like, putting him on RTI [Response to Intervention], and she had reading data for him, and he had, like, lost six reading levels over the summer … I said, “How does a kid who's being worked with every single day lose six levels of progress in, like, essentially 12 weeks … when he's got somebody working with him.” I said, “And I'm not saying it's on you,” meaning the teacher. She was like the first-year teacher, and I think I scared her … So, we put him into RTI … uhm … and he really wasn't making gains … yeah. We had the first RTI meeting, and they wanted to do another six

> weeks of data and come back. And like, they had six weeks of data, and they wanted to do another six. And I was like; we're not going to play this game. I said, “We can start the evaluation process now.” I said, “I can tell you that there is a familial history of learning disabilities… I want to get the evaluation process started. So, you can still evaluate him while you collect your data, and do it simultaneously … simultaneously, you don't have to wait.” … umm … and so they agreed … they actually knew I was a special ed teacher. Like, knew I knew what I was talking about … And I think to myself a couple of times, even to this day, if I was just like your traditional parent navigating the system for the first time without an advocate, without fully understanding my rights, would it have played out the same? Like, I wonder ... like, I wonder, like, how long this would have gone on.

Kathy was successful in having John tested. She also successfully stood up for herself and her child during the eligibility determination:

> When they started testing, they found him eligible underneath SLD, with a primary in reading. And they determined a secondary eligibility of speech-language. He also has a deficit in auditory processing …uhm … they tossed around the autism eligibility, which I was like; this kid is not autistic. And they said, “Well, he, you know, likes repetitive tasks. You know, he puts things in his mouth,” … you know, things like that. I was like, “Well, he's a boy. He puts things in his mouth,” like. He's only ever on the swing. So, I was like, yeah, he's always loved the swing. Also, he plays on other things, you know, he has friends and talks with adults. I'm not seeing what you're seeing. And ... and they had a

> pretty strong rating scale for the teachers, but the parent scale obviously wasn't there. … uhm … and I said, "It's not an issue of me turning a blind eye towards my child." I said, "But I've been able to see him across multiple domains that you guys don't see. … uhm … you're just catching him doing things because you're looking at those things specifically." You know … uhm… so, they ended up not going with the autism diagnosis because, again, like, there wasn't anything from his pediatrician to support it. There wasn't anything from the behavior scales. And knowing the familial history, it made more sense that it was a learning disability. That's kind of what I knew in my heart of hearts, too.

Kathy was not intimidated by the school staff and could repeatedly advocate for herself and her child, but she also brought experience and training as a special education teacher. After John was found eligible for special education, he received services in a resource, or small group, placement for reading and writing from second to fourth grade. In fifth grade, he moved to team-taught for reading and writing. Kathy remembered:

> He started to really, like, devour books. We went through a ton of the Magic Treehouse books, you know, the bad guy series, you know. The stinky books, you know, all that stuff … You know, he was really beginning to make progress. And it was doing that, you know, from third grade to fifth grade, as we would drive to school in the morning, you know, on the way home.

Kathy provided significant support at home for John's reading development. Kathy described the transition to sixth grade as going smoothly. The family had moved over the summer from the district where Kathy worked into the neighboring district, where Kathy did not have any contacts or relationships with school staff. Kathy described the sixth-grade case manager when discussing the transition to middle school:

> She was the epitome of what you would want for a sixth-grade case manager ... She was available when he [John] needed something in school and when things weren't working. And she was great about communicating that with me and vice versa. I never felt it was a burden to reach out to her … uhm … and I never … I never tried to take up much of her time. It would always be like, "Hey, we're new to the county. How does this work here?" And she was great at responding with those things, never making me feel like it's a dumb question … uhm … because she understood that we were coming from a different county and that, you know, while the law is the same, counties have their own individual ways of operating things.

Kathy reported that things changed when her son was rezoned for seventh grade and started attending a new middle school. In seventh grade, she received very little communication from the case manager. John was also bullied at the new school. When John's annual review occurred in October, Kathy had to address the bullying issues and determine why John was not receiving his reading service minutes per his IEP. John was supposed to be in a reading class separate from his language arts class, which had not yet occurred in his schedule. Kathy had noticed it but was waiting to see if the school addressed it, given it was a brand-new school. She also reported not receiving her parental rights or copies of her IEP before the meeting. Given Kathy's background and training, she questioned the process:

> How are they getting away with that? I mean, I … that's honestly, like, what I want to know, is, how is this allowed? Like, where's the communication breakdown? You know, even though it's ... we see that it's not a county-driven procedure.

As Kathy entered the October IEP meeting, the staff was unaware of her background or that they had not been providing the required service minutes for reading. They also were unaware that she was used to procedures that included providing an IEP draft and parental rights before the meeting. As the IEP meeting progressed, Kathy questioned the school about not delivering the required service minutes. Kathy reported that the school staff began to scramble through their paperwork, only to realize that she was correct. Because of her knowledge, she followed up the meeting by contacting the Director of Special Education for the county and requesting a response on how the school system would recoup her son’s service minutes. Kathy reported that the school quickly held a follow-up meeting:

> It came down to us talking during the meeting, and they said that we'll ... basically, that we'll figure out what we can do to make it right. But let's come up with a plan to see what his true needs are because we can't make a reading class, okay? So, we can do targeted individual instruction. Okay. Well, what are you going to target that instruction on? Because accurate data keeping hasn't been done. He hasn't received services.

Kathy reported that the school system had their reading specialist assess John to determine his reading weaknesses, and the grade level department chair [lead teacher] worked one-on-one with John to address the gaps and provide the service minutes that the school had not delivered. As a result, John worked with this teacher to complete a reading intervention program consisting of 150 lessons during both seventh and eighth grade. The school also reworked the master schedule to provide literacy support as a connection class in the second semester, which provided the remaining service minutes for John’s seventh-grade school year. When Kathy reflected on her relationship with the school in seventh grade, she stated the following:

> So, I can't make a school change their master schedule. I can't solve their ability to hire a certified teacher in that domain [reading]. So, I had to give grace. But I had to do what was right for my kid. And I felt like the ball was rolling in the right direction at the end of the year, that they knew me, they knew him, they knew I wasn't going to joke around, that I knew our rights. I knew the law, and that they knew to have it together. I never heard much from the case manager [that year].

As Kathy reflected on John’s upcoming high school year, she was not as concerned because John had developed independence. She stated the following:

> It's been kind of a principle of how my husband and I have parented: if you're doing what you need to do, I'm not going to get involved, and I'm going to give you these opportunities to fix it. Along the way, if I need to step in, you know, and be Mama Bear, or if you're not doing what you're supposed to do and I have to hold you to the fire, I'm going to do that because that's my job. Uhm, and he has done well with that, you know … uhm … and it's because of the amount of time and energy, you know, being put in along the way, that I think, when he finished this year, you know, he had all As and Bs. He felt like he owned that because he had done the work himself … So, that's kind of like where we ended

> up. So, we'll see what happens when he starts high school. His case manager is going to the high school, so I don't know if she'll become the case manager again. Uhm, but she, you know, has a good rapport with him … uhm … and they spent a lot of time together working on things. You know, he's [John's] always been, said he's been, you know, very respectful, and on it. You know, I don't hear much from his teachers unless I have to.

Kathy reflected on her relationship with the school over the last few years since she had to confront the middle school staff about the missed special education service time:

> [The] last meeting we had in April …uhm … everybody was there. And, you know, he was a part of it as well … uhm … so I think that mainly just became the norm for them. But I think, too, that I didn't know if it was an issue of them realizing, like, I'm not out to get them. And that was kind of my whole approach, like, I'm not out to cause trouble. I just wanted the situation to be made right. I want to know what you're going to do, you know, to make the situation right … uhm … because it's a partnership. You know, if I am ... if I'm that parent who is loud and obnoxious, then that's not going to help my kid either. Right? Because then you start working with my child out of resentment rather than because he's a good kid who needs it. Right? So, that's kind of why, too, going back to the discussion we had last week about, you know, not pursuing things like the data more. Is that the bigger issue here? And the more significant issue is that … uhm … I mean, a ... a situation that's wrong to be made right. And I need for him to get what he needs. So, am I going to push for all the other things? Probably not … uhm … because my goal, again, is getting him ready for high school. Because I

> know teachers don't want to deal with parents as much in high school. They want the kids to be successful, which is what I've been working with him to do anyways. But yeah, I mean, he will be on his own in a couple of years. So, I have to start getting him ready for that.

As she thought about what high school would be like for John, Kathy shared memories of her mother advocating for her younger sisters in high school. At the time, Kathy was a new teacher. She remembered her mother feeling “railroaded” in placement decisions and fighting for Kathy’s sisters to get a high school diploma instead of a certificate of attendance. Kathy recalled her feelings watching her mother struggle to advocate for her little sisters:

> The hardest part, I think, for me to watch was her heartbreak because I didn't understand why it had to be school against the parent and vice versa. Like, if this child has this document, it is supposed to be a committee. Why does a parent have to fight for everything?

For Kathy, advocacy in special education was essential both personally and professionally. Kathy reported seeing where “educators aren’t as competent as they should be.” For this reason, she often had to weigh what questions to ask and what to focus on in her concerns. Kathy was hopeful but hesitant to send John to high school. Her past experiences in this school district made her less inclined to trust that things would go smoothly in the transition. She reported that she found out who the case manager was through her son instead of through parent-teacher contact, which made her more apprehensive about starting the school year. She acknowledged that her past experiences with the middle school impacted her approach to the high school staff.

When Kathy reflected on how her education impacted her ability to navigate special education, she stated the following:

> I wish it was mandated that as soon as a child enters the RTI cycle, an informational brochure is given to parents, or they are connected with a parent advocacy group. If you don't have that educational background, if you don't have any previous experience with any of your kids going through this, it's not your fault that you don't know. You don't know the questions to ask.

Kathy said she was fortunate that she had the education and experience to advocate for her son. While she was skeptical about trusting the high school staff, she was hopeful that she and the high school IEP team would work together to resolve problems that may arise as she helped her son navigate his educational journey. The upcoming high school staff, most likely, was not aware of the history that Kathy had with the middle school staff and her apprehension as she approached high school, suggesting that the high school staff may benefit from listening more at the start of the school year to determine a larger context, or chronosystem, for parental concerns.

Family 3’s Experience: Sheila, Don, and Their Son, Evan

Sheila and Don were white, middle-class parents living in a suburb of a metropolitan city in a southern state whose local high school was part of the suburban school district. Sheila was in her early 50s, and Don was in his early 60s. They had been married for almost twenty years and had one son, Evan, who was sixteen and a rising high school sophomore. Don had two children from two previous marriages who were grown and married with children. Sheila was an elementary school teacher, and Don was a retired electrical lineman. Sheila and her family were Southern Baptists and had been actively involved in their church community for years. Her mother lived nearby and was actively involved with the family, especially since Sheila's father had passed away. Don's older children and grandchildren lived on the West Coast, so he did not see them as often. On an exciting note, Evan recently became an Eagle Scout, and the ceremony occurred at the family's church.

Sheila and Don began their story with Evan's birth and his first 100 days in the hospital. Sheila and Don vividly recalled that Evan was born prematurely at 27 weeks, 13 weeks early. As a result, his lungs had not developed, so he had to be on 100% pure oxygen. They shared that the doctors said that being on 100% oxygen may cause brain damage or learning disabilities but that there was no choice. Sheila shared the following:

> He was born at 1lb, 3oz. And part of the problem with his staying in the NICU for so long was that he wouldn't gain weight. He still doesn't gain weight. My 16-year-old weighs 85 pounds. But that was the only thing. And what … And at a certain point, the insurance company said, "Is there anything you are doing in this hospital that they cannot do at home?" They offered us 12 hours a day of nursing and all of that. When we sent him home, he just wouldn't gain weight. He's never gained weight. He was on a feeding tube for months. He was on a heart monitor and a machine to monitor his blood oxygen saturation for the first year.

Sheila and Don described how many precautions they had to take to protect Evan as an infant. They had to be highly aware of germs as he was so fragile. As Evan got a little older, Sheila stated, "He had to go to every '-ologist' that exists, cardiologist, pulmonologist, endocrinologist. We had 'em all. We went to all of them, all the time." Evan had severe asthma and a heart problem. Sheila says that the doctors said it would get better and that he would get bigger, but neither has happened. Evan is still highly reactive to the environment with his asthma, and at 16, he is 4’9” and 85 pounds. Sheila reported that doctors even tried growth hormones when he was seven years old, but all it did was send him into puberty early. She added, “We had a nutritionist. We had a dietician. We had all this. They tried protein shakes, and drinking them was great, but he wouldn't eat anything else because he was full from them. So, it was the never-ending.” Evan has been behind on most milestones:

> Size, weight, height, non- none of it. He is never on any kind of, the only thing about him that has ever been considered normal, the only time we ever heard the word normal was when he was little … was the dentist. His, his teeth developed normally. And I sobbed in the dentist's office when they said that he was normal, cried … that was the first time that anybody had ever used the word normal because everything was, he's delayed, he’s delayed, he’s delayed.

For Sheila, the delays worried her as she saw what delays looked like in a classroom every day.

When Evan started kindergarten, Sheila and Don were hopeful until their first parent-teacher conference, where the teacher recommended that Evan repeat kindergarten. Evan had a teacher who had taught for 30 years, and Sheila remembered the following:

> She [the teacher] just did not think that he was ready for kindergarten. And I ... did not handle that well. Don handled that much better than I did. I cried and cried and cried. I'm like, “He's going to be 19 when he graduates from high school.” I talked to a friend of mine at school, and she said, “Sheila, he just needs the gift of

> time.” Then, he did kindergarten again, and the second round of kindergarten was fine. But we found out that all the little girls in his class thought he was a doll and did all his work for him during his first kindergarten year. And so, they would finish theirs and then do his for him because isn't he cute? ... and like, learning sight words. He'd have them. He would have it. The first day he would have it, and he'd go home the next day, and go to school the next day, not be able to do it at all. And so, the sight words were the first indicator, hmm, that maybe it wasn't a maturity issue, which is what we thought, which is why we retained him. Maybe it wasn't maturity. So, when we started first grade and his struggles continued, that landed him in the RTI process.

Sheila and Don described the elementary principal as a wonderful support and advocate. They said she knew every child’s name and greeted every parent, especially the special education parents, which meant a lot to them. When they described the principal, it was with great fondness and trust. They emphasized that the principal always had their best interest at heart. Sheila shared an example from when the RTI team asked Sheila about Evan’s speech.

> Well, he says “Plublix” and “lellow” and “You’ve lelled at me” and it's “lesterday.” And they [IEP team] went, “Well, that's developmental.” And the principal says, “He's a year and a half older than every child in this class. It's not developmental anymore. It's a speech problem. Let's get him evaluated for speech.” And she looked at me, and I said, “Yes, please, let's do that.”

As a result, the team requested a complete psychological and speech evaluation.

Sheila reported that the school district her son attended differed from where she worked in that the evaluation done in her son's school district always included behavior as part of the evaluation. During Evan's evaluation process, she said the behavior tracking upset her son very much whenever he did not hear the teacher say 'good job' on his behavior chart. Sheila stated that her son had always been hypersensitive. Sheila reached out to the school, knowing it was Evan's hypersensitivity but questioning the need for this part of the process. At the next meeting, the principal asked why testing included behavior and stopped that part of the testing process as the principal knew Evan and behaviors were not a concern. During the testing process and before the eligibility determination, a friend whose child attended Evan's daycare mentioned to Don while they were picking up their children from daycare that she saw Evan had qualified for special education. Sheila reported being livid about the violation of their confidentiality and immediately emailed the principal. The violation occurred because the special education lead shared a calendar between the two schools where the friend worked as a teacher. Evan's name was on the calendar, and their friend saw it as she was a teacher at the other school. The principal immediately addressed the violation, and the trust remained intact.

Sheila asked the principal to help again after Sheila had reviewed a copy of the psychological evaluation before the eligibility meeting because she was concerned that the school was suggesting attention deficit disorder, which her husband did not believe was a real disorder:

> And so, I happened to be at the school, I don't even remember for what, and ran into the principal. And after all the problems that we had had, she asked me how

> things were going and I said, “Um, are you coming to the IEP meeting … to the initial?” And she goes, “Do-do I need to?” And I said, “Yes.” And I said … and I told her what the IEP said or what the psych said. And she looked at me, and I said, “I have to sleep with him, you do not. I may need you to pull him out of the tree or keep him from coming across the table and killing somebody.” And she was like, “Okay!” And so she walked into the meeting, and the lady that we had had so many problems with, with the calendar did not know she was coming… more because I needed her [principal] to be there to explain to him [Don] with somebody that he knew and trusted about the ADD thing. And she- ‘cause she was-she [principal] was not pleased that they had put attention deficit all over that thing because he's not, he is a 150% LD and 150% processing.

Eventually, Evan qualified for a specific learning disability, other health impairments for his processing related to prematurity complications, and speech. Don was very passionate about how Evan would be labeled. He said the following:

> I didn't want him categorized into a hole with 14 other kids. I mean, nobody does. Nobody wants their kid over here. “Well, we're going to put him in this group, and that's the group he's going to stay with because he's this.” I wanted him to get out of it. He's got the same disability that I had. Nobody ever noticed it on me. And I had to fight my way through. I didn't want him to have to do that. So, if there was some help that he could get, let's do it. Not well. “He's ADHD, and we're going to put him over here, and we're going to tell you.” One of them told me I needed to take him to the doctor and get him some pills for it, and that's when I lost it … that was the same lady that put his name on the calendar … that's

> what I looked at was this lady didn't want to have to deal with LD. She just wanted to put him in this category.

The principal did sit in on their first eligibility meeting, which was four hours long. Sheila said the meeting lasted so long because the principal made sure that they explained everything to Don in layperson’s terms and made sure that he understood what was happening in finding Evan eligible for special education services. The principal also explained the IEP. Don’s childhood educational experiences were negative, so he was very protective of Evan. I asked Sheila if the principal recognized this; she thought she did. Evan began receiving special education services in second grade. From second to fifth grade, he was in a resource, or small group, placement for math, reading, and language arts. He also received speech services from second to fourth grade.

Sheila and Don said they were fortunate to have had people who cared about Evan at the elementary and middle school. The school principal was their elementary-level advocate, and Dr. Smith was their advocate in middle school. Dr. Smith was one of Evan’s special education teachers in sixth grade and his special education case manager throughout middle school. Evan’s sixth-grade year was COVID, which was “hellacious,” according to Sheila. Sheila recalled the following:

> Dr. Smith knew I was working, and he [Evan] was home alone. And so, she called him several times each day. I checked in with him. And it's not that my child wasn’t old enough to stay home alone because he was, you know, that was not the problem. It was the “huh huh,” [perseverating], and he got stuck and couldn't move forward. But she was absolutely amazing. She is the reason why he was successful in middle school … We encouraged him to reach out and advocate for

> himself, but often I would have him email her, and then I would go through and email her and say, “He's supposed to email you, but this is what is happening. Help me.” And so, she was amazing. And again, I had her cell number. Evan had her cell number. He called her, texted her. They still text … she was the one who got him into the ROTC program, found out about the class that they were doing extracurricular, sent us the paperwork, and got it signed. He took it to her because he was too afraid to figure out where to take it at the middle school, and she delivered it to the person. She got him into this after-school class, and she got him into the ROTC program.

While Don and Sheila benefited from having a professional advocate for them at each school level, Sheila also benefited from being a teacher and having access to her colleagues’ training. Her special education colleague, Marie, reviewed Evan’s IEP for years. Sheila stated that the school staff noticed the notes on her IEP draft each year and even asked who wrote the notes. Sheila just responded with “a friend.” Sheila and Don believed that the school thought that they had an advocate:

> Marie went through every IEP, having looked at every progress report. She went through the whole thing every time and made sure everything was right- and she would make notes. - she got him transitioned and helped us get the initial one done. And then she even told me what words to say, in that IEP- in that initial meeting … we had long conversations about it …

To Don, the school staff was not trustworthy, so having Sheila to advocate for Evan was a relief. He described Sheila in the IEP meetings as “it was like watching an orchestra! So, I mean, it was … I knew that regardless of anything else, Evan was going to be taken care of." When Sheila and Don attended the transition meeting for high school, they discovered that Evan was being placed back into all resource, or small group, classes for high school, a decision made without their input. Fortunately for Sheila, the school held the IEP meeting virtually. Sheila stated, "He [Don] knew I was about to lose it, so at least I hit leave before I broke into tears." She said that she felt like Evan was going backward again. She then talked to friends and found out that the high school started everyone out this way. While she questioned how this met the least restrictive setting mandate, the other parents assured her that most students transitioned into team-taught classes for the second semester. It was an emotional roller coaster of deciding what was best for Evan and if they should trust the school's decision to return him to a more restrictive placement. They chose to trust the placement change.

Sheila and Don have lived in the same home since Evan was born, so he has attended the same school district since qualifying for special education in second grade. When I asked her to reflect on her special education journey, Sheila stated the following:

> Never have we encountered anybody from kindergarten through ninth grade who has not been willing to sit down, listen, and help him … but Don sees that everything I ask for is a fight, and I don't see it as a fight. But when it comes to this one [Evan], he just wants the best for him. He just wants him to have a level playing field and be like everybody else. But I don't say I'm listening to him thinking, I don't really think it's me. I really think that it's a team of people, and I just ask about something … I think the IEP has given him the power to be successful … I think it's given him what he needs to succeed, but he has to work much harder than everybody else. I think parents don't realize how much the

> teachers do that's not in their document, how hard the teachers work to ensure that the kids get what they need, and how genuinely these teachers care for them. I think the parents need to keep in mind that the teachers really do have their kids' best interests at heart, and the teachers really do want the kids to be successful … And you've got to give those teachers a chance to get to know your kid, to really understand, because it takes ... with my kid, it takes a good six, eight weeks to get to know him as a person, him as a student, him as, you've got to be able to figure out ... figure out the whole thing, and you've got to give him some time to meet ... to build that relationship but also to figure out what it is that he's good at and what it is he struggles with. And for my kid who won't talk to them, because every time the first meeting is; well, he won't ... he's not going to, you know, he won't have long enough. But I mean, I think you've got to tell those parents that you've got to give the teachers time to get to know your kid.

Sheila and Don talked about how different their knowledge bases were and the importance of schools recognizing what parents did and did not understand as they proceeded through the special education experience. Don did not understand any part of the process and was very apprehensive and distrustful because his own educational experience was very negative. On the other hand, Sheila was a teacher who assumed the best and knew how to navigate the system. The couple discussed how meeting the parents in the middle differed depending on the parent. For example, Sheila knew to ask for the psychological evaluation results in advance, so she could have time to process them and have her friend, the special education teacher, review them with her. Don said he would have been overwhelmed hearing all that information for the first time in the meeting. I noted that Sheila closed the gap between her knowledge and the school’s knowledge by seeking outside support so that when she met with the school, she met as an equal.

As she reflected on whether she was an equal with the school, she added the following thoughts regarding placement and services in the IEP meetings:

> They had already decided where to put him before we even walked in the door. And those decisions, I don't feel like they have ever been team decisions. I feel like they have always been decided before we get there. I've asked why a few times, but never totally disagreed, no. That was the only time I really was like, oh, and had to have conversations with other people. And she [Marie] and I spoke afterward and explained to me why. But I really do not feel like, ever, ever, ever, ever, that there's ever been actual. “Let's have a conversation and decide what we all think.” I feel like it's always that: this is what we're doing. [I don't] ... The accommodations, the goals, those kinds of things, absolutely [they listen to us]. They're very open to those kinds of things. But placement, I don't feel like we've really ever had any input.

Even with all of Sheila’s knowledge and access to resources, she described having limited control or input regarding her son’s placement for services. Fortunately, his placement worked out each time, including the high school transition. Listening to more of their story, I noticed that Sheila continuously provided significant academic support to ensure Evan’s placements remained successful. She often helped him study and created quizlets for his tests and quizzes, so she worked consistently behind the scenes, supporting Evan. She actively advocated for her son’s education, which may have mitigated any problems that may have arisen otherwise. For Don, his wife’s knowledge and ability continued to ensure that his son was protected and had the best opportunities, which he did not have when he was in school.

Family 4's Experience: Ann and Her Son, Kevin

Ann and her husband, Scott, were white, Catholic, middle-class, college-educated parents in their late 50s living in a suburb of a metropolitan city, which was part of a suburban school district in a southern state. They had been married for more than 37 years and had five children. Kevin was the youngest at 18, while the first four children were 22-36. They had relocated to the area from a nearby southern state. Ann was a stay-at-home mom, and Scott worked in business and traveled often. Ann began telling her story about Kevin by saying she started "fighting for Kevin at age two." When Kevin was two years old, Ann knew something was wrong. At first, her pediatrician tried to say, "Let's wait and see," but Ann insisted that something was wrong because Kevin was not speaking or engaging with others. Ann said Kevin regressed into his own head between 13 and 18 months old. At that time, she did not know what autism was, but she "simply knew something was wrong." The pediatrician referred Kevin for an evaluation, and the "easiest diagnosis was a developmental delay." Ann stated that the developmental delay diagnosis was also less costly for the government than an autism diagnosis. Regardless, early intervention services came in, and he began receiving occupational therapy (OT) services. During this time, the occupational therapist said, "We're not allowed to tell you he has autism, but he has autism, and you need to have it tested. You need to have him tested." Ann shared that she had not heard of autism at that time and lived in a neighboring state where services were more limited than in her current state of residence.

Ann pursued testing through the local school system when early intervention services evaluated Kevin at three years old. Ann shared the following when asked how he qualified for special education:

> And they actually did the testing … uhh … and then they offered us this program … uhm … but at the time, they actually did an autism test. And it's funny. Since then, I have had so many educators tell me, "I'm surprised they did that test. You must have been really obnoxious to get them to do that because normally they do not like to do that test because that is like the gold standard for autism." And I don't remember the name of it. And I probably- I had been a little pushy, but not … I mean, I guess I think I was, I was a parent, I was an educated parent coming into the system. This is my fifth child. I asked questions. I wanted to know why. I wanted to know how, you know. And after everything we had gone through with the early intervention, I was a lot less trusting than I would have been a year before ...

When Kevin was three, he was diagnosed with autism, and Ann shared that the school system offered her a Pre-K classroom with 20 other children with special needs and said, "This is what we're going to give you. This is it. Take it or leave it." Ann toured the classroom and remembered that the children had many needs, including Down's syndrome, autism, and physical disabilities, all in one room. Kevin was not potty-trained, had feeding issues, and did not speak. She was worried he would be lost in a room with 20 other high-need children. Ann recalled researching on the internet, trying to figure out what to do for Kevin:

Oh my God, I was still such a baby [in terms of knowledge], but yeah. And so I was, you know, researching, learning about ABA [applied behavioral analysis], learning what speech was, what play therapy was, what, you know? And, what's interesting is so now I talk to so many of my friends around here who have kids at the same age group, and, I mean, they were doing therapies that I didn't even know existed, you know? Because it was available up here. There was so much good stuff available up here. We had none of that where I was … We had speech and OT offered through a private company and that was it. And any more than that, you know? And then I had to fight insurance like crazy just to get those because back then insurance would not cover speech and OT. And so, then, uh, I found out about a program that was offered through the university, which was about 45 minutes from where we lived … uhm … and it was an autism-specific school. And they had just opened up an autism-specific pre-school, which was like way ahead of the curve at the time. Um, and so I, it was like two weeks before school was supposed to start, I found out about this program. I called the director and said, you know, and there wasn't even a price on it. Because what these kids were doing was these kids were coming out of the local city school system into their program. But then the director was like, “Well, you know, sometimes we get kids from farther away. Yeah, they'll pay for it. We just have to, you know, ask them.” Um, so we went ahead and got him in. It was amazing. It was just fabulous. It was the best thing we could have done, you know? I found it on the internet. I was just at home googling like crazy.

The director of the university’s preschool accompanied Ann for a meeting with the school district to advocate for Kevin’s attendance in the autism program. Ann recalled the following:

> It was the preschool director, my husband and I, and ten educators across the table from us. And they were like, “Well, that's fine. You should go to arbitration. That's your … If you want it paid for then, you know, go to arbitration.” She [the preschool director] walks out and goes, “Everything they just did was just completely illegal.” She said, “But here's the thing. You're going to have to either pay for preschool or you're going to have to hire a lawyer.” So, you know-

Ann and her husband figured they could pay the preschool tuition by the time they hired a lawyer. For the next two years, Ann drove Kevin 45 minutes each way to attend the specialized preschool so he could get applied behavioral analysis (ABA), which the public schools did not offer where they lived.

Realizing the lack of services available for Kevin, Ann and her husband decided they could not have Kevin attend the public schools where they lived. As a result, they relocated the family to the school system near the university where Kevin had attended preschool. As a result, her other four children had to leave their school and friends to move an hour away, which took an emotional toll on the family. During this time, Ann also reported getting “plugged into” autism advocacy groups. She stated that only a few advocates or lawyers for special education existed in the state, but that one lawyer was a father of a child with autism and had started providing training seminars for parents on special education law. Ann would drive two hours each month to attend the training he offered in a nearby city.

Kevin continued to be non-verbal and had trouble with eating. By five years old, he was less than 35 pounds. Ann kept researching and trying to determine if something more was happening with him. When Kevin was six years old, Ann found a doctor in another city and took him to a specialist who worked with children with autism. Kevin was diagnosed with eosinophilic esophagitis, which is an inflammation of the esophagus caused by eosinophils, the white blood cells related to allergies. Ann reported that while the correct diagnosis helped with Kevin's eating, he was not potty-trained until he was almost 11.

While Ann worked at home to help Kevin medically, she also advocated for him in school. She recalled pushing for Kevin to be served in a general education classroom setting with a categorical aide. In retrospect, she was not sure this was the best placement for him. She stated the following:

> I thought that was what was best for him. He … I wanted him to be with the other children. I wanted him to have that. And that's what they were doing. And, and if it ever became a problem, they, they … I mean, it really was. He had a great situation. Um, he loved his teachers. The kids were really sweet. We had two amazing elementary schools … uhm … but in hindsight, he wasn't being held accountable, you know- to do the work. It was low expectations. Yes, he's sitting here. He's being still, he's being quiet, um, and he's with his friends, but he doesn't have to do any of the work. She gave him a coloring sheet to keep him busy while the rest of the kids were doing academics … So, we didn't even know he knew his ABCs until he was like in first or second grade. And because he was playing these games, it was like, "Oh, crap." He taught himself to read. He taught himself.

Ann was begging the elementary school to work on functional skills like holding a spoon or fork in occupational therapy. Given his instructional placement, she reported that the school would only do instructional skills, not functional skills. When Ann reflected on what it has been like learning about Kevin's diagnosis and trying to meet his needs, she said the following:

> You have to understand that from the time our child was diagnosed at age two, when they're born, whatever, we have to fight for everything. We fight from the minute they're born or from the minute they're diagnosed. We fight the schools. We fight the doctors. We fight the insurance companies. We fight everybody. So, we are in this headset mind frame, or whatever, that we're going have to fight for everything. And so, we may come across, and I think that's what happens in so many IEP meetings, is we go in there loaded for bear. We got our notes, we got our stuff. We, because we know we're going to have to go in there and fight to get everything our child needs. So, we come off as being combative when we're not combative people. It's just this is the only way we've been able to get anything in the past.

Ann acknowledged that her past experiences have negatively impacted her approach to new staff because she anticipates conflict.

When Kevin was transitioning to middle school, the family relocated to their current state. Ann was well-connected in the autism community and sought recommendations for what school district to choose. Many parents recommended her current district for their special education services. Ann shared that she had spent years learning her former state's laws and was too exhausted to learn the new state's laws, so she hired an advocate to attend the transition IEP meeting to help her with the new school. She knew the advocate through the parent advocacy group that she had been driving two hours every month to attend on Saturdays.

Even before the initial IEP in the new school district, Ann reported being taken aback by the services offered there. The assistant director of special education evaluated her son before they had a meeting to get a better sense of his needs, as the county provided a range of services for students with autism. Ann said the school system "offered" transportation, which had never happened in her former state. When I asked if she felt she needed the advocate, Ann said she later became friends with Kevin's teacher, who told her that the school district "did IEP meetings completely differently when they know she [the advocate] is going to be part of it." Ann continued:

> So, yes, I am glad we had her, but I did not know that at the time, and I did not use her again in middle school. I did not need to. I guess we set the tone in the first IEP … I needed somebody to have my back. And my husband's great. He's wonderful … um … but he doesn't have time to learn all this stuff either, you know? And so, he is my biggest supporter, and he's there. You know, he's ... He goes to every IEP meeting with me. But I needed somebody who knew. And she also knew the players there because she'd worked in that school system, in that school. Her son had actually gone to that school. So she went, and she's got a son on the spectrum. So, she went in with this is what we need to do. And we wrote a beautiful transitional IEP ... [she impacted] the services and ensured he got everything he needed. And when they told us why he couldn't have it, they had to explain why … they removed his categorial because he was in a contained

> classroom with six boys ... so they basically said, “You need to try this. Okay. He's, he's a big boy now. He's in middle school. This is part of the middle school process. Let's, let's see how he does.” Yes, let him have that independence. We'll work on those life skills.

Ann continued to talk about how accessible the district was. She was amazed at the services offered, including assistive technology services. During COVID, she was hesitant to mainstream Kevin into choir or band due to his health issues, so the principal agreed to release him early each day to avoid the large class sizes of connection classes like band. Ann reported an excellent working relationship with the school staff, but Ann had also learned to be her own advocate. She stated the following:

> One of the things that I did, and I should have shared this with you last time. One of the things I don't like about the IEP program is I do not like the fact that in April we're looking at everything a child is doing, we're making all these plans for next year, and six months later or four months later or whatever, that's a different kid … and so one of the things I hear about … I don't remember if … I don't remember if the training by the lawyer taught me to do this or if I just decided to do it on my own. But I tell all my teachers in April that we will meet in September. I will give you six weeks to get to know my child. Because in April you don't even know who his teacher will be. You don't know anything. We don't know who his aide is going to be. We don't know who his teacher is going to be. We know nothing. How can we make all these plans in April for something we do not know what it will look like in September? So, the thing I have always done, and I haven't done it in high school, is I have more communication in high school,

> so it's not been a big deal. But in elementary school and middle school, it was the middle of September. Go ahead and put it on the calendar because we're going to meet.

While Ann had become a proactive advocate and appeared confident managing the special education component of Kevin's life, she continued to struggle to find something that might reach the person locked inside her son’s body. Ann discussed searching for ways to access Kevin and what he knows, thinks, and feels. She said she was never quite sure if something would click and help him come out of his head:

> Kevin has an output problem, not an input problem. And he does read. He reads very fluently. He understands everything he reads. He doesn't always process auditorily. I definitely think we have auditory processing issues, and it takes him longer to process things. And if there's a lot of confusion and chaos, it's out the window because there's just too many things for his brain to process … uhm … so, and so for us, the problem was … And I haven't figured it out, and no teacher has figured out the right way to handle this. I haven't figured out the right way to handle this. I believe that he was happiest when he was in elementary school and a gen ed classroom when he was being exposed to everything the other kids were being exposed to. Once he got pulled back into a contained classroom, we started having more behaviors. We started having more, you know, acting out, not wanting to do the work …uhh. … and his teacher and I are really close friends, and she and I talked about this so much. It's like you have to presume competence with this kiddo. Because if you start dumbing things down for him, he gets angry and lashes out because … And so, middle school for us was finding that balance

> of, you know, exposing him to harder things, but trying to get some kind of data out of it. Because, you know, they just let him sit there in elementary school. They never … He was never held accountable. He never did the homework he needed to do … it's like he's like a victim. He is trapped in his own body.

Ann said she felt supported by the school staff, who saw that Kevin could read and compute. Unfortunately, Kevin provided no feedback. Even though school staff understood Ann's desire to challenge Kevin, they said that without any response from him, they could not put him in a mainstream general education class. When the staff explained to Ann that they had to have some written evidence of his understanding, Ann understood why Kevin remained in the modified autism classroom. Ann was fortunate in that she established close relationships with his teachers, so they talked openly and honestly with her.

Ann said that she did not trust the school when reflecting on her relationship with the high school. She trusted teachers. In ninth grade, she trusted Kevin's teacher. She lacked confidence in his current teacher because she believed they "give up" on the students by only working on functional goals in high school. Ann shared, "I felt like we were doing academics in middle school, but we were … When you get to the high school level, they've just given up." Ann talked about a mock interview script that Kevin practiced all semester. Kevin only used taught scripts to express himself. While he used scripts, he could not independently generate his own ideas in words. Ann said as she listened to the scripted interview, she thought to herself, so while he learned a job interview script, if the person did not follow the script, it wouldn't help him in a real-life situation. I asked her what the answer would be for that teacher to prepare Kevin for a job interview. Ann was unsure of the answer as she shared that Kevin often gets frustrated when he cannot express himself, so she knew that no easy solution existed. She exhaustedly said, “It is a non-stop puzzle.” Ann had also worked with the district’s assistive technology staff and said the following about her experience:

> We’ve tried everything … I mean, whatever I need or what she is there [assistive technology specialist]. So, I have to give her so much credit. She's been great about working with me. But, you know, it's just we haven't found the right way to help him. We haven't found that breakthrough yet with him.

Ann went on to describe how Kevin could engineer songs on his computer. She said that he would pull sound effects and recordings and create tracks. Ann was determined to unlock the code that would finally access the Kevin locked inside his body. Underneath her determination, she acknowledged grief and acceptance:

> Academically, I've pretty much given up. I think we're done. We're not going to get anymore academically. I think he'll learn what he'll learn. He, he, he watches TV. He looks … I mean, he watches things on the computer, he looks at stuff. He, he loves to teach himself things. So, you know, we're just going to keep working on that. And that's going to be, you know, on through the adult programs that we do or what, you know, whatever it is we do. It's about supporting him and learning, just being open to learning at this point out. So, these kids are out in the community two days a week. This past year, well, the first year it was like post-COVID, so they did the park. So, they basically went to do janitorial skills at the park. However, they've moved into a more normal situation this past year. And so, one day, they were at a grocery store and worked in the deli. They're all kinds of

> different things. And then they alternated that with a pizza restaurant here in town. And so, they would go and fold pizza boxes and fold and, you know, roll. So, they really are working on doing job skills. But then, like I said, we were at this party, it was his birthday party yesterday, come to find out they had them doing janitorial work at school, wiping down tables in the cafeteria, and I didn't even know that. And this mom was like, “Yeah, that's a hill I'm going to die on this year. So are you … Do you want to join me?” And I'm like, “Yes, because they should not be seen as the janitorial staff.” I'm all about whether they want to do a recycling program. But no, we hire people to clean in the school because that isolates them from their peers.

Ann was apprehensive about the start of the school year. The director of special education was new, as was the teacher. She talked about the energy it took to re-establish and build a relationship of trust so they could work well together. She hoped it was not a new, young teacher as she stated, “Junior and senior is such a hard year because they're, these are the big transition years, and we don't need, we don't need somebody we're teaching.” Along with a new special education director and classroom teacher, the school also got a new band director. Kevin played more than one instrument. Ann stated the following about seeing if Kevin could mainstream into the band class:

> Well, we're going to say we'll see. But I'm going to ask since we're going for a new band director, I'm going to ask because the other band director blew me off, so he didn't want to deal with it. So, it'd be interesting to see if this new band director is open to that or not and if the new special education director is open to that. But I'm going to ask ... Though it never hurts to ask. You don't get if you

> don't ask. That's the … All right. So, if I could give you one phrase of my, my whole idea is you don't get if you don't ask because they're never going to offer it.

Ann reflected on her time in her former state. Back there, she had no options. The school system was not scared of lawyers or advocates because they were unavailable in the area. She said, "You got to get a lawyer from a big city willing to take your case and come in. But equality comes with money, which is unfortunate, but that's the way it is." In her current county, access to services came with access to more resources, lawyers, advocates, and parent advocacy groups. Still, Ann had not found the answer to reach her son. When she reflected on her special education experience, she shared the following:

> [In his elementary years], you're just constantly researching, looking, and trying. From the time you get a diagnosis, you're just wanting to figure out, "How can I help my child? How can I help my child?" Then you get into the junior high and high school years. Actually, the healthiest ones [parents] are the ones who step back and go, "You know what, we're in a good place." Or "We are where we're going to be." You still want to help them, and you always want to try to do more. But you also have to find that balance. There's definitely grief and acceptance. Absolutely. There's no magic pill. Took me a long time to get to that point. We're still doing other things. We're never stopping. I was on the phone several times with this biomed doctor in Florida today fixing some stuff that needed to be taken care of. So, we're not stopping. But it's hard.

To date, Ann continued to research music therapy as an option. As Ann continued searching for her next steps in this journey, she considered that Kevin could stay enrolled in the public schools until he was 22. After his senior year, he would be called a super senior. When Ann talked about herself and other parents looking at the possibility of a super senior year, Ann said this:

> You see kind of grieving, too. I mean this like [for some parents] you know, this is their only child, and this was their hope, and now he's our forever child, you know? But then we have that as well. Yeah, we have that. We're supposed to be getting ready for retirement, and that won't happen. Well, it's so easy for high schoolers because the high schools because they're like, “Oh, you can just stay for a year, you know? I mean, just let him stay in super senior for a year.” And I'm like, “For what? What is he going to accomplish here?” I would much rather him be a Project RISE where he's learning job skills and there, you know, working on socialization and all that or in a job, you know? And we are so lucky to have so many businesses in this county to support our kiddos.

Ann reflected that she was unsure what would happen with Kevin as few group homes or programs existed in the area. Ann did not seem to know what to ask from the school because she had exhausted all the resources she could access, and still, Kevin remained mostly unresponsive or “minimal or limited verbally,” as Ann preferred to say. Ann remained positive but also unsure about what Kevin’s future held.

I asked Ann what she wanted teachers to understand about parenting a child with limited verbal skills. She shared the following:

> Well, for me, the number one every year, every IEP meeting is communication. My child is not going to come home and tell me what happened today. So, it's up to you to be able to communicate that to me. Now, one of the things we did try last year … Unfortunately, I don't know why it fell apart. I'm sure it was just a lot

> of stuff going on in the classroom because it's a very busy group of boys. But one of the things that she was trying to do as his teacher last year, and I'm really going to push to try to continue this, have Kevin take a picture of the schedule on the board so that I know what they're doing that day and then send an email to me telling me what they did during the day. It gave us a starting point to say, "Hey, I saw you guys talked about electricity in science today. What do you think about that? Let's go get a book out, look up about electricity." And it just opens up those conversations. This is contrary to the high school's desire to limit parent contact. For us, it is the only way we know anything.

Ann also shared additional insights. Ann currently worked in a day treatment program for adults with autism. She had noticed that the more verbal adults tended to dominate the staff's attention. She had made a point of maintaining her attention on the quieter people to allow them wait time to see if they had more to contribute. She also really wanted to emphasize that teachers presume competence. Presumed competence meant to assume the nonverbal person knew what was going on and just could not respond, versus he was unaware or did not understand.

As we concluded, Ann further reflected on the toll the journey has taken on her family. Kevin later developed Lyme disease, but it was hard to determine as he could never verbalize his symptoms. She ended up bringing him to a Lyme disease expert in Connecticut. The expenses, travel, and emotional toll impacted all of her children. Ann and her husband have tried to give Kevin every opportunity to heal and flourish throughout Kevin's life. She said, "Now, his brain may always be broken. But at least his body is healthy, and he will be able to live a normal life." Ann said she will continue to fight to find ways to reach her son even as they move into the new phase of adulthood with new agencies, expectations, and options. As stated, Ann described her experience raising Kevin as battling and fighting to help her son, a stance that she acknowledged took an emotional and financial toll on her whole family. As the parent-school partnership began this school year, the high school staff working with Kevin, who are all new this school year, did not know the "battle stance" Ann had adopted after more than 15 years of advocating for her son. Again, the high school staff would be wise to listen to Ann and hear her concerns and story because her deep history impacts the parent-school partnership.

Family 5's Experience: Victoria and Her Son, Randy

Victoria and her husband, Bill, were white, middle-class, college-educated parents living in a suburb of a metropolitan city in a southern state. Their local high school was part of a large metropolitan school district. They had been married for more than 25 years and had four children. Victoria was in her early 50s, and Bill was in his late 50s. Both had heavy Southern accents, and Victoria mentioned growing up in the South. During our interviews, Victoria frequently referenced their strong Christian faith. Before having children, Victoria was a school counselor but had stayed home when the children were young. Bill was a manager in business. Their oldest daughter, Shannon, recently graduated from college and got a job teaching fourth grade about an hour and a half south of the metropolitan area. Their daughter, Makayla, was a first-year student in college, and their two sons were seniors in high school. Randy was 18 and had Down's Syndrome, and Roger was 18. Makayla and Roger were adopted when they were four and three, respectively. Bill has been the primary provider for the family since the children were born. When Randy and Roger were in third grade, Victoria began working as a paraprofessional at the children’s elementary school, which she still does despite her school counselor background. When asked about her experience with Randy, Victoria started the story as follows:

> When I was pregnant with him, we had tried to get pregnant for, you know, our first daughter came really quick, so we assumed that when we were ready for a second, it would just happen, and it didn't. So, we went through a lot of … umm … medical. We did IVF; we did all that. [It] Did not work and never found out why or why we were having trouble … so then we decided that we were going to adopt. So, we started the adoption process, and I think because the meds were still [there] about 3 to 4 months after we had done the last … um … procedure, we got pregnant. And, of course, then we were like, okay, let's figure everything out. So, it was just like a rollercoaster at that time. So anyway, when we were pregnant with him, they had asked us, I was 34 … I turned 35 right before he was born, so I wasn't really considered high risk only because our issue was not the pregnancy as much as it was getting pregnant. So, they offered the amnio and everything, but we just kind of said no because we had had so much trouble getting pregnant, we didn't want to risk anything, and we wouldn't have done anything anyway … That was kind of our agreement, my husband and I. When we went to deliver, we had no clue that the baby had Trisomy 21. You know, when I look back, my husband and I both have said, you know, it worked the way that it was supposed to work with us. God is working. Yes, I would have worried a lot during the pregnancy when he was just a typical baby. You know, it really wasn't anything. It was just

> more or less processing all the information of what the future would be like. That was in what you know … But as far as bringing him home … getting adjusted … having already been a mom *once* [emphasis added], and knowing he really was no different. So, I think I would have worried more than necessary.

Victoria said that Randy did not have the cardiac issues that were common with Down's syndrome. She said the ultrasounds did not pick up Down's syndrome because he did not have the more pronounced features. When they first found out, she said this happened:

> The hospital immediately came in, gave us all the brochures, and connected us with the Down's syndrome (DS) association. With other parents … and I will say we felt very supported at that time, not being prepared. Like I've got some friends that knew six months ahead of time and did their research then, and they were ready once they went into labor … you know … We … I felt that we … the hospital handled that very well. When we came home, the state's early intervention services were at our door … because with Randy's diagnosis, everybody … You know, the pediatrician, all the specialists, it is pretty much known … there will be delays. It's just a matter of getting him the services he needs to try to close that gap as much as we can … it was in a way, easier because people were on board immediately.

Although Randy's development was delayed, it was not drastically different, so when Randy was about three, Victoria and Bill reconsidered adoption. They had initially considered adopting internationally, specifically in Russia, to avoid any prolonged custodial issues connected to a foster care adoption or local adoption. Just as they started reconsidering adoption, the adoption agency contacted them to see if they were still interested in adopting. Victoria shared the following:

> Russia shuts down for the summer, so we thought we would not get our referral until next fall. So, we were kind of taking a breather for the summer. Our agency called us and said, “Listen, we know you're planning to go to Russia. But we have this unique situation. It is domestic. The children have been in foster care for a week. The parental rights have voluntarily been terminated. So it wouldn't be, you know, drama. Nobody’s changing their mind. It would just be smooth … The only thing is that there are two of them. And they are ... umm … 14 months apart.” So, they were three and four years old, and we had a three-and nine-year-old ourselves … And so, they were like, would you be willing … we want to try to keep them together. Would you be willing? And Bill and I were like, I think, you know. We were nervous about traveling to Russia and leaving Randy here with family for that long. So that was the only thing that I was really nervous about. But … umm, we just felt like this is what's meant to be. It wouldn't have been this easy if it wasn't meant to be. It was just put in our lap. So, we said, yeah, and a week later, we had them. And everything was finalized in October.

The four-year-old was a girl named Makayla, and the three-year-old was a boy named Roger. Their parents were young and had recently divorced. The mom, who lived several states away, had decided she could not handle the children and sent them to live with their father. While the father loved his children, he was deployed to Afghanistan for two years and had no family to help him. When he placed the children for adoption, he had asked that the children keep their first names and that he have some communication.

When he returned, he asked to contact the children. Since the children remembered their father, the Joneses decided seeing him was in the children's best interest. Victoria described the relationship:

> So anyway, we talked to them, and they talked to him on the phone, and we would put them on speaker so that we could at least hear what was being said to make sure it was, you know, not going to affect their continued adjustment or anything. And it was really all just good, a good, healthy conversation. So, it reached a point where they wanted to see him, and he wanted to see them. And he was always very polite and respectful of our time and privacy. And, you know, if we weren't comfortable with it, he would kind of say, I understand, but ... We're on the side of seeing these children who remembered him, and how could we not allow that? I mean, it's needed for their continued growth. They needed to kinda ... not reach closure, but at least have that outlet with him. So, we started meeting him like in a neutral place. He was in a city a few hours away, so we would meet him halfway at a park and let him see them. I think the first time they saw him was at a McDonald's. And it was I mean, it's hard for me to even talk about her, especially when she saw him for the first time after two years. It was just an incredible experience. And them to see each other. Now, again Roger was right there with her, but I don't know that he … he remembered as much. But now, through the years, of course, he's got a relationship with him, with his father, too, but so thereafter, it became more of a … umm ... of every summer we would at least meet. It was usually once or twice a year. Sometimes, it was maybe like the break at Christmas. We would go down and see ... meet him. And then it was the

summer. Now, the only thing that we did have to say no to him for ... my husband and I both were concerned that at one point, the kids asked him, “Will you come to our house ... will you come to our town?” There was one time that we were near their city, and we did go to where they lived. And it was only for a day, and they saw his house ... by that time he had met a new wife. And so, they were living on … I think they were on base … But they were near the base, and we went by and visited. So then after that, they … the kids were probably … you know, seven, eight, eight, nine. And they wanted him to come to our house and see us. And the only reservation I had is I didn't want with ... my, you know, counseling background, and maybe it wasn't a big deal, but it seemed … them to have that memory of saying goodbye to him at our house. One thing that had been really difficult for them was when the adoption agency went to get them because he didn't bring them to them. They drove down with the foster mother and got them … was them separating from him, her especially. And it was very difficult. It was difficult for him, the father. It was difficult for Makayla. And I think Roger was just kind of going with whatever. But they shared with us that there were many tears. They had to peel her off of him. And it was just not a good situation. So, with that in my mind, I was like, the worst thing is for her to see that in her own house that's ours now and have that memory of him driving down the driveway and saying goodbye. I didn't want those feelings or those memories to come up again. I just felt like there needed to be neutral ground, and my husband was the same way. We just didn't think that it would be healthy for her. And I mean, I think that was right because then it was easy. I mean, it was hard when

> they would say goodbye to him when we would meet him, but they would go back to their everyday life with no memories of him here and do whatever. Whereas I felt like if we mixed the two too much, it would be harder for 'em. But … umm … But so, we would meet him. And then he … moved to an Army base out West. And he lived there. So, then it got really harder for them to see him regularly. So … umm ... but they communicated with the ... When they got to middle school and high school, they got their own phones. And they would text him, and they would FaceTime him.

At the time that Randy was developing, Victoria was balancing the adoption and adjustment of a three- and four-year-old who left a parent that they vividly remembered and loved. For Victoria, this part of her story was more pronounced than the challenges faced by Randy at the time. When I asked her about Randy during this time, she said that Makayla and Roger helped him more than she could have ever imagined because he had constant interaction with two children his age all the time. Victoria said this about Randy's relationship with his siblings:

> He learned from Makayla and Roger, And I will say that right there really laid a strong foundation for Randy. It is going to be really hard for him this year when Roger goes off to college because Randy has never been by himself. He wants everybody together ... in his mind … we have to all be together.

Victoria shared that she and Bill had agreed that Makayla could visit her father now that Makayla was an adult. Makayla was visiting her birth father in another state during this interview. She also had decided to attend college at a college with an extensive ROTC program as she was considering following in her birth father's footsteps. All these things weighed on Victoria's mind as she sat down to meet with me and most likely influenced what she chose to share. She acknowledged this later as she reflected in her third interview. Victoria did not operate in a mesosystem that only included the parents and the school regarding Randy; she was balancing Roger's and Makayla's needs as they joined the family. The other children's needs equally pulled Victoria's energy and thoughts even in her storytelling. We returned to Randy's pre-school years, which occurred at the same time as the adoption:

> We had him in a church preschool for like two days a week because I wanted him to have that socialization. Right. And he was with typical kids. It was just ... You know, two-year-olds. Then when he turned three in January. Of course … he was with early intervention services. So, he was getting his PT, he was getting OT, he was getting speech … um ... All private, of course, at that time. And ... umm ... so then early intervention services, when they turn three, is hands-off because it becomes the public-school system. Compared to kids his age, physically, he was fine. His physical skills are his strength. They say with DS there's one area that's stronger than the others. And his was more of the kinesthetic or the physical. He did … um ... PT ... when he was a baby … umm … and he was on the move. I mean, he learned to walk pretty early. But we also did aquatic therapy because the PT that he worked with did … um ... aquatics over at a local indoor pool, and that is how he learned to walk because when he was crawling, he would do the army crawl and early intervention services would come to your house. And so, she would come to my house and try to get him on the exercise ball, and he would just zoom away. He wouldn't do what you know or always do what she wanted him to

> do. But she realized he was on the move. He was gone. So, it was more her chasing after him to get him to do this activity. Or do that. And he was crawling everywhere. So, at some point, she said, I think he would do better just doing aquatics and not so much land therapy. Because in the pool, he can't just swim away. You know … He's more focused, and he has to do it. So ... umm ... we did just the aquatics, and they have a ramp, and he would crawl. Instead of doing the army crawl, he would have to get up on his knees because he would go underwater. And once he realized if he didn't hold himself up, he was going down. He did it, and he would stand. I could not have worked back then because my life was … making sure that I was filling out all the paperwork, getting everything done, communicating with the insurance companies, communicating with early intervention services or, you know, the school system. And getting his medical waiver because that was paying for whatever insurance would not pay. The Down's syndrome Association was very supportive. We got connected with a network of parents that were in the area.

Victoria recalled how strongly the DS Association encouraged parents to have advocates as the children entered the public-school system. She remembered that the DS Association had many workshops about how to advocate in the IEP meetings and why you should have an advocate. As a former educator, Victoria remembered being confused as to why the relationship with the school was assumed to be so adversarial. The DS Association encouraged parents to push for their children to have a categorical aide in the general education setting [as the service placement]. As a former educator, Victoria was not convinced that was always the best placement:

> I don't want to throw the DS association under the bus or anything. I feel like they are there to support, and their intention was to prepare parents for what's ahead. And I mean, they have, you know, been a huge and valuable resource to us through the years. But I do feel that there is a part saying that you have to fight for your child. And I've not always understood why they feel like they must do that. I've never felt that way myself, being a parent.

Victoria shared a story that significantly impacted how she and her husband navigated the special education journey. They attended the networking groups with the DS Association and heard a mother share this story in one of the workshops:

> Randy was a baby ... he may have been a year old. There was a parent who had an older child who was probably in high school, and she said, "I pushed all these years for my son to have a one-on-one categorical [aide], and I wanted him to be in the regular classroom. I wanted him to be doing what all the other kids were doing. I pushed so hard, and I went in, and I got it done. In elementary school, he was with a categorical [aide] throughout elementary school; he did not go into the program classes." It was kind of like she wanted him to be with the typical population because in her mind it was as if I wanted to prepare him for the real world, for when he's older and I'm gone, he's got to know how to interact in the real world and be and develop those skills and interact with people and know what's appropriate and know appropriate behaviors. Whereas she said at some point that, you know, in the small classes he picks up on all the other behaviors of the other special needs and you know, she brought that up and, and she said, so I pushed so hard all the way to maybe seventh grade. And by the time she ... umm

... he was either in eighth grade or even in ninth grade, his first year of high school. So, she went and always ate lunch with him at … umm ... elementary school and in some middle school. And again, I don't remember what school system she was with. I don't remember if it was a private school or public. I just remember this story. And she said she went … she was at the school one day ... and she would ask him, he was verbal. She was at the school one day, and she walked by. He was in the cafeteria, and they were all eating, and he was at the table by himself. And that hit her. And so, when he got home that day, she asked him, “Who do you eat with? Who were you eating with at lunch?” And he said, “Um…Nobody. You know, I eat by myself.” And she's like, “Why aren't you eating with your friends?” And he goes, “I don't have any friends. Nobody sits with me.” And she said, “Well, you talk about friends.” And he goes, and he was high functioning enough to say, “Those are people like me, Mom. I want to be with people like me. I want to be with others that are just like me.” And to hear that story, when Randy was a baby, I mean, it really stuck with me. It stuck with my husband, really, because he had not been in the school system enough to see how special ed, you know, is with gen ed and, you know, we said at that point, our goal is to have Randy where he wants to be and … in the back of my mind, that was always an image that I never wanted him to feel like he didn't fit in. And so even though we were struggling those years, going from first to second grade to knowing where he needs to be, I remember conversations my husband and I would have. We don't want him not to feel like he doesn't fit in … even though we would like him to be in the gen ed class and get as much interaction with the

> typical population ... and having all that. I want him to be where he feels like he's got a group of friends. And I mean, I will say his elementary school did a great job, and our experience was always that with P.E. and those gen ed kids really did well with the program classes' kids. And I think ... I never had a question about that. But looking ahead to middle school and high school, when we decided to put him in the program classes ... I didn't worry as much about it because I didn't want to push harder to be in a gen ed class with a categorical [aide] because I wanted Randy to have kids to feel like he fit in wherever he was. So, he went to the pre-K for two years, and then the following year, he entered the special needs kindergarten, did well, and got the therapy that he needed. He worked with the OT ... he got PT, speech, and ... umm ... Then, he repeated kindergarten with the same teacher. So, he stayed in the special needs' kindergarten.

When Randy entered kindergarten, Makayla was also in kindergarten. Randy repeated kindergarten, so he was then with his brother, Roger. Victoria was concerned that Roger might have Asperger's disorder and some speech issues. She asked the principal to include Roger in the co-taught class to give him extra support, which meant Randy could not be in the co-taught class. Victoria was balancing the needs of all three children during this time, so Randy remained in the special needs kindergarten class so Roger could be in the team-taught kindergarten classroom. Randy was also in aquatic therapy outside of school and in a sports league during kindergarten.

For first grade, the IEP team decided to try a team-taught placement. Randy was in the resource, or small group, setting for reading, language arts (ELA), and math and team-taught for science and social studies. While first grade went well, Victoria stated that “first grade was probably the ceiling for him… we were starting to see that he might not get to the point of really being able to sound out words and read…the gap was not closing…it was growing … ” Victoria described her experiences with the school staff as allowing her and her husband the freedom to consider their choice of more or less restrictive placement as they navigated what was best for Randy each year. Randy was qualified as having a mild intellectual disability for special education services, which now is called mild/moderate intellectual disability (MOID). For second grade, the school offered to place Randy in a self-contained class with other MOID students, but the servicing school would be over a half hour away. Victoria and her husband were worried about such a long bus ride for Randy, but they were also concerned that he was not progressing in his current placement and would fall further behind in second grade. Within a few weeks of first discussing a self-contained placement and visiting the servicing school, Victoria said the principal of Randy’s home school called her. The principal told her that a self-contained class was approved for placement at their home school for MOID students in grades K-2. Victoria, still to this day, was not sure how the principal made it happen. She was incredibly grateful and said she did not ask more questions. As a result, Randy stayed at the same school as his siblings, which made the decision to move him from the resource/team-taught placement to the self-contained MOID classroom easier. Randy remained in a self-contained MOID classroom for grades 2-5 at his home school.

While Randy stayed at his home school for elementary, the nearest self-contained middle school class was at a nearby middle school but not his home middle school. Victoria reported that middle school was a significant shift for her. Victoria had worked in Randy’s elementary school as a sub and then as a paraprofessional, so she knew his daily routine. Middle school was quite different:

> I didn't know any of the teachers really because they weren't in our community… We also stopped doing a lot of his private therapy because it was just too much for him. It was too long of a day, and he wasn't getting home until five. So that was a change that I look back. And I wish there was some other way I could have gotten him more speech, especially because he still got it in the school, but his speech is one of his biggest struggles, especially now that he's in high school. And he is ... we're to the point where he's in the CBI [community-based interventions] Programming. Community-based. And, you know, he had a … I guess he had a talking device ... at one point in middle school. But he is so vocal, and he is so social that he didn't want to use it. He just wants everybody to understand him because he knows what he said.

When I asked Victoria to reflect on her experiences transitioning Randy to middle school, she stated the following:

> Coming from an educational background, I've always trusted the system. I've never felt like I needed to have my own advocate. I've never felt like we needed to bring an attorney in … but I know many parents that feel that way because they feel ... they feel like they're not heard or it's one of those that they feel or, you know, as parents, they feel like they know their child best and they know what their child needs. And they feel like the school sees the child as a number or as just another child with special needs. Whereas I've not really necessarily always felt that way. I mean, there have been a few incidences where we felt like, you

> know, maybe he wasn't getting exactly what he needed or a teacher. There was not a great mesh with the teacher, and we would sit down and ask for a conference and talk about those things. But as far as his IEP meetings and what services he's gotten, I feel like we've not had to push as hard as maybe some other parents feel. Now, I will say … my husband and I have always been those that we've wanted to really focus on academics as much as we have. We could … and with him going into middle school. I know typically the middle schools kind of step back from academics and want to do more daily living because they feel like if they haven't learned the academics by this point, you know that, that window of opportunity. But we. we really wanted to continue to push the academics because we felt like Randy's, … um ... you know, with being a late bloomer, just that it would click, and some things did. But I will also say this, some things never did and … and haven't. And that's just … I mean his reading … is not what I think we probably would have envisioned looking back with him now. You know ... he can memorize … he's got words memorized. He's got the high-frequency words. He's still got the chart up in his bedroom that we, you know … and he, he can read those words, but phonetically it never fully clicked the way that I thought with time and work that it would. I think it's just so much for his brain. He knows the letter sounds, and he knows the letters, but to put the sounds together to form, to phonetically sound out a word is there … it's like too many steps for him. His brain can't.

Randy transitioned to high school during COVID, so it was not a usual transition. He was unable to tour the high school. Fortunately, he was going to his home high school with his brother and sisters, so he was familiar with the school. Because Randy was in the self-contained MOID class, his placement and services remained the same from year to year, so the IEP meeting was not unexpected or eventful. Victoria reported that communication in middle and high school was limited from the school. She tried to give the school the benefit of the doubt by saying that they want the kids to be more independent, but then she said not all the students in self-contained classes were verbal:

> And I will say Randy communicates. Well, I'm not going to say you can always understand him, but he tells a lot. So, I did … my husband and I both felt comfortable that he would come home, and we would ask him, how was your day? And he might at first say, oh, it was good, and not elaborate. But then, the more questions we ask, the more information we would get. Now, I have some friends whose children are nonverbal, and that to me would be much harder because I was relying on Randy to give me information and still do to this day. You know, he'll come home and tell me who was there at school, who, what, and who did this. And then, when I start asking questions more about academics, he can't always answer. I'll say, well, what do you learn in this today? But there are other parents I've understood that are more concerned because maybe their child doesn't vocalize to them, and they really feel more in the dark. I just think that there are ... some teachers who communicate a lot to parents … and others may not feel that need because they want the students to be ... more ... independent. And ... um ... I don't know or if it or it's just not their style to … I mean, Randy's had both ... He's had a teacher in high school who has been a really good teacher

> for him. But I will be honest: we don't get a lot of information, but we get a lot from Randy.

As a mother of four, Victoria understood the middle and high school push for more independence but seemed to subtly question if it made sense for children with intellectual disabilities. Victoria reported that the high school tended to want to focus on more life skills than academic goals, but she kept pushing for Randy to be able to read:

> And I pushed. I was like, you know, I want him to … if he's not going to be able to sound things out phonetically, I want him memorizing these words so that he can be out in the community and at least can read ... And his teacher was okay with that. It was not what he really would have recommended for one of his academic goals. But he was good about saying, okay, well, we’ll leave that in as [one of his goals]. And then this past year, his 11th-grade year, you know, we sat there, and we talked [IEP team]. And I think I'm beginning to realize more and more that, you know, he's hit his ceiling. There's, he's really, I mean, I can work with him at home, and I can have, you know, apps on his iPad for him to learn and but, but he's not going to be able to [sound out words]. Part of it is by the time they get to be, you know, 17, I mean, he was 17. I thought-we'd been working on this since he was three. And that was something I had to come to grips with within myself. I mean, you have certain expectations, and it's always a struggle to know what will eventually develop and what's ... What do you have to accept what this is, what it is. And ... umm ... I think this year was one of those years for me, realizing that, you know, the academics aren't going to be ... aren't going to improve, but maybe now as he's getting ready to be 18 ... an adult, we do need to

focus more on how he can go out into the community. How can he work a job? How can he, you know, would I like for him ever to be able to do a college program? Absolutely. But that's you know, I don't know that that'll be in his future. Would he be able to take a class or two at a college and learn a skill? Maybe so. I mean, I know he's got … um ... some definite strengths. It would just have to be finding him a skill and a job that would fit his interest and capabilities. The school understood why I kept pushing for it and accommodated me until I was ready. Across the country, there's so many different ways that school systems handle the different, you know, special populations. And I've known that because we've had friends that have lived here and then moved elsewhere. And their son is the same age as Randy. And then his experiences in other states are different because they ... well … like … He moved to Connecticut, and according to them, more of the classes are co-taught in Connecticut. You know, they try not to have program classes. They want to mix as much as possible. And so, then he was always in a co-taught class. But that's just what the school system or the state of Connecticut did then. … um ... I think the other thing about looking at it is that I think parents feel like through all the years and through the history of Down's syndrome and in special populations is that there's always been a separation. And how do we get to where there's no longer a separation? … parents push to be co-taught is because they want that interaction, and they want that inclusion. Okay. So, we wanted that for Randy, but we felt like that's something we can do on our own. I mean, he goes to our church youth group. He did vacation Bible school throughout elementary. He did baseball with typical kids. He and his brother were in baseball, you know, doing little league up until Randy was … maybe six or seven. So, he was getting that interaction with typical kids in the community and learning how to integrate into those activities. That's kind of what we felt now ... I don't think that he would have learned as much as he has if there hadn't been a separation. But I'm also coming from school systems that have always had that option of program classes. If I had lived in Connecticut all my life and he had started with co-taught, and that's what he went through the whole time, then I guess I wouldn't know any different, you know, that would be what we'd be offered. There's always that question: am I doing the right thing? When I put him in the adaptive leagues, it's not inclusion. It's like a program class. They're playing with other kids with special needs … and the same with the school. So, there's always a what if, you know, you never … I mean, that's this journey. You never know; am I doing what is right for them? And that's where I come back to say, you know, you have to know your child, you have to know your child's limitations, you have to realize, and you can find what you feel you want your child to do … what you want the focus in their education to be. But like myself, everybody's going to get to a point where you realize, okay, I've done what I can do and may or maybe I didn't do enough of this, so I need to ... it is a journey of acceptance. And it was really just this year or just that … yeah, just this year that I probably let that go a little bit more and more so than … because we had his IEP meeting in November, and I remember I had pushed still to work on the high-frequency word. You know, there's like three there's about four lists. … I pushed all the way through high school.

As Victoria reflected on her child’s journey, she realized that she was fortunate to have had a relationship with the elementary school principal. She had positive relationships with the staff at the middle school. While she has had a good rapport with the high school, the relationship had been more hands-off. With Randy turning 18, Victoria stated that she feels like she is starting over, like when he was a baby because there was so much new information to learn. During the most recent IEP meeting, the school discussed whether she and her husband had determined if they would be obtaining legal guardianship of Randy now that he was 18. In the interview, Victoria shared that some people questioned why she would want to take her son’s legal rights. She said she thought to herself that she and her husband would be obtaining legal guardianship to protect Randy given he had a 62 IQ and was unable to communicate clearly. While she thought obtaining guardianship was the responsible choice, Victoria wondered if she was missing something and discussed seeking the school’s input about legal guardianship:

> I mean, I feel like as a parent, I am wanting, I ... see the teachers as experts. I see them with the knowledge, and I am wanting that information. But there's a hesitation because of legalities. And they don't want to put themselves in a position that will come back to. … And, you know, and unfortunately, a handful of people have done that. And then it's affected the rest of the pop … of us, you know. I asked his teacher that. But he won't say.

Victoria described being overwhelmed with the new paperwork and information she must learn as her son turned 18. She and her husband decided to pursue legal guardianship of Randy. As a result, the advocacy of the special education experience was not truly stopping for Victoria and her family; it was shifting into the adult phase with new information, agencies, and staff. Victoria said navigating this latest phase had become a full-time job, so she continued to delay her return to her career as she prioritized Randy. As she began this new journey with Randy into adulthood, she wished the school was not afraid to give her more guidance.

Family 6's Experience: Leah and Her Son, Andre

Leah and Curtis were white, middle-class, college-educated parents in their early 40s living in a suburb of a metropolitan city in a southern state. Their local school was part of a large metropolitan school district. They had been married for over fifteen years, and both were working professionals until recently when the children's needs led to Leah staying home. Curtis is an information technology professional, and Leah had worked in the business field. About eight years ago, they adopted Andre and his two siblings from the foster care system. When Leah and Curtis adopted the three children, Andre was six and in first grade. His older sister, Nadia, was ten and in fifth grade, while his little brother, Isaac, was four and starting preschool. Leah described the children's birth mother as being in and out of prison so frequently that the birth mother eventually ran out of relatives to care for the children, leading to the termination of her parental rights when she returned to prison again. Since the children were older when child protective services removed them from the home, they had memories of their mother, some of which were positive.

For this reason, Leah and Curtis continued to allow the children to see her once a year, which Leah said has caused behavioral issues with Andre at times. However, Leah saw it as necessary to mediate his attachment issues. In addition to the history of caregiver instability, there was also a history of physical abuse and drug abuse in the home. Leah reported that the history of trauma and the instability of the parent-child dynamic led to attachment issues with Andre. Attachment issues often result in difficulty with emotional regulation and the ability to empathize with others, and Andre struggled with emotional regulation and empathy (Seim et al., 2020).

Consequently, the family had participated in therapy for the past eight years, with multiple different agencies involved at various times with the family and children. When the couple adopted the three children, they unknowingly began a long-term balancing act of managing the children’s emotional and educational needs. As the journey started, Leah described first grade for Andre as follows:

> Okay, so he came to us while he was going into the first grade … ummm … we had already known that he had some (pause) ... some … tendencies … to sort of have some issues specifically on buses and getting just in trouble from like moving around, doing too much in school ... so no one really was paying attention to his educational issues at that point in time [voice lilts up] because ... I mean, foster care just sort of is what it is … everyone was attributing that [behavior] to A. trauma and B. ADHD. So, those were the two things. And they had him on some depression medication, as well, at that point … Yeah, all my kids came with medication … umm … They did not all stay on medication ... because they did not all need it [chuckle]. Let’s be real … we had three days to get him completely up and running and then to turn him over to someone else … school [laughing nervously]. It was a huge transition.

Leah and Curtis were not just managing Andre’s education. They also had adopted two other children with emotional and educational needs:

> Nadia was going into fifth grade, which was … that was hard. She had been in ten different schools at that point (sigh), and so we actually had, and I'll explain that too, because we started in the system … in the special education system with her before we started with Andre, and partly because we didn't have enough information about Andre … to basically figure out what we needed to do.

Leah described how Nadia's fifth-grade teacher immediately helped the family get a 504 plan. A "504 plan" is short for a legal plan based on Section 504 of The Rehabilitation Act of 1973. A 504 plan provides support and accommodations to students with disabilities impacting a major life function. However, a 504 differs from an IEP because it does not provide specially designed instruction and progress monitoring of goals (Schultz, 2022). The fifth-grade teacher worked with Nadia to catch her up but encouraged the parents to retain her. Leah described how Nadia had been parentified in her role with her brothers before coming to Leah and Curtis's home. During the first year of placement, Leah had to encourage Nadia to be the child and not be responsible for her brothers. Leah shared that when drug use is present, the oldest child is often parentified as a caregiver and struggles to return to a child's role. Leah reported that Nadia's parental role with her brothers affected their educational decisions for Nadia. Nadia was significantly behind when she came to Leah and Curtis. The school recommended fifth-grade retention to give Nadia time to catch up with her peers. When Leah reflected on that decision to retain Nadia in fifth grade, she stated the following:

> She [Nadia] needed it ... She almost needed to be a kid for that year. Like, that sounds crazy, but she needed that … the way that we talked to her about it was that this is not about you being a bad student. This is not about you doing

> anything wrong. This is about you not having the opportunities that you should have had prior to this year. So, we’re holding you back, and we want you to know we don’t think you’re dumb. We don’t think any of this and if anyone says otherwise. Too bad. Whatever. But it was also part of our reasoning for moving to a different city.

The family stayed at the same school for Nadia's second fifth-grade year with a teacher who worked intensely with Nadia to close the academic gaps. Leah stated that Nadia credited that fifth-grade teacher for getting her back to grade level and avoiding the need for special education. After that second fifth-grade year for Nadia, the family moved so that Nadia would not be embarrassed to be in sixth grade when she went to school with the now seventh graders. Moving to protect Nadia showed sacrifice and thoughtful consideration of meeting her emotional and academic needs. While this was not part of their “special education experience,” Leah and Curtis made these choices to remediate Nadia’s learning needs and provide her with a fresh start for middle school.

While Leah managed Nadia’s educational needs, she also monitored Andre’s education. When Leah first started navigating school for Andre, she did not realize how far behind Andre was. Leah reported that when she asked the second-grade teacher if she was concerned about Andre academically, the veteran teacher would respond as follows:

> No, no, it’s fine. He is going to hit his stride. Just wait it out. Just wait it out. And that’s what we kept getting told … umm … through second grade. We went then to third grade at the new elementary school, and it was a similar situation that was sort of, you know, it was … it was a teacher that had been there for a few years, and she was just like, Oh, no, no, he’ll find his stride, he’s fine.

Leah was similar to other parents in this study in reporting that a well-intentioned teacher told them their child would “outgrow it and to wait it out,” only to feel later as though the well-intentioned teacher delayed their child getting help. In third grade, Leah was concerned because Andre was throwing himself on the floor at school and having tantrums. She stated, “Every single day, a behavior checklist was sent home, and we would have to talk to him and the therapist … it was extremely exhausting.” She was also getting negative behavior feedback from the aftercare program each afternoon. The school met to make a behavioral plan to address the escalating behaviors, but Leah stated that the school did not formalize the plan in a 504 or IEP. As a result, Leah reported that the third-grade teacher would not stick to the behavior plan and then would call the parent to complain about Andre’s behavior. Instead of a 504 or IEP, the counselor would go to the class often to help Andre calm down, which Leah saw as a temporary fix. As the year progressed, the third-grade teacher continued to call home. During these calls, Andre would be acting out or under the table screaming while the class was evacuated, but still, the school did not develop a 504 or take action toward an IEP. Leah’s sister, a teacher, pushed her to demand a 504 or special education behavioral intervention plan as Leah was getting called by the school every day. When I asked what the school did to address the behaviors, she stated the following:

> The school did help by sending in the school counselor. I 100% trusted her, but they were pacifying the situation. I knew it was not a solution. But at that point in time, I was willing to take anything because nothing was being given, if that makes sense. Like I was fighting so hard and getting nothing in return. I think they all just thought he would grow out of it. And I’m like, It’s not. And I think

> part of it is that they kept trying to tell me he's too smart for one [an IEP], like, he's too smart for these services. And I'm like, once I figured out, it's not about his smarts but behavior. And I mean, part of that was having my sister as a teacher, and part of it was I joined a Facebook group of ADHD and ODD people, and they were talking a lot about don't let the schools tell you it's about grades … because behavior is a big factor in them being able to accept the learning that they're getting. And I'm like, it was a combination of just trying to … see what I needed to see because I don't know what I need to know. It was third grade with that teacher because I got pissed enough. That sounds terrible, but I got so mad that I went through so much research. I went through so much research … I realized that if I didn't tell them what he needed, they weren't going to give it to him, see it, or offer it.

Leah reported that it was not until the fourth-grade teacher said, "I see you. I see this, and I want to put this in place," that Leah felt like the school helped her. Leah reported that the fourth-grade teacher was pivotal in accessing the special education process because that teacher initiated collecting the data and pushed the testing process forward, which is the year he qualified for special education.

Fifth grade went smoothly as school staff successfully managed his at-school behavior, but the family stayed in in-home counseling to address Andre's behavioral issues in the home. Leah stated that the transition went well because the fifth-grade IEP team put the goals and services he needed in place, so he went to middle school with the services required. While the start of sixth grade also went smoothly in school, the family still faced challenges in the home. Andre's primary challenges occurred when the parents set boundaries by saying no to what he wanted to do, especially regarding the use of technology. Technology was also a challenge at school because Andre could not shift tasks in the classroom away from the computer. Andre's behavior continued to escalate throughout the fall of sixth grade. As a result, over the holiday break in sixth grade, his behavior was aggressive to the point that he was hospitalized for two weeks. Leah reported the following:

> They didn't want to release him back to me. That's why he was there for two weeks. He was actually … and the hospital … you're typically not there for two weeks. I mean, they had to give him the calmshot in the butt, is what they call it. And they had to do a couple of different things. I mean, they called me one night, and you could hear him screaming bloody murder in the background. Like they were seeing these behaviors, and they were changing his medication up, which did help. Let's … let's be real. There was some help there. But they … they basically, they were like; this is just … this needs to be addressed. He needs to go into residential. But the insurance company refused, and, basically, we were told we could pay $30,000 monthly if we'd like.

When Andre returned home from the hospital, wraparound foster care services provided an in-home therapist for Andre. Andre's behaviors were impacting the family at home more severely than at school, creating a larger context for his behavioral needs than simply the parent-school partnership. The family was involved with an in-school therapist, the school social worker, the wraparound services therapist who works with foster children, and multiple therapists working with the family. In addition, they had therapists at the hospital and at the residential facility where Andre was later hospitalized in eighth grade. The school staff was just one group of professionals that the family interacted with regularly. Leah was addressing both Andre's educational and mental health needs and felt like she had to fight the experts in both fields:

> It's a constant battle. And we're not just battling getting him what he needs at school; we're battling the issues at home or battling the therapist to get to what he needs at therapy; we're battling the psychologists, we're battling … I mean, I had … we had a doctor who tried to tell me that he doesn't have any ADHD and doesn't need medication for it. And we're like, oh, he's coming to your house to live for a week. Like, don't tell me he doesn't have it. Let's … let's … let's be 100% right. And I'm like, if you want to tell me that he has trauma brain instead, I'm … I'm there for you, that's fine. Let's have that conversation. But you cannot tell me that there's not something wrong that doesn't need to be fixed. Like, he was trying not to … I think it was during COVID, it was an issue with his medication, and we couldn't get into the therapy or the psychologist. We couldn't get in, you know, to … to anything, and he would have to approve the medication. And the general doctor was just like, I don't know if this is right. I'm like, you are not going to do this to me during COVID, with everything else going on. You're not doing this to me.

By seventh grade, Leah was overwhelmed and frustrated. She stated the following:

> I could not [keep up.] Like I was drowning on top of it, but then I was still getting these emails every day from Andre, Andre's teachers. And the problem is, I think they got to the point where none of them were talking to each other. So, no one had any idea I was getting bombarded with all these emails because everyone was

emailing me. And it wasn't every day. One-it might be once a week for each teacher, but I have 11 teachers. So, I was getting at least an [email a day]. So, we had a meeting with the school and made a plan. [They] weren't supposed to be calling me nearly as often. They had a plan ... an actual, like, three-tier plan. If something happens in the classroom, step one is to address it directly with Andre. If that doesn't work, you know … Or try to remove him with a team teacher, or whatever the case may be, one of the teachers. Try to remove him from the situation and just give him a calm-down period. They have the calm-down rooms; they have all that stuff. If that doesn't work, they call the special education lead, and she would have that; well, come and either take him out of the room or have a conversation with him, whatever needs to happen. And then, only then, if he can't go back to the classroom because he can't get … because he can't get unstuck, it's the only time that you call the parent, is if it's [the reset]. And things got a lot better for a few months, [to be] totally honest. … I wasn't getting the daily emails. I was getting, still emails, but not daily. And then, towards the end of the year, that started switching again. And this one teacher started calling me on a regular basis. … uhmm … and she literally would call me frantically, telling me I don't know what else to do. I don't need … I need help, blah, blah, blah, blah. He's in the middle of a rampage. And so, my question was, did you call the lead? Well, no. And I said it's in his IEP. Do that. I said, "What do you want me to do? Come to the school and, like, help you? Like, what do you want?" And she's like, "I don't know." Like, ... And I hear him screaming in the background. And I'm trying to do my job … I don't disagree he's screaming in the background, but

> what do you want me to do? I am five miles away. Like, not really. Two miles away. It's still 5 minutes. Like, he could literally punch you by then, like. There's a plan in place. So, I got to the point where I was just frustrated, and I was just … I … I got so pissed off. And one day, she called, and I found out, after when Andre came home, I was talking to him, and he's like, "Yeah, she was telling everybody to … to push the button [office button] to call the … police on me, and … And she was … she was making … she basically made fun of me in the middle of the classroom." And so, I, like, lit up. Because I had already heard how she talked to me, I'm like, I don't deny any of that. I don't … I 100% believe what Andre is telling me right now because this is not okay. All the kids are making fun of him and saying, "Can we press the button for you, Ms. So and so, can we do it? Can we do it? We want to see Andre in trouble." Like, literally, like, egging it on. Like, and she made everything worse so. That … once I heard that, I shot off an email, because I was done. I'm like, I have had it. I'm like, and I don't care if my email looks like I'm a completely crazy bitch at this point, let's be honest. But I shot off an email. I copied the special ed lead, I copied the principal, I copied the vice principal, I copied everyone that I could possibly copy, and I said I'm done. I'm like, I want him out of the classroom. I want him out of that classroom now, and I will not take any other answer. And so, I got a pretty quick response.

Given the situation, the school removed Andre from that class for the last few weeks of seventh grade. By eighth grade, his behaviors had escalated even further. Andre began eighth grade at a residential mental health treatment facility, given the risks to his parents and his safety. Leah shared the following:

> He was there for three months because he kept getting into fights. He kept showing the same aggression that he showed at home, which is good, bad, indifferent. I am glad that they were able to see it so they can help him address it ... if that makes sense.

After he returned from the facility, Leah and the facility's therapist met with the school to create a plan for his safe return. One of the stipulations was that he would not use the computer to prevent behavioral escalations. Since fourth grade, one of the areas of concern was that when Andre got on the computer, he could not shift to get off the computer, which would cause problems. The fourth and fifth-grade teachers simply kept him off the computer. Every year in middle school, Leah had asked for no computer use to avoid behavioral outbursts, but every year, the teachers wanted to try it. As a result, Andre would have behavioral outbursts every year when the teacher took the computer away, especially if the teacher physically grabbed it from him. Leah shared the following:

> In seventh grade, Andre was sent home four different times from school because of behavior in the classroom … most of the time it was they would ask to take his computer, and he would refuse. They would then yank it from him. That's never a good solution.

To avoid such an escalation, the school staff, a staff member from the residential mental health facility, and Leah made a plan to prevent computer use when Andre returned to eighth grade at the school. Leah reported that all the teachers cooperated except for one, as she said, “It seems like there’s always one” that did not read the IEP. Leah was so frustrated at that point that she stated she did the following:

> I created a PowerPoint to show them all of the failures that they had made already, which was, like, literally, like, just not letting me know of things and then sending me an email saying that he’s not going to receive a grade because he didn’t turn enough work in. He’s not going to get this, and he’s not going to get that, and blah blah blah blah. And I’m like, all of these things are your fault because you didn’t follow the plan. The frustration came in because, I would say stuff, and of course, people [professionals] always are like, well, I know better, and it’s fine. But do they … do they really know better? Right? Like, while I appreciate some things, I have to remember that I’m the one with him every day. I see all of the extreme highs and extreme lows, and I need to protect him from the extreme highs because the extreme highs are going to be really bad. And if they get that, he will not have anywhere to go to school. He will literally ... I will be home-schooling. I will be finding something else. And that is going to be even worse for him.

As Leah shared her experiences of Andre’s special education, she often returned to Nadia’s story. Frequently, Leah would wonder aloud if she was a total failure. It was as though she shared Nadia’s successes because she was successful in helping Nadia but desperately still trying to help Andre. Nadia was now an honor student, a high school senior, and close to Leah.

After listening to her story, I asked her to describe the collaboration with teachers as the story had many twists. She said it depended on the year. She felt like fourth and fifth grade were more about working together to solve problems and share ideas. Since middle school, Leah shared that she felt like this:

> I say and do the same things over and over again every year. And I already know that's going to happen for high school because when we called and had our IEP meeting for high school, it was very just. Oh, yeah. Okay. Yeah, yeah. Okay. Okay. Yeah. We'll just keep it this way. And I'm like, Great for this. Gonna be fun.

Leah reported that she does not feel listened to but has to balance advocating for her son with angering the school. She stated that she feared that if the school was angry with her, her son would be more severely penalized for his behavior. To build positive relationships, she shared that she volunteered with the orchestra:

> I want them to know my name. I want them to know my phone number, and I want them to be comfortable to come and talk to me. And if I can do that in advance, if I can get them prepared in advance, usually they're a lot kinder, are a lot more, I don't want to say lenient, but a lot more understanding of the situation.

By the end of middle school, Leah felt like she had support from people at the middle school who understood the extent of the behaviors they experienced at home and why she advocated so much for their consistency at school. She predicted that the first year of high school would be like starting over and getting everybody on board, so she had to be patient and lenient. Sometimes, Leah shared, the new staff want to minimize the issues, to which Leah intended to respond as follows:

> I need them to understand that these issues have been long coming. These are longstanding issues. We are still working on them. We have been working at them

> for years. They don’t have kids like this at home. Most of them do not have kids that they have to deal with like this at home. They don’t understand it from both sides.

When Leah considered being more confrontative with staff, she weighed the pros and cons and shared the following:

> When I do cause a big stink, it’s because it’s like I’ve given up at that point. Like it has been just time after time after time after time with a specific teacher or a specific issue. And that’s usually when I finally have … I use my voice now to say, I need a meeting.

The day before our second interview for this study, Andre had purposely broken Leah’s antique vase to hurt her. They had spent the day on the phone with several therapists to get him to repair the relationship. When I asked her about her thoughts about high school this fall, she replied as follows:

> Oh, I think it’s going to be a total mess. I’m, I suppose, terrible to say, but I foresee a lot of roadblocks, and I foresee. I worry that, in some respects, he’ll just start doing school refusals and just not go … umm … But at the same point, he loves school for other people. So, my other fears. Okay, yes, I still go to school, but I will get kicked out. He’ll eventually get kicked out somehow or get sent somewhere else. So, I try to find the ones [teachers] I can work with to sort of advocate for him versus against … I’m afraid he’s going to lose all his services. To be totally honest. And he’s going to miserably fail because one of the services he absolutely has to have is that whole time to get work done because sometimes that truly is he needs extra time. He’s not … He’s not ... to write papers. He’s not

> going to do that stuff. It takes him a while to process, and he will erase it. He would literally erase an entire paper and start over again. He still does that crap. Because, like, it's just once he's made a mistake, and he's frustrated. It's just that it's all gone. He can't shift. I'm always looking for the other shoe to drop and looking for him to get in trouble where he will get kicked out or whatever. Granted, the IEP safeguards me from that, and to be honest, that's my power. Like, I can keep him from being kicked out of school. Not entirely. But he's given more chances.

As Leah headed into high school with Andre, she doubted herself as a parent and how she was navigating the process:

> It's maybe me. I'm a terrible mom, according to him. And I mean, his therapist and everyone has basically said, "Look, you need to stop doing things for him." ... Well, I know he needs to fail. The problem is that Andre won't see or understand that he failed. It'll just be my fault he failed because I didn't help him with these things.

With an emotional and behavioral disorder as complex as attachment issues and trauma, there is no easy answer. Based on my thirteen years of clinical experience as a social worker with child protective services before I became an educator, children with a history of trauma and attachment disruption, like Andre, have significant and complex challenges. Most educators do not have the training to understand the complex issues occurring and why consistency is so important, making Andre's behavioral intervention plan essential to follow. Consequently, Leah pensively feared the start of another school year and the consequences for her son and wondered who their advocate would be this year.

When I thought about the research questions, I discovered that Leah's story had so many nuances. She already was anticipating high school would be a "total mess." Her previous experiences with the school included being ignored, being minimized, fearing for her son's safety, and ultimately fearing that he would be kicked out of school or institutionalized. At the same time, she profoundly questioned herself and her parenting, wondering, even at times, if the children would have been better off with their birth mother. While she said that aloud to me, she then stated she knew that was not true, but she talked about how hard Andre's lack of compassion or empathy was, even though it is not uncommon in children with attachment issues. She passionately wanted him to be successful, but he seemed to lack empathy for her and had repeatedly been violent towards her, breaking her teeth, biting her, and hitting her. Leah even reported that her sister worried that Andre may kill her or her husband one day. When Leah enters the parent-school partnership each year, she brings all of these complex emotions and experiences to the dynamic. As Andre started high school this fall, his ninth-grade teaching team most likely had no idea of the magnitude of the situation, emphasizing the importance of beginning the school year with the parent as the expert and establishing communication early in the school year. The complexities of Leah and Andre's situation surpassed the scope of most classroom teachers' training, making the daily management of Andre's behaviors and academics challenging for his special education teachers and his parents, thereby requiring strong parent-school collaboration that may also need to include his mental health professionals.

Summary

Each family described how they advocated and agonized over what was best for their children socially, physically, emotionally, and academically in multiple settings. They had researched and gathered as much information as possible through each phase of their children's lives. They had continuously worked with their children at home to help them, and some had postponed their careers to manage the needs of their children. All of them had purposefully worked to have positive relationships with school staff. At the same time, each carried past experiences into their relationships with the school, usually leading to anxiety and apprehension about how school staff's choices would impact their children each year. As a special education teacher meeting my students' parents for the first time, I now wondered if my new students' parents shared a journey of similar depth and length as the parents who shared their stories with me for this research. As I wrote each of their stories, their love, dedication, and determination to help their child to the best of their ability was profound and humbling to be able to share.

Chapter V

DATA ANALYSIS AND RESULTS

The purpose of this qualitative study was to give voice to parents' experiences of the special education parent-school partnership across multiple school years to uncover parents' untapped knowledge and insight. This information may help educators better understand and empathize with how parents experience special education parent-school partnerships (Hampden-Thompson & Galindo, 2017; Heller et al., 2019; Lo, 2008; Weiss et al., 2014). When parents perceived that educators treated them with empathy and as authentic equals in the parent-school partnership, they often shifted from a "soldier preparing for battle" mentality to an empowered participant (Lalvani, 2012; MacLeod et al., 2017; Mazher, 2012; Rosetti et al., 2021; Santamaria Graff et al., 2021). By gaining this more profound understanding of parents' experiences, school staff may better understand how to successfully negotiate the special education process, which benefits student achievement (Burke et al., 2019; Osborne & Russo, 2010). The population included in this study was parents whose children had received special education in a public-school setting for more than two school years. The participants who volunteered had children who had participated an average of 8.4 years in special education, specifically ranging from three to 15 years in special education.

I analyzed the data according to the methodology stated in Chapter III. I listened to each interview twice to ensure accuracy in the transcription and included non-verbal occurrences during the second round of listening to the transcription. In the first cycle of coding, I used holistic coding. I holistically coded stories within the narrative and evaluated each story's structure using Clandinin and Connelly's (2000) three-dimensional space narrative structure to frame stories. In labeling the stories as past or present, it was striking how some past stories still held great significance for the families, especially professionals who would not help them or who significantly helped them. What stood out was the positive or negative difference one educator could make as their stories recurred throughout the interviews. I also applied narrative coding with Labov and Waletsky's (1997) model of narrative structure to consider the meanings more deeply within the narrative. Using this coding, I gained insight into why stories may have been shared at specific times during the three interviews and the story's deeper meanings. In an additional cycle of coding, I used emotions and values coding. I then adjusted my focus to look for connections in the data, an analysis method Maxwell (2013) defined as connection strategies. The following themes emerged by analyzing the data through coding and connecting:

- The Difference One Professional Can Make
- Can We Be Equals Because We Are Not Really Equal?
    - Inequality in Knowledge
    - Parents Helping Parents
    - Inequality in Access
- Balancing and Navigating the Professionals
- Depth of a Parent's Unwavering Love
    - Could I Do More? Blame to Acceptance
    - A Precious Gift Worth the Sacrifice

The Difference One Professional Can Make

Listening to the parents share their stories, I noticed that just one or two professionals’ names often recurred in all three interviews. In some stories, the professional had a positive impact; in others, the professional caused significant angst. For each family, it was often just one educator who changed the narrative of the family’s special education experience. When the professionals showed compassion and empathy towards the families, the families reported that they felt like someone was in their corner.

When the professionals' actions were perceived negatively, the families’ stories were markedly resentful and frustrated. For example, Iris and Mark, whose daughters, Laura and Lisa, had dyslexia, still cannot understand why one person stood so vehemently in the way of their daughter, Laura, getting help. To them, this one person was the source of so much angst and anxiety. Iris recalled the following:

> *That woman* [emphasis added] that was in there she was trying not to move forward with special ed services. I don't know why she's trying to deny services, but that was the impression that I got. And I was like; do you even know my daughter? Have you met her? She is so clearly dyslexic. Flip over that piece of paper. What's my daughter's name? Huh. She didn't know. She ... she had never met my daughter before.

When Iris and Mark shared this story, they could not understand why they had to push for testing instead of the education professionals recognizing their daughter’s disability. To them, the educators should have been the advocates, but rather, the educator was the one they were battling.

Once they successfully navigated into special education, the one professional who made a massive difference for them was the assistive technology (AT) specialist. Iris described the AT specialist as a "magical person, who makes everybody's life amazing … we had … this amazing contact that I had the email of. … (sigh) … And I could reach out or call her anytime something happened or when I needed help." With the AT specialist, Iris and Mark felt like they had someone in their corner. During the interviews, we discussed each school year, including middle school, where Laura had twelve teachers each year. Despite Laura's many teachers over the past six years, the stories Iris and Mark shared were dominated by the positive and negative of these two women.

Kathy, whose son, John, had a learning disability, possessed the knowledge to be her own advocate and fight her own battles. As I reread Kathy's story, I noted that after she struggled as a child and then watched her mother struggle with her sisters' special education experience, Kathy chose to become her own significant educator for her son's special education experience. Kathy stated the following regarding her own and her mother's experiences with special education:

> But I really went into education, special education in particular, because I knew how much I had struggled … I told my mom when she came home, and she was in tears, [talking about sisters' education] I said, you need to fight … The hardest part, I think, for me to watch was her [mother's] heartbreak because I don't understand why it has to be school against the parent and vice versa. Like, if this child has this document, it is supposed to be a committee. Why does a parent have to fight for everything?

Kathy’s story was different because she saw that her mother did not have an educator to help her, so she made special education her career. She chose to make a difference for other parents and for her son. Her past experiences in special education led to her career choices as an adult and impacted her role as a parent of a child receiving special education services. Additionally, her experiences impacted how she interacted with her students’ parents to ensure they understood the process. A focus of her career became making a difference for other parents because she knew what it was like for her mother not to have an educator as an advocate.

For Sheila and Don, Evan's parents, two significant educators stood out: the elementary school principal and Evan’s middle school special education case manager. Sheila recalled their first special education meeting in second grade after the confrontation about her son’s information being on the shared school calendar, violating their confidentiality. Don stated about the special education lead, “This lady was snarky. It felt like ‘I'm going to show these two hayseeds that I know what I'm doing and you're going to listen to me’ because …” Sheila added that it was not until the principal walked in that “the temperature in the room went from ice cold to WOOOH.” In each interview, Sheila and Don returned to stories about this principal and how she knew everyone’s names and went out of her way to acknowledge parents. For Sheila and Don, this principal was the only person they consistently described as advocating for their son in elementary school. The principal built a foundation of trust by being present and acknowledging the parents' anxieties and concerns. Consequently, Sheila and Don knew they had an ally, so second to fifth grade went smoothly.

In middle school, Sheila and Don credited their relationship with Dr. Smith, the special education case manager, for making the special education experience much less stressful for them and their son, Evan. Sheila recalled that whenever there was a problem or “something happened, I would email her, and she'd say, ‘Oh, we're not doing that. I will fix that.’” Sheila said Dr. Smith would take care of it before her son got to school the next day. Given her son’s anxiety and tendency to perseverate, this proactive approach provided much relief to the family. Sheila and Don credited Dr. Smith with Evan’s success in middle school: “She was absolutely amazing. She is the reason why he was successful in middle school.” When Sheila and Don talked about Dr. Smith, tears welled up in Sheila’s eyes when she said, “I knew that someone loved him and was looking out for him.” For Sheila and Don, the stories of Evan’s struggles from his premature birth were still very present, so knowing he had protective people at school appeared to provide great comfort and reassurance.

Ann, whose son Kevin had autism, had several professionals help her along the way. First, the preschool director at the university preschool shared her knowledge and expertise in advocating for Kevin to enroll in the autism preschool program. Ann shared that before Kevin started in that preschool, she knew very little about autism. Ann stated that through the preschool program, “We were exposed to so many wonderful parts of the university.” She then also met an attorney “who has a pretty severe autistic son.” Ann learned from this attorney, who started offering training to other parents of children with autism. When she described him, she said:

> I don't know what I would do without his information and ongoing support because he has a Facebook group. And now he has his paralegal run it. But back

> then, he was actually answering the questions on the Facebook group. And if he knew you, he'd direct message you.

In middle school, Ann became friends with one of Kevin's teachers and now works at a day treatment center for adults with autism with her. Kevin's teacher opened herself up to a personal relationship with Ann, allowing Ann to have a trusted ally and a place to further advocate for the autism community. She created her own network of people to help her navigate by becoming involved in autism advocacy groups, building friendships, and immersing herself in what she calls "the autism world."

Victoria, whose son, Randy, had Down's Syndrome, was fortunate to have worked in her son's elementary school and had personal relationships with his teachers. When Victoria and her husband had to decide if their son should be bussed to a servicing school almost 20 miles away to be in a MOID class, the elementary school principal was able to get a MOID class housed at their home school so that her son did not have to travel so far. Even though Victoria continued to work for this principal for ten more years, she never asked her how she did it. However, she remained extremely grateful as it allowed Victoria to work in Randy's school until he went to sixth grade. The principal helped Victoria avoid a tough decision and allowed Victoria to stay actively involved with Randy's education, which made an enormous difference for Victoria.

For Leah, whose son, Andre, had emotional and behavioral needs, there was a significant professional for both her daughter, Nadia, and for Andre. For Nadia, her fifth-grade teacher made a significant difference. Nadia was adjusting to a new home and repeating the fifth grade. Leah described Nadia's fifth-grade teacher as follows:

> [Her teacher] became her … support. So, like, she would actually go and have lunch with her and just sort of hang out with her and try to like, make sure things were going well just so that she had a constant. And that sort of helped her through it. And honestly, she did immense things just because, you know, all the help that she gave us. She hit us at a time when we needed someone to care for us. She was amazing. She is still Nadia's favorite teacher. Because of her help, Nadia caught up and did not need special ed.

Leah gave this teacher credit for Nadia not needing special education and becoming an honors student today.

In Andre's story, the teacher who made a difference for Leah was Andre's fourth-grade teacher. Leah remembered struggling through second and third grades trying to get the proper help and accommodations for Andre. She described the fourth-grade teacher: "She was our saving grace in fourth grade because she came right in and said, 'I see you. I see this, and I want to put this in place.'" She helped Leah through the process and paperwork needed to get Andre into special education and get the support he required. She made Leah feel heard.

While Leah acknowledged the positive impact that these two teachers made in their lives, she lamented that each year, there is "always one" teacher who did not follow the special education plan. In middle school, it was the teacher who would often call her, asking her what to do as her son was screaming in the background. As she anticipated Andre's upcoming freshman year, she hoped one person might build a positive relationship with her son. However, she was more inclined to expect that one teacher would be the source of problems because they did not follow his IEP. Leah's past interactions with school staff suggested a more pessimistic than optimistic outlook. Her past interactions with school staff led to feelings of anxiety, worry, and the expectation of problems as Andre headed into ninth grade.

When each of these parents recounted stories of the professional that made a positive difference, they each shared, "I knew that they cared about [loved] my child." The parents who experienced care and concern from an educator repeatedly returned to stories about those educators during the interviews. The students discussed in this study had dozens of teachers over the years, yet I only heard stories about the teachers or professionals who caused distress or those who cared and went out of their way. The parents never mentioned the dozens of other professionals, even when I specifically asked about each school year during the interview process. In addition, all the parents discussed how even when problems arose, they “gave grace” if they believed the educators had their children’s best interests at heart. In listening to these stories that often spanned over a decade, this theme emerged: One professional or educator can make a lasting difference for a family.

Can We Be Equals Because We Are Not Really Equal?

While IDEA (2004) called for parents to be equal participants of the IEP team, one of the parents said to me, “Can We Be Equals Because We Are Not Really Equal?” What was striking was that she was the parent with the special education background, the one with the most equal educational background, and yet, she sensed that lack of equality between herself and the school system. More than one parent noted that the school was a government system with its laws and rules and that the parents' interests were inherently in legal opposition. As I analyzed the interviews, inequality emerged as a theme on multiple levels.

Inequality in Knowledge

Parents described how hard it was to learn to navigate the special education system. When I asked parents to reflect on what they would want a new teacher to know as parents of special education students, the parents who were not educators described how hard it was to learn about special education. Iris, whose daughter, Laura, had dyslexia, stated, “Parents are scared and don't know what's happening. So, if you could just help them and break the [rules] or bend the rules and tell them things, that would be so beneficial.” For Don, whose son, Evan, was born prematurely and had learning problems, his advice was, “Don’t walk in there thinking you’re the smartest person in the room.” Don stated that without his wife’s knowledge, he felt like his son would have been “put in a box.” Even Don’s wife, Sheila, who had years of teaching experience, thought she lacked the knowledge to navigate special education. She relied on her coworker to guide her and help her to understand the process. Sheila said that it would be helpful to start where the parents are, but instead, the “schools are … we have 45 minutes to get this eligibility meeting. Go, go, go, go, go, go. Whereas, sometimes it might be helpful to the parents, particularly those that are just starting, to spend a little bit more time.” Even after years of meetings, Sheila still never entered a meeting without consulting her special education colleague because she wanted to ensure she had equality.

When Kathy, the special education teacher, reflected on how she navigated John, her son with a learning disability, through special education, she wondered how long he would have lingered in Tier 2 or Tier 3 had she not known to push for testing. She questioned if he would have fallen behind more like Iris and Mark think Laura did due to the delay in identifying her learning disability. Iris and Mark shared that Laura, who had dyslexia, was four years behind academically when she was found eligible for special education. However, Lisa was only two years behind when she was qualified because the school was more proactive in helping her. In their opinion, Laura’s more significant academic deficit led to her anxiety. They suggested that Laura's anxiety disorder stemmed from the distress she had in elementary school, wondering what was wrong with her when she struggled to learn and could not get any help. Laura’s parents associated the educator, who was an obstacle to Laura's accessing services, with Laura’s present anxieties, which may be why the story of “that woman” was often referenced in their interviews. As a result, Iris and Mark, Laura’s parents, now advocate for parents “to do all the research you can before you go in there, just so you can see what's BS and what's not.”

While Ann, whose son Kevin had autism, is an active advocate for autism today, she said it took her almost two years to feel knowledgeable about the special education system and her son’s disability when her son first started in special education. Ann learned that an advocate or an attorney could quickly balance the inequality in knowledge. After years of research and learning the laws of her former state, Ann did not have the time or energy to start over when they moved to their current state, so she hired an advocate. She said, “Equality comes with money, which is unfortunate, but the way it is.” She learned this when Kevin was in preschool. In her former state, there were few advocates or attorneys. The school system took advantage of that. When Ann’s son was going to be placed in a room with 20 other high-need preschoolers, the school system gave her two choices: the offered placement or arbitration. Then, she chose to pay for preschool as she did not know an advocate or attorney. Ten years later, she made sure to have an advocate when she negotiated Kevin's IEP in a new school district. A school system will almost always have more money for a legal battle than a family, making them inherently unequal. An advocate helped Ann to level the playing field.

Parents Helping Parents

Because the knowledge base between a parent and school staff usually began as unequal, parents often turned to other parents as vital sources of information to help balance the scale. As Mark and Iris educated themselves to help their daughter Laura with her dyslexia, they talked to as many people as possible:

> We did a lot of ... a lot of research … and just talking to every parent you can find to find out what they knew. And there's Facebook groups … some of it was Google searching, but a lot of it was that Facebook community and then posting, like; oh yeah, here's the trick you need to know. Oh yeah, here's the piece of paper you need to ask for. Oh yeah, here's this thing or that thing. Or here, go look at this. Here's where it talks about the laws… Networking and the Internet, the power of the Internet.

On the other hand, Victoria, Randy's mother, was plugged into the Down's Syndrome Association from birth with Randy. She said she had to filter some of the support as the association almost assumed an adversarial relationship with the school:

> I do feel that there is a part that is saying, you know, you have to fight for your child. And I've not really always understood why they feel like that they have to do that. I've never felt that way myself being a parent.

Victoria talked about how much she learned from parents with older children with Down’s Syndrome. She and her husband tried to learn from other parents’ journeys as they made decisions for Randy. For Victoria, other parents did not help her balance the scale with the school so much as they helped her to better navigate the lifelong journey of parenting a child with Down’s Syndrome.

Leah, whose son, Andre, had behavioral needs, also talked about researching and educating herself and how difficult it was to learn more:

> I got so mad that I went through so much research. I went through so much research. I went over to like one of my neighbors who had a kid on an IEP for completely different reasons, and I was talking to her. I was like, “Look, this is what's going on. Help me.” And now I help her, like, because I'm like, I've fought and plotted the system so much at this point. Like, it's gotten to the point where I'm like, she'll say something like, Oh, you need to ask for this, this, and this now … Pinterest was, a godsend for me and to be fair, I was on there constantly looking for IEP suggestions because I realized that if I didn't tell them what he needed, they weren’t going to give it to him or see it or offer it.

Leah had multiple helping professionals involved with her family and was still searching to understand how to better navigate the special education system. Unfortunately, Leah shared that she was alone in many ways, as few parents understood her situation, and helping professionals often worked in parallel instead of collaboratively.

Sheila, whose son, Evan, had learning disabilities related to prematurity, said having other parents to consult with offered reassurance that they were making the right decisions for their son:

> But I think having other people that I knew and was comfortable with, that had been through this ... been through the transition ahead of time, and say, well, this is what they want to do. And being just devastated by it, they were like; no, no, it's okay. It's good. It's a good thing what had happened.

Other parents helped Sheila balance her professional educational experience and knowledge with her emotions regarding her personal experience with her son's education.

All six participants said at one point in their interviews that they had to know what to ask for because the school was not going to just offer it, or "volunteer it." This did not mean some participants did not think the teachers had their children's best interests at heart. On the contrary, all six participants stated that almost all the teachers they had dealt with seemed to genuinely have their children's best interests at heart. The parents referenced the larger "system" as the "they" controlling access to services and placement. All six participants viewed individual teachers positively but viewed the district cautiously and apprehensively. They all shared that other parents helped them learn how to navigate the larger system and to know what services and placements to ask for in the IEP meetings.

Inequality in Access

Not all the participants had the same tools to access educational resources, which may have been part of the reason participants often characterized the school system as the "they" who controlled services. The parents who were educators already had some of the keys to access systemic resources more easily. For example, Kathy, John's mother and a special education teacher, did not need the educators to allow her access to special education because she already knew how to unlock the door to gain access to a special education evaluation. Kathy knew her rights and the law and what she could say to the committee:

> They had six weeks of data and they wanted to do another six. And I was like, we're not going to play this game. I said, we can start the evaluation process now … And I think to myself a couple of times, even to this day, if I was just like your traditional parent navigating the system for the first time without an advocate, without fully understanding my rights, would it have played out the same?

Kathy was able to get the evaluation process started for John proactively. As a result, he was qualified for special education services before the school year ended, which was the same year the RTI began. Response to intervention was a required step before considering special education under IDEA (2004). The RTI process could often take an entire school year, and the evaluation and eligibility process could take six months.

Unlike Kathy, the other parents did not know how to be as proactive. Leah, whose son, Andre, had emotional and behavioral needs, recalled being desperate for help, but she did not know how to activate additional help at the school. When the school offered interventions that Leah saw as temporary fixes for Andre's behavioral problems, she said, "I was willing to take anything because nothing was being given, if that makes sense. Like I was, I was fighting so hard and getting nothing in return." It was not until the fourth-grade teacher got involved that Leah could access special education services or evaluations. The teacher granted access, which Leah had asked the school to do for two years. Leah did not know the right words to start the process until the teacher intervened.

Iris and Mark, whose daughter, Laura, had dyslexia, summed it up well when they stated the following:

> But trying to get in [to special education] is so hard, and there's like, it's ... it's ... it's like Fight Club. The first thing about Fight Club is that you don't talk about Fight Club, like … If you're not in the know, it's a closely guarded secret.

Just one committee member seemed to block access to special education testing for Iris and Mark's daughter. To circumnavigate the educator's obstacle, Iris researched until she found the “IDEAs Act.” Iris and Mark had to find a way to unlock their daughter's access to the system. Iris said, “From a parent perspective … it's like there's this wall or gatekeeping, and once you get past it, you're in. And like, once you get in,” Mark finished the sentence, “It becomes easy.” If access had occurred earlier, Iris and Mark wondered if Laura would still have the anxiety and self-doubt that she has today.

Access to services had a different connotation for Sheila, whose son Evan had learning difficulties related to prematurity. She knew how to access special education, but gaining access meant acknowledging that Evan was not catching up as they had hoped. Sheila described her tears and sadness with each step toward special education. As Sheila described, her son’s deficit meant she was failing him as a parent since she was a teacher and should have been able to help him. While she could access more resources, doing so was hard for her. When the time came to access special education services, even Sheila, with her background and training, asked the principal to intervene to support and advocate for her in the IEP and eligibility meeting. The principal eased the path of access as Sheila’s emotions impacted her ability to access services objectively. Given her background, Sheila said she projected her concerns down the road and worried about what Evan’s future would look like academically.

Ann, whose son Kevin had autism, learned about inequality in access when Kevin was very young. When her son was in preschool, he did not have access to therapies and programs, and the school system in her former state said to take them to arbitration if she didn't like it. Ann did not have the resources to fight back then, but she quickly learned. By the time Kevin enrolled in kindergarten, Ann successfully advocated for him to have a categorical aide, which "was the gold standard" in their district then. Like Victoria's story about the woman who fought so hard to get her son a categorial aide, Ann now wondered if this was best for her son. "The gold standard in that school system was a one-on-one aide. That's the most we could hope for." Ann did not realize that he was not doing much work in his elementary school classes. He was with his general education peers but was "not accountable." In retrospect, Ann was unsure if a different placement would have made a difference. Even though Ann had gained access, she now questioned if it was the best choice for Kevin. Unfortunately, the school district at the time had fewer choices than where she lived now. Inequality of access decreased simply by moving to a state and district with more services, modalities, programs, and resources for special education students.

Only Victoria, whose son Randy had Down's Syndrome, had easy access offered to her. Her son's disability was easily diagnosed and well-understood medically. Victoria described how services were offered from the moment he was born, starting with coming to meet with her in her hospital room. For Victoria, unequal access was never the issue. In her case, she worried about balancing inclusive placement with choosing the best fit for her son socially. She wanted him to have access to his general education peers but also feel like he had a friend group. For her, equal access had a different meaning. She always had access to services. She wanted to make sure she chose the right balance of services where he felt like he fit in socially but also where inequality of access did not mean that she isolated him from other children without disabilities.

Despite very different disabilities, each parent sought to access the best services for their children as they navigated the special education journey, not always knowing exactly what those services should be. Victoria, whose son Randy had Down’s Syndrome, summarized it well when she said, “That is this journey, always trying to figure out what is the best thing to do.” What struck me in interviewing each of these parents was the intense love, thought, concern, and advocacy that went into their decisions for their children. Each child's needs and situation differed, and the parents did their best to find the best solutions with the information they had available at the time.

Balancing and Navigating the Professionals

Each of the parents talked about balancing their interactions with the school to maintain a positive relationship, if possible. Ann, whose son Kevin had autism, summed it up when she said that when an issue with the school arose, she would ask herself, “Am I going to die on this hill?” The stories shared showed parents balancing maintaining goodwill with the need to advocate. A common underlying concern was that school staff would take out parental frustrations on their children, which was why the parents viewed a positive relationship as necessary.

All the parents reported that they assumed goodwill on the part of the teacher unless they determined the teacher was uninterested or overly negative regarding their children. As a teacher and Evan’s mother, Sheila shared this:

> I think the parents need to keep in mind that the teachers really do have their kids' best interests at heart, and the teachers really want the kids to be successful. And you've got to give those teachers a chance to get to know your kid, to really understand.

Sheila stated that she tried to give teachers the benefit of the doubt as she knows how busy teachers are. When Sheila contacted teachers with a concern, she usually received a positive response. Sheila did note that she must ensure all the teachers follow her son’s IEP each year, as there will often be one who may not each year.

Iris and Mark, whose daughter Laura had dyslexia, described how they tried to establish a good relationship with teachers. They said the following:

> Go in there [IEP meeting] with positive intent. It’s a system, and you got to work the system. You just have to be patient with all of the rules that it has and the ways that you have to go about things because it is what it is. It’s government.

Iris and Mark stated that they work around negative teachers and build relationships with the positive teachers. Iris and Mark have strong relationships with their daughters and work with their daughters to navigate challenges first before involving the school if possible.

Victoria, whose son Randy had Down’s Syndrome, encouraged goodwill between teachers and parents when she shared the following:

> I would tell them [new teachers] to listen to the parents because they are, you know, their child's first teacher, and they know their child. However, they don't see their child in the same setting as the parents ... and [parents] don't see their child in the same setting as the teachers. So, it is different. But I think the key

> thing is that it is a team approach, to have open communication with those parents, and to present it as a team. It's not an us and them. I sometimes feel like that hasn't been my experience, but I feel like hearing from other parents that there are times that it's become us and them. And, you know, parents have contributed to that model and so have teachers. You know, it comes from both sides. So, I think to really try to present a team and listen to the parent, just because you're listening to the parent doesn't mean that that's what's going to actually happen. Sometimes parents just want to feel like they have a voice and to be heard, even though it may not be, what the school can do or what the school is willing to do, or what is available. Sometimes parents just want to be heard and then once they feel heard and, you know, then they're willing to move on past that request or whatever, you know.

Victoria emphasized the importance of listening to the parents and acknowledging their expertise as equal.

For Leah, whose son, Andre, had emotional and behavioral needs, building goodwill was a priority. She was aware that her son was difficult and could anger people. She wanted the school to know she was available and willing to help. Leah stated the following:

> And I am here to support you in any way you need. Call me if you need anything. I'm here, and I mean, I'm ... I'm also offering to do stuff like … I'm going to be organizing their t-shirt thing. That's fine. And I do that because I'm like, I want them to know my name. I want them to know my phone number, and I want them to be comfortable to come talk to me. And because if I can do that in advance, if I

> can get them prepared in advance, usually they're a lot kinder, they are a lot more ... I don't want to say lenient, but a lot more understanding of the situation and more willing to come and just sit there and say, okay, look, this is the issue we're dealing with. How do we work together? Right? If I'm already putting myself out there, they're willing to usually put themselves out there. But this is high school … so far, it looks like the orchestra teacher loves that.

Leah had already started volunteering with the orchestra to build relationships with the high school before her son had even started high school. She volunteered this summer. She wanted to create a positive relationship so that if problems arose, the teacher would feel comfortable reaching out to her and working as a team. Leah said that on her part, she must extend goodwill or grace to the new staff when Andre moves schools. She stated the following:

> I have to be extremely lenient [when he moves schools] because it's always, again; well, when they get to high school it's different. Okay. When they get to middle school, it's different. Things are different. I don't disagree with that. I 100% understand all of that. But his behavior hasn't changed. I don't want people not to have hope in him … but at the same point, I need them to understand that these issues have been long coming. These are longstanding issues. We are still working on them. We have been working on them for years. We will still be working on them until he's an adult, you know, and then it's going to be up to him to work at them.

Leah stated she understood that most school staff do not have experience with children with attachment issues and abuse histories and the resulting emotional issues, so she must assume goodwill even when the staff did not listen and think, “It will be different” this year.

In the stories shared, the participants only mentioned a few educators who were combative. Instead, the parents described most of the problems with educators as being due to a perceived lack of interest or concern. For example, Iris and Mark discussed how they know if a teacher will be a co-collaborator or a detractor in their daughter’s education. Iris stated this:

> Usually, those teachers are going to come in, and they’re going to be pessimistic … They’re not interested in change. They’re not interested in working with us. They’re not interested. And they’re just like, well, this is what it is. Okay, well, you don’t need to talk anymore.

Mark added, “But if it is like that, they’re not going to say anything useful … we don’t all of a sudden shut them down … it’s like ‘That is an interesting opinion, what do you think, Mrs. [positive teacher]’ … our end goal is problem-solving.” All of the parents described how they worked around teachers who seemed uninterested or did not follow through on needed accommodations, bringing us back to the importance of the one professional who helped or went out of their way. Often, these occasions were when the parents turned to the significant educator, who often helped them solve the problem. The one educator “who makes a difference” often mitigated the educators who were not as helpful.

Depth of a Parent’s Unwavering Love

Clandinin & Connelly (2000) stated that how participants choose, arrange, and express their experiences or stories provided insight into how participants viewed themselves and others. As I listened to each of these parents share their stories, their stories showed their unwavering love and their determination to help and support their children, as illustrated by their self-reflection, decisions, and sacrifice. As they navigated special education as just one part of their children's childhood, they sought to gather as much information as possible to make the best decisions and provide their children with the best opportunities.

Could I Do More? Blame to Acceptance

One of the most surprising findings to me was that each mother had a piece inside of herself, big or small, that at one point blamed herself for her child's disability. That was a question I would have never thought to ask, yet each mother touched on the subject in her own way.

Even though Evan, who had learning difficulties related to his birth, was seventeen, a part of Sheila still carried some blame for his disability. She stated the following:

> I mean ... I mean, I ... I have a lot ... I have a lot of guilt, he does [Don] too, about, it's our fault. I had him early. If I hadn't had him early, he wouldn't have been on oxygen. Don probably has a learning disability himself. If he hadn't, then ... I mean, I think there's a lot of ... I think in a lot of cases there's a lot of guilt there. I mean, there's nothing I can do. He came when he was, you know, there's nothing. I mean, going back, there's really ... we knew when we chose to put him on pure oxygen, for as long as he was on pure oxygen, that there was the possibility of a learning disability. But the alternative was … we wouldn't have him. So, we knew that, and there was a lot of guilt there, too … Because Don and

> I looked at each other and I said to the doctor; are you telling me that there's really … I don't really say that we have a choice. And she goes; you don't. She says, no, not really. I just have to tell you [about the risks]. Okay. So, I think … I did this … It's my fault.

While Sheila intellectually knew that she did not purposefully give birth to Evan prematurely and that she had to agree to give him oxygen to save his life, she still reported guilt. For this reason, his progression through special education had been more difficult for her. Sheila, a teacher, thought that she should be able to help him at home so that he would not need special education. As a result, Sheila perceived Evan's need for special education as her own failure, which her intellect knew was not true, but her emotions still screamed. Don talked about how Sheila also struggled with Evan not getting all As since school was "her thing." For example, Sheila stated that when Evan started team-taught language arts in high school, "His grades plummeted. I mean, he had a C … it was bad." Don also responded:

> That wasn't that bad to me. That was the other thing ... the grade thing is … The grade thing to me is a C is awesome [Sheila gasps] to her a C is failing [Don is laughing at Sheila's gasp]. So that's one of the things that I that I've talked her down … a C is Okay … a 79 to me is a B. To her, it's no-o-o! … It's a [looking at Sheila] ... I still love you AND your expectations are too high. You have to look where we started and look where we're at. She's a bulldozer. That's what her mother told me when I talked about getting married. She's a bulldozer. She's up full steam ahead. She doesn't stop. And so, and I'm more of ... You know, just relax. It's okay ... It's all right. A C is awesome.

Now that Evan is in high school, Sheila said she sees that he "is okay," and the guilt was lessening. Don had helped her become more accepting of Bs and Cs and accept that Evan would be okay as an adult even if he did not attend college. School staff who interacted with Sheila and Don over the years most likely would not have detected the intensity of emotions connected to Evan's education or known that they related to the guilt and sadness around the circumstances and consequences of his birth or Sheila's expectations of herself as a teacher mom. This story showed the depth of experiences and emotions that interact in the special education parent-school partnership unbeknownst to educators. With intense emotions like these underlying the need for special education, it would not be surprising if parent-school interactions also became intense. Don said more than once that if Sheila had not been at the meetings with him, he would have just blown up and been "escorted out of the building."

In contrast to Sheila's experience, Kathy, whose son John had a learning disability, had accepted that her children most likely would have learning disabilities. For her, the special education journey was expected and well-traveled. She had watched her sisters overcome their SLD and become successful adults. She had accepted the blame and was confident she and her son would handle it together.

In my interview with Iris and Mark, whose daughter Laura had dyslexia, I was again surprised when Iris mentioned blaming herself for Laura's disability. For Iris, she stated that dyslexia was not a shock as it ran in Mark's family, and they thought Mark probably had it. Iris referenced Laura's amblyopia when discussing her self-blame:

> I think it was more with the amblyopia that Laura has because my background is in chemistry, and I was a grad student when I was pregnant with Laura. So, I was

> ... there was a little bit of that, like, oh my God, I was working in a lab. What if I somehow damaged my baby? Uhm, but then I was like, it ... well, she was going to be something. Right? And then what are you going to ... what are you going to do with it? But that's a ... that's a ... a general life principle that I ... that I have, that I've developed over the years, is just that, like, the ... the acceptance. But maybe that's a lot of therapy, so … we're doing all of the things that we can. And if it wasn't this, it would probably be something else. Right? Like, nobody gets off scot-free … Yeah. Because there's only so much in life we can control.

Iris and Mark both appeared to have more acceptance of their daughter's disabilities. I wondered if this was because both girls were doing so well in school. Both girls needed less special education support each year as they progressed through the grades. In addition, Mark said that he had dyslexia and had a successful career, so "things worked out." Iris and Mark may also have moved from blame and acceptance through therapy, as Iris stated, but also as their girls improved academically each year.

Both Victoria, whose son, Randy, had Down's Syndrome, and Ann, whose son, Kevin, had autism, referenced their sons as "forever" children. For them, blame and acceptance was a different journey. Victoria talked about her age, 35, when her son was born and that she did not think she was that old when she had him. She gave several reasons why they did the right thing, not doing any prenatal testing, and gave several reasons why he might have had Trisomy 21, but then she would shift her story to a positive note. Her storytelling made me wonder how much she had wondered about the cause of his Down's Syndrome and if it was her age or something that she did, but then her storytelling shifted to a positive tone, and she remarked that it all happened the way it was meant to happen. Throughout all three interviews, Victoria always tried to see the bright side and looked for the positive. At the same time, Victoria questioned herself and wondered if she could have done more to help Randy when he was younger. For example, she described how her three other children's conversations surpassed Randy now that they were adults, and he got upset when the conversation moved faster than he could. She said her other children did not mean to leave Randy out of the conversation, but they would start talking and found it more challenging to simplify the topics now that they were all adults. As she described this dilemma with her children, I could see that she had gone over and over in her mind trying to find another way to help her son communicate better because he loved to be social, but he was difficult to understand. Even though she had worked with the school for years in speech therapy and assistive technology, she still questioned herself:

> When he was really little, we did a lot of the pictures and did the, you know, where do you want this, or do you want this? And he would do the pictures. But then as he got older, it just takes a lot of time. And we didn't do as much of that. And, you know, as a parent, you always wonder, what if ... I'm not saying that it would have made [a difference] but there are times that I'm like, oh, would that have helped his speech more or would that have helped his making choices more. You know, in his cause and effect, some of that is ... just going to be the reasoning is hard. He's never going to be completely where he can see what the outcome is going to be … And you assume that he would get that at some point, and he doesn't. You know, that's the harder thing, I think, as a parent is seeing that the age progression and thinking that that's going to develop and improve with age.

> And it doesn’t and it gets easier in some ways, but then it gets harder in others. And he has a very hard time making choices. Like if you say, do you want this or this? He wants both … You know, even clothes. Do you want to wear this or wear this? He's like, I want both. You know, he'll put one shirt on and put another shirt on top of it because it's hard for him to make that choice unless it's something that he really wants. But if it's just something that he can't decide between the two, or if you're trying to work with cause and effect. Like, say that we're not going to do this right now because this will happen. He can't, he can't see that.

Victoria talked about how this year, his senior year, she has really had to look at her acceptance. She realized that some of his reading goals had been things she had been working on since Randy was three years old. He has had sight words posted in his bedroom since he was three. Now, he is seventeen and still does not know the words. She said the following:

> And then this last year, his 11th-grade year, we [IEP team] sat there and talked. And I think I'm beginning to realize more and more that, you know, he's hit his ceiling. There's, he's really, I mean, I can work with him at home, and I can have, you know, apps on his iPad for him to learn and but, but I think he's getting to where he's hitting his ceiling. He's not going to be able to [sound out words]. And that was something I had to come to grips with within myself. I mean, you have certain expectations, and it's always a struggle to know what it is that's going to eventually develop and what's … am I giving up … What do you have to accept what this is, what it is. And (long pause). I think this year was one of those years for me, realizing that, you know, the academics aren't going to be ... aren't going

> to improve, but maybe now as he's getting ready to be 18 ... an adult, we do need to focus more on how can he go out into the community and how can he work a job. How can he, you know, would I like for him to ever be able to do a college program? Absolutely. But that's you know, I don't know that that'll be in his future. Would he be able to take a class or two at a college and learn a skill? Maybe so. I mean, I know he's got some definite strengths. It would just have to be it would be finding him a skill and a job that would fit within his interest and his capability.

Victoria did not want to underestimate her son, but she also was working on accepting that he may never read. His speech may never be clear. She was unsure if she would continue to pursue therapies into adulthood or solely focus on work skills. Victoria stated that Randy's turning 18 felt like when he was first born because she was learning everything all over again. She reported that this year, she had spent countless hours on paperwork and research, learning the new systems for adults with special needs. She noted that she felt like she was starting over on the learning curve while still working through her own acceptance.

Ann, whose son Kevin had autism, had also talked about how hard it was to see her child trapped in his body. She wondered who was in there and continuously searched for a way to access that person. Ann put it beautifully when she said the following:

> You still want to help them and always want to try to do more. But you also have to find that balance. There's definitely grief and acceptance. Absolutely. There's no magic pill. It took me a long time to get to that point. We’re still doing other things. We're never stopping.

Ann and Victoria had a different level of acceptance than the other parents. They had to accept how far their children would develop in their abilities. They also had to accept that their children would likely live with them forever. Their acceptance did not mean that they would not continue to seek positive therapeutic, employment, or placement options for their sons. However, it did suggest that for today, they realized that their sons may have reached their academic potential, and their focus should turn towards helping their sons navigate creating their adult lives.

Leah’s situation, parenting Andre with his behavioral needs, was starkly different compared to Victoria and Ann's stories. Leah blamed herself for Andre’s problems even though she was not his birth mother or the cause of his trauma. She had even questioned if he should have remained with his incarcerated mother, even though her intellect knows that not to be healthy. With the help of the family’s therapist, Leah was working on accepting that Andre must help himself; otherwise, Leah may not be able to save him from the emotional challenges he experienced before he became her son. Leah wrestled with self-blame and anguish as she raised her three children and worked diligently to overcome the challenges that they brought with them when they entered her family. Accepting that one’s child may not be successful is difficult, so “Leah keeps fighting, maybe too much,” the therapist said.

A Precious Gift Worth the Sacrifice

Each family in this study saw their child(ren) as a precious gift worth every sacrifice they made. Throughout the interview process, not one parent complained or lamented how hard it had been to overcome their children’s challenges. Some sacrificed careers to be available to meet their children’s needs, and all sacrificed family resources to meet their children's physical, emotional, or educational needs. These families were fortunate to have the financial means to provide outside services for their children, and each participant's current school district was in a metropolitan area with substantial resources for special education. Each of these mothers had a college education and supportive husbands who were actively involved in their children's education. In addition, all of these families had remained in the same one or two homes throughout their children's lives, so their children had attended only one or two school districts, which provided consistency in service delivery for special education. These parents benefited from significant cultural and social capital, which they utilized to benefit their children while also making great sacrifices to help them reach their fullest potential (Bourdieu, 1986).

Iris and Mark sacrificed for their daughters, Laura and Lisa, to help them reach their potential. Once Laura, who had dyslexia, qualified for special education, Iris and Mark enrolled her in a reading intervention program, which she attended for four years. Her sister, Lisa, attended for two years, costing the family around 500 dollars a month for each child. For a year, Laura participated in the reading program three times a week, which was a more significant financial and time commitment. This intense intervention, combined with special education and assistive technology, helped Laura close her four-year reading deficit, so she now reads at grade level like her sister. Both girls have progressed to reading on grade level, requiring minimal special education support. Iris and Mark never complained about the time or the cost and spoke of the reading program as a given that had to be done to help their daughters. The financial sacrifice and time commitment were part of their family norm of doing "what is best for my baby."

Kathy's sacrifice for her son John, who had a learning disability, was in time and energy. Kathy began advocating for John when he was two years old. She displayed such perseverance as a working mother when she described working daily in little notebooks to retell stories. She used her time in the car and at home to reinforce skills with John. She read to him every day. She practiced missing skills and did her own progress monitoring. Because of her intense support at home, she knew he was not progressing as he should and recognized when it was time to push for special education testing. She gave all her time and energy to ensure John got the help he needed instead of waiting for the school to reach out to her. She also focused on her son's strengths and the growth he had made over the years, briefly alluding to some depression that he dealt with in middle school. Like the other mothers, she focused on his strengths as he entered high school.

Leah and her husband, Curtis, whose son, Andre, had behavioral needs, spent years making sacrifices for their children. The family had been working with mental health professionals for the past eight years to provide Andre and his siblings with the needed services to heal from the trauma they experienced as children. When Nadia repeated fifth grade, the family moved homes and schools so she would not be embarrassed to encounter her peers at the middle school. As a result, they relocated across town to give Nadia a fresh start. At the same time, the children's ongoing therapy required a financial commitment, an exhaustive emotional commitment, and a time commitment. After Andre's most recent hospitalization, Leah and Curtis decided to have Leah stay home to coordinate all the needed services for Andre. They were making another financial sacrifice to meet the children's needs. With more time available, Leah took the opportunity to volunteer at the school to build goodwill as a protection for her son. All of Leah’s interactions with the mesosystem, including interactions with her employer, the school, mental health professionals, neighbors, and her family, focused on helping her children. She acknowledged that it was a lonely road as few people understood the impact of attachment issues on child development, but she said she could not just watch Andre fail.

In addition, Leah and Curtis built a relationship with Andre’s birth mother. Leah said that at first, it was difficult because his birth mother challenged how they were parenting the children. After each visit with his birth mother, Andre would act out and be more disruptive. In addition, Leah said, “Andre has always sort of seen me as someone that's taken him away from his mom and that kind of stuff … so I get all that anger.” Despite this, Leah and Curtis continued to allow the birth mother to visit with the children and have a relationship because they thought it was best for the children. Leah said that Andre usually did worse when his mother was in jail because he did not have contact with her to know she was safe. For years, Leah said that the birth mother minimized Andre’s behavioral problems. Recently, his birth mother confronted him on his behavior and told Leah that she was sorry that she had not supported her. On a recent visit, she saw the behaviors Leah had been telling her about over the years and had “yelled at Andre.” Even though the birth mother further complicated a problematic situation, Leah and Curtis opened their home and their lives to her by including her in their lives like a “family friend” because it was in the children’s best interest. During our third interview, Leah shared that Nadia was visiting her birth father’s family in Texas for the first time because she was now 18 years old. Leah and Curtis loved these three children enough to be their parents and work through all the trauma and therapies, AND also include their birth families in their lives.

Victoria had been taking Randy, who had Down's Syndrome, to different therapies since he was an infant but still questioned if she could do more. Even now, as he turned 18, she wondered if there were more services that she should have accessed through middle and high school even though she had him in church groups, recreational baseball leagues for socialization, adaptive sports leagues, and speech, OT, and PT therapies through the fifth grade. She worked on sight words with him herself from ages 3-17. She described implementing the choice boards, if-then statements, and other strategies professionals gave her. She stated that when he was younger, she could not work because of all his therapy appointments. She reported that now she was busy learning all the new information and completing the necessary paperwork for an adult with special needs.

Despite all of her efforts and time committed to helping Randy, Victoria repeatedly brought up her doubts about what else she could have done to help Randy develop his speech and reasoning skills. She discussed how difficult it was to accept that those skills may just not improve given his disability. Victoria described how hard it was to know when Randy had "hit his ceiling" because she did not want to give up on him. Victoria was Randy's biggest cheerleader, sharing so many stories of his strengths and fun personality. When Victoria briefly alluded to a challenge with him, she would quickly tell a positive story. Victoria sought to see the positive in the schools, teachers, her other children, and Randy. She spoke positively of him being their forever child and living with them if he wanted. She never complained and was only focused on what was best for him. Victoria epitomized optimism joined with self-sacrifice.

Victoria and Bill (Randy's parents), like Leah and Curtis (Andre's parents), adopted children placed in foster care and chose to include their birth families in their lives because it was in the children's best interest. Victoria and Bill had also adopted Roger and Makayla, whom they took to visit their biological father each year until he moved to another state. They allowed the children to maintain contact via phone through their teen years. During the interview process, both Leah and Victoria's daughters, by chance, were in Texas visiting their birth fathers' families. I asked how each of their husbands felt about their daughters going to see the birth fathers. Both women said that their husbands understood that the birth fathers were part of who their daughters were and understood why they wanted to meet them. Neither father resented the birth father's involvement even though each of these men had made many sacrifices raising these children. Both men embodied sacrificial love. Given the time and sacrifice these families had made to raise these children, the selfless love of including these children's birth families in their lives was remarkable.

Due to his premature birth, Sheila and Don began Evan's life with intense diligence and sacrifice of time and energy. Sheila and Don described how careful they had to be for the first five years of Evan's life because of Evan's medical needs. Sheila said that she would come home from her job as a teacher, wash her hands, and change her clothes before she held Evan to protect him from germs. Their families helped with childcare, as Evan could not attend a large daycare because of his weak immune system. Sheila stated that even now, she cannot vacuum with Evan in the room, or the dust triggers his asthma. She cannot have candles or scents in the house. While the family has had to take many medical precautions, Sheila also discussed hiring a tutor when Evan was younger. Sheila and Don hired a reading tutor to help Evan learn to read in second grade. In middle and high school, they hired math tutors for Evan. Sheila regularly has supported Evan at home, creating quizlets and study tools. Whenever Sheila could not support a subject, she hired a tutor. Sheila and Don recognized Evan's weaknesses but worked to maximize his strengths to help him overcome them. The intensity of their love and support and the depth of thought of how they could best help him showed optimism and self-sacrifice as all their time, energy, and resources went to Evan.

Sixteen years ago, Ann began to immerse herself in the "autism world" when Kevin was first diagnosed and has remained active in the autism advocacy community to date. Ann said that navigating the autism world and Kevin's needs took an emotional and financial toll on her family. When she realized that the school district in her former state did not have preschool services to meet Kevin's needs, she drove 45 minutes to the university preschool, so she had to have friends help carpool her four other children to school. At the time, her other children attended private school, but Kevin could not. As a result, the family moved 45 minutes north to be near the university and the school district so that Kevin could get better services, which meant her other children had to leave their school and friends. To attend parent advocacy groups or trainings, Ann drove two hours on Saturdays, which meant she was away from the family for much of Saturday once or twice a month.

Not only did Kevin's autism require his mother's attention, but so did his physical health. When Kevin would not gain weight, his parents could not find solutions in their community and eventually took him to a Lyme disease specialist in Connecticut and a holistic medical doctor in Florida. While both were able to help Kevin, the cost impacted the family financially. While the financial cost was high, Ann stated, “Now, his brain may always be broken. But at least his body is healthy.” Ann had to give Kevin every opportunity to heal and possibly unlock the person inside. When they relocated to their current state, Ann based their housing decision on the best school system for Kevin’s needs. While Ann did not elaborate further on the toll on her family, she mentioned the “emotional and financial toll” more than once as she referenced all of their efforts to help “unlock” Kevin. When she alluded to the toll, it was never negative but more honest as she had four other children who needed her time and energy. While Ann had many children to balance with Kevin's intense needs, Ann spoke of Kevin the same way as the other parents in this study: as a precious gift. Her intense longing to know the person locked inside of him drove her desire to keep trying to find therapies that might help him even as he was now an adult. She acknowledged the money that she and her husband had spent taking Kevin to specialists to heal his health issues and stated how grateful she was that she was able to do that for Kevin because of the peace it gave him and her. She wondered what it would be like for a mother who could not get that help, so she knew to be thankful. She optimistically hoped the Kevin locked inside would come out one day, but until he did, she would keep searching.

Many parents go out of their way to help their children and provide them with opportunities whether or not their children have a disability. Each parent in this study had an unwavering love and drive to protect their child and ensure they reached their full potential. Each of these parents, some more than others, wrestled with the question:

“Have I done enough?” Sheila, Don, Iris, Mark, and Kathy answered this question more easily. In each of their third interviews, I reflected that they seemed more peaceful as their children headed into this upcoming school year. They agreed and shared that their children had grown in independence and self-advocacy. Each parent acknowledged that their child was managing school with less and less parental support. These parents felt less of a need to protect as their children had shown that they could advocate for themselves at school. In addition, as their children advocated for themselves, the parents did not have to have as much school contact. For them, the road to their children’s education was becoming less winding, with fewer obstacles to their children’s potential and success.

Unfortunately, given Andre’s emotional and behavioral challenges, Leah worried that Andre’s road may become rockier and more treacherous as he entered high school. Leah had an intensely unwavering love that wanted to protect her child and ensure he reached his potential. The problem was that his situation was more complex than the others. His physical violence put others at risk. Leah expressed intense fear that he would be expelled and have nowhere to go. Leah and Curtis have been working with professionals for years to help Andre. While Leah never wavered in her desire to help him, no professional has given her clear guidance. Leah keeps stumbling through a dense forest, trying to find a road for her and her son and hoping they do not get lost or hurt on the way, a risk she remains willing to take.

Victoria, whose son, Randy, had Down’s Syndrome, and Ann, whose son, Kevin, had autism, possessed unwavering love, which led them to many questions about what else they could do. While they had never met each other, their questions overlapped.

Could they have done more when their sons were younger? What other options are available now? Should they encourage the boys to live independently, or was staying with their parents, okay? Randy was hard to understand, and Kevin had limited verbal skills. How could we better comprehend what they want? Do we keep doing therapies, or do we stop now that they are adults? All of these questions underlie what Victoria and Ann described as grief and acceptance: “Grieving what we had hoped he could achieve and accepting where we are as we head into adulthood.” The love that radiated from these mothers who wanted so much to help their children communicate with the world was overwhelming. Ann sought to balance trying to continue to find ways to access the person locked inside her son with accepting his disability. As long as new information emerged, Ann thought she would continue trying to reach her son. Victoria was eternally optimistic and battled with trying to be realistic about what her son could do. She did not want to limit him but also said she had to accept that he might have reached his ceiling.

As Ann and Victoria each described their sons, they rarely described any challenges regarding the boys’ behaviors or special needs. Any challenges described were often from outside agencies or schools. Victoria mentioned a few times how difficult Randy could be to get to cooperate, but she quickly refocused on Randy’s positive attributes. Ann did the same. She mentioned Kevin’s intense food issues, his toileting concerns, his fear of televisions, and other behaviors, but she never elaborated. Instead, she refocused on stories of his strengths and abilities. Neither of these mothers complained or lamented other than to say they were both working on acceptance now that their sons were 18 and had probably reached their academic potential. I chose not to ask them to focus on the negatives and instead to listen as they returned to the positives about their sons. As I reviewed the interviews, I thought both mothers strove to highlight their sons' strengths and personalities because their sons were more than just their disability, which both women alluded to more than once.

Not one of these eight parents ever complained about the challenges that their children's disabilities presented to the family or the additional costs of outside resources. Each of these families emphasized that the disability was just a part of their child, not who their child was. The seven children in this study had parents who gave their children unwavering love, dedication, and commitment. The parents committed their time, energy, and financial resources to provide their children with many opportunities. They selflessly sacrificed and put their children's needs first by giving up their careers to be home and by including their children's birth families in their lives. These seven children were fortunate to have parents who saw them as a precious gift, not as a disability or burden.

Chapter VI

DISCUSSION AND CONCLUSION

The purpose of this basic interpretative study was to explore how parents of children who qualified for special education and had participated for two or more years in the public-school special education process described their experiences in the special education parent-school partnership. The conceptual framework for this study incorporated concepts from Bronfenbrenner’s ecological systems theory (1979), Epstein’s Overlapping Spheres of Influence (1987), and The Hoover-Dempsey and Sandler Model of Parental Involvement (1995). In his ecological systems theory, Bronfenbrenner (1979) theorized that the interactions of multiple systems within children's lives impacted their development. In their model of parental involvement, Hoover-Dempsey and Sandler (1995) used the ideas of systems from Bronfenbrenner's ecological systems theory to describe how those systems interacted to produce varying levels of parental involvement with the school. In her theory of overlapping spheres of influence, Joyce Epstein (1987) also applied Bronfenbrenner's idea of interacting and overlapping systems to describe the systemic interplay within the community-parent-school relationship. The concepts of these three theories help to describe the dynamics of the parent-school partnership in special education. Through the basic interpretative study approach, I aimed to understand better how parents experienced the special education parent-school partnership. With the results of this study, I hope to give voice to parents’ experience, provide a larger context in which to nest the special education experience, and highlight the importance of educators' roles in creating a positive impact on families.

Research Questions

The research questions were designed to gain a deeper understanding of how parents' perceptions shifted in response to historical experiences to identify and uncover barriers to collaboration when establishing the parent-school partnerships required in special education each year. To better understand these experiences, I answered the following research questions:

> RQ 1: How do parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences?
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> RQ 2: How do parents of children who have participated for two or more years in the public-school special education process describe the impact of previous experiences and perceptions in the special education process on how they currently interact and collaborate with school staff?

Interpretation of Findings

Based on the findings from the participant interviews, I developed four themes and their sub-themes, outlined in the previous chapter. I have answered the research questions in this section considering the findings, themes, and their connection to theory and the literature reviewed for this study.

Research Question 1: How do parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences?

Bronfenbrenner and Ceci (1994) updated the theory from an ecological to a bioecological model to encompass the influence of the child's biological characteristics on interactions with their ecosystem. For children with disabilities, this updated model captured the impact of a disability on a child's microsystem (Kirksey et al., 2022). A microsystem, by definition, includes the people in the group, their activities, relationships, and roles (Bronfenbrenner, 1986; Shelton, 2019). Bronfenbrenner (1986) viewed the child as the center of the microsystem of their family, and the family’s interactions with the school occurred in the family’s mesosystem.

In answering this research question, I propose that each school be viewed as a separate microsystem operating parallel to the family before the child or family enters the system, with special education being a component of the school’s microsystem (Kirksey et al., 2022). The school’s center would be the rules and laws determined in the exosystem, combined with the culture created by the people within each school. This concept is similar to Epstein’s (2010) view of the school as a sphere of influence. The people in a school have often known each other for years and may have relationships in and out of the school setting. Staff members, such as special and general education teachers, have defined roles in the microsystem. When new teachers enter the school microsystem, they must learn the culture, roles, and pattern of activities within it. Iris and Mark perceived this boundary of the school microsystem regarding special education when they said, “Trying to get in is so hard, and there’s like, it’s – it’s – it’s like Fight Club. The first thing about Fight Club is, you don’t talk about Fight Club.” Because of the Family Educational Rights and Privacy Act (1974), the elementary, middle, and high schools only share educational records, which include brief meeting minutes in the student’s IEP but cannot legally include more information regarding the parent-school partnership or family history. Given the limitations on information contained in the record, each school is like its own microsystem interacting in the mesosystem with other schools in the county or district.

Not only do I propose that each school operates as its own microsystem, but that educators often only see a parent within the school-centric, isolated context of a school year and not within the chronosystem of the child’s educational experience (Lawson, 2003). The families described each school year’s staff as a new, small microsystem interacting in the family’s larger mesosystem and chronosystem. Each school year, the parents had to determine how willing the educators were to incorporate them into the school microsystem. For the parents, most teachers were just one stop along a road of many that they had and would encounter in their children’s educational journey. Based on my calculations, the parents in this study and their children had experienced a total of 59 years of special education and approximately 260 teachers, including both their general education and special education teachers. The parents had to adapt each year to the new mesosystem interactions based on the culture of that year’s school microsystem. Depending on the educators each school year, the school microsystem varied in how open its boundaries were to include the families, which is why one educator could make such a difference for a family.

The Difference One Educator Can Make

During our interviews, I ensured that I asked about each school year before the end of the interview process. Even with this year-by-year discussion, none of the families specified more than five specific educators throughout their interviews despite having experienced over 260 teachers altogether. Of the educators mentioned, all but one were positive educators in the children's and families' lives. When viewed through Bronfenbrenner's (1986) systemic lens, the specific educators who made a difference united the school and family's microsystems instead of continuing the parallel microsystems; therefore, I will refer to them as significant educators.

If viewed through Epstein's (2011) overlapping spheres of influence theory, significant educators created a greater overlap in the spheres of influence. When the spheres did not overlap, Iris and Mark described it as follows:

> So, if new teachers, if they could, when they sit down with a parent to tell them something, be like, like a therapist, "Hey, we're here to work on this together and do what's best for little Bobby. Let's figure it out together." Because when the school holds its power, we think, "Why won't you help me? Why won't you help my baby? There is something wrong here. I don't understand. I'm not an educational professional."

For Iris and Mark, their significant educator was the assistive technology professional. Whenever the family had difficulty navigating the classroom experience, they contacted her to help them navigate the school microsystem. She was able to flow between the family and school microsystem to create a more significant microsystem overlap and alleviate the family's concerns.

For Sheila and Don, two educators, the elementary school principal and the middle school case manager, were the significant educators who strongly connected the family and school microsystems. Whenever a concern arose in the school microsystem, Sheila trusted these two educators to help her navigate it. Sheila said she would email Dr.

Smith, the middle school case manager, whenever a problem arose: “and she'd say, ‘Oh, we're not doing that. I will fix that.’” Dr. Smith would take care of it before Sheila’s son got to school the next day. By uniting the two microsystems around Evan, Dr. Smith made the middle school microsystem manageable for Sheila, Don, and Evan. Baxter et al. (1995) found that parental anxiety decreased when parents believed that teachers valued and cared for their children, and with Dr. Smith, Sheila “knew that someone loved him [Evan] and was looking out for him.” Dr. Smith’s care and concern for Evan and open communication with Sheila merged the two microsystems, or as Epstein (2011) would say, led to maximum overlap.

Ann, whose son Kevin has autism, ran into the firm boundary of the school microsystem when Kevin was in preschool, even with a significant educator, the preschool director, helping her. The school system told Ann to “take it or leave it” regarding Kevin’s placement. Ten years later, Ann made sure to have an advocate to help her negotiate with the school the next time she challenged the boundaries of a new school microsystem. When Ann second-guessed if she had needed the advocate, Ann’s teacher friend let her know that the school operated differently when the advocate was present. The advocate most likely brought the spheres, or family and school microsystems, into closer overlap than the family alone could have. In middle school, Ann was fortunate to build personal relationships with her son’s teachers, so the two microsystems fully united around Kevin sharing resources and information (Bronfenbrenner, 1986). Ann now works for her son’s former teacher in a different setting. With all new staff this year, Ann was concerned about the microsystem boundaries being rigid again and having to renegotiate the mesosystem relationship.

For Victoria, the elementary school principal was the significant educator. Victoria was able to work in her children's school, allowing a uniting of the family and school microsystems, where information flowed seamlessly between the two systems in the mesosystem as the systems were at maximum overlap (Bronfenbrenner, 1986; Epstein, 2010). When the elementary school principal secured a self-contained classroom for students with mild and moderate intellectual disabilities in grades 3-5 at Randy's home school, Victoria could remain merged in the school and family microsystem. When Randy went to middle school, Victoria talked about how difficult it was to be outside the school microsystem. She did not know any teachers as the school was outside her community. In middle school, Victoria described having no significant educators and stated she knew little about what happened at school. For Victoria, the family and school microsystems moved apart in middle school and remained distant into high school, even when Victoria wanted more overlap (Epstein, 2010).

For Leah, two teachers were significant educators. Nadia's fifth-grade teacher immediately helped the family get a 504 plan when Nadia first came to live with Leah and Curtis. In doing this, the teacher quickly united the family and school microsystem around Nadia. The unity of the two microsystems gave Nadia the room to renegotiate her role in the family microsystem to that of a child, as she had been parentified in her role with her brothers in the past (Bronfenbrenner, 1986; Shelton, 2019). The school and family microsystems remained united, or at the maximum overlap, for a second year when retaining Nadia (Epstein, 2011). Leah stated that the fifth-grade teacher worked closely with Nadia during that second year to provide emotional support and close her academic gaps. When the family and school microsystems worked in unison at the maximum overlap, Nadia benefited and began working at grade level, and eventually excelled to become an honor student, as the spheres of influence theory would suggest (Epstein, 2011).

The second significant educator for Leah was Andre's fourth-grade teacher. Leah reported that it was not until the fourth-grade teacher said, "I see you. I see this, and I want to put this in place," that Leah felt like the school helped her. The fourth-grade teacher helped to draw the family and school microsystems into closer overlap by beginning to connect the two microsystems better (Epstein, 2011). Leah's family also included a mental health microsystem that continuously interacted with the family and school and complicated the mesosystemic dynamic each school year. During the middle school years, the special education lead teacher and Leah worked to unite all three microsystems, but one teacher could quickly disrupt the balance (Bronfenbrenner, 1986). For example, the middle school implemented a tiered behavioral plan for Andre. Leah described how the phone calls lessened, and she was relieved from the constant emails and phone calls for a little while. Leah then stated the following:

> And this one teacher started calling me on a regular basis … uhmm … and she literally would call me frantically, telling me I don't know what else to do. I don't need … I need help, blah, blah, blah, blah. He's in the middle of a rampage. And so, my question was, did you call the lead? Well, no. And I said it's in his IEP. Do that. I said, "What do you want me to do? Come to the school and, like, help you? Like, what do you want?" And she's like, "I don't know." Like, ... And I hear him screaming in the background. And I'm trying to do my job … I don't disagree he's screaming in the background, but what do you want me to do? I am five

> miles away. Like, not really. Two miles away. It's still five minutes. Like, he could literally punch you by then, like. There's a plan in place. So, I got to the point where I was just frustrated, and I was just … I … I got so pissed off ...

In this instance, one educator's lack of follow-through significantly disrupted the behavioral plan, leading to anxiety and fear in both the family and school microsystem. In Andre's case, the complexity of his needs made the role of the special education lead, the significant educator in the middle school, more difficult to fulfill, as one teacher could disrupt the microsystem and mesosystem. Epstein's theory would view this as the school, community, and family spheres working together toward maximum overlap (Epstein, 2011).

Inequality in Knowledge

Researchers have consistently found that the special education process and its educational jargon can be intimidating, impersonal, and overwhelming for parents (Fish, 2008; Hess et al., 2006; Mueller & Buckley, 2014; Zeitlin & Curcic, 2014). Under The Individuals with Disabilities Education Act of 2004, known as IDEA (2004), parents were supposed to be equal participants, but parents may not possess the knowledge to establish this equality. Iris, for instance, stated, "Parents are scared and don't know what's happening. So, if you could just help them and break the [rules] or bend the rules and tell them things, that would be so beneficial." For Iris and Mark, this knowledge took almost two years to gain through internet searching and experience, which they perceived was at the expense of their daughter's increased anxiety and academic deficit.

Even Sheila, a teacher, sought her special education colleague's guidance to understand the process better. When Sheila and Don thought the school staff might not listen to them, they recruited the principal to be their advocate in the special education process, which helped them to maintain their equality. In addition, although Sheila had professional knowledge, her emotions as a mother made some educational decisions for Evan more difficult. Trainor (2010) found that educators often did not realize that what they perceived as a value-neutral discussion of disability may be value-laden for the parent because the parent may not divulge their vulnerability. Sheila was willing to ask the significant educators to help her navigate her two roles because Evan's disability was not value-neutral for her.

Kalyanpur et al. (2000) argued that schools expected parents to know what the professionals knew, such as the meaning of a diagnosis, placement, or their rights to participate equally in the special education process. When Kathy reflected on how her education impacted her ability to navigate special education, she stated the following:

> I wish it was mandated that as soon as a child enters the RTI cycle, an informational brochure is given to parents, or they are connected with a parent advocacy group. If you don't have that educational background, if you don't have any previous experience with any of your kids going through this, it's not your fault that you don't know. You don't know the questions to ask.

Kathy operated in the professional paradigm and, thus, established equality with the school microsystem more easily than Iris, Mark, Ann, or Leah.

When Ann reflected on her knowledge at the beginning of her special education journey, she said, "Oh my God, I was still such a baby [in terms of knowledge], but yeah. And so I was, you know, researching, learning about ABA [applied behavioral analysis], learning what speech was, what play therapy was, what, you know?" Ann had not even heard the word "autism" when her special education journey began. Ann described years of exhaustive efforts to immerse herself in the “autism world” and become the expert that she is today so that she can effectively advocate for her son. Kalyanpur et al. (2000) suggested that expecting equity between parents and the school contradicted the knowledge hierarchy embedded in the positivist paradigm of professionalism. In this paradigm, the objective nature of professional knowledge would outweigh the subjective nature of a parent’s perspective, creating a contextual barrier to shifting to the paradigm of the family as an equal expert and participant, which IDEA (2004) required. Leah directly addressed this perceived knowledge hierarchy by saying the following:

> The frustration came in because, I would say stuff, and of course, people [professionals] always are like, well, I know better, and it’s fine. But do they … do they really know better? Right? Like, while I appreciate some things, I have to remember that I’m the one with him every day.

Leah challenged the unspoken knowledge hierarchy and asked for equality. Trainor (2010) noted that educators often overlooked parents' intuition and experience regarding their child, suggesting a school-centric view of collaboration.

Victoria sought to balance the educator’s and parent’s perspectives. Victoria said, “I mean, I feel like as a parent, I am wanting, I ... see the teachers as experts. I see them with the knowledge, and I am wanting that information.” At the same time, Victoria said, “I would tell them [new teachers] to listen to the parents because they are, you know, their child's first teacher, and they know their child.” Victoria expressed that both the teachers and the parents shared knowledge and that the two microsystems should be seen as equal in the knowledge paradigm and not hierarchically.

Other than Kathy, all the parents in this study described how they had to learn the special education process and how to understand its language. The parents who were not educators said it took them a couple of years to feel comfortable in the IEP process. For parents to participate equally in the IEP process, school staff must ensure that knowledge is shared or risk becoming hierarchical and school-centric by overlooking the expertise in the family microsystem and prioritizing professional knowledge.

Parent to Parent

Santelli et al. (1997) found that when parents utilized parent-to-parent support programs, their acceptance of their situation and sense of coping increased. Parents in this study discussed the importance of learning from other parents' experiences and how to access services, resources, and their rights. Ann began attending parent advocacy groups to learn as much as she could about autism once Kevin was diagnosed. Leah spoke to her neighbor and her sister to learn about the IEP process. She also remarked that "Pinterest was my friend" as parents posted information and ideas. Iris discussed accessing parent special education Facebook groups to ask questions and get information. These three non-educator families described how difficult it was to access information online and on websites like Wrightslaw.com or parent-to-parent of (said state) websites. They shared that they did not know where to start educating themselves as so much information existed in various forms. If a parent was newly navigating the special education process, the learning curve was steep, so other parents helped to filter all the information and "point them in the right direction."

Inequality in Access

The families in this study were active and involved participants in their children's education, yet access to the school microsystem was not always easy. Trainor (2010) found that educators often did not recognize the significant cultural capital needed for a parent to effectively be an equal participant in the IEP process, such as understanding the jargon and IEP legalities. For example, Ramirez (2003) conducted research with Latino families and found significant barriers to their access to the school microsystem due to limited access to translators, poor parent-school communication, and teacher apathy. Ramirez found that parents simply wanted the school staff to listen more and to know that the staff cared, but instead, the microsystem interactions remained school-centric. Iris and Mark described not understanding why the school would hold its power and not want to help their child. Don stated about the special education lead, “This lady was snarky. It felt like, ‘I'm going to show these two hayseeds that I know what I'm doing and you're going to listen to me.’” Even when Sheila and Don possessed cultural capital, they perceived an inequality in access at the initial IEP eligibility meeting.

Geenan et al. (2005) interviewed seven Native American, 10 Hispanic, and 14 African American parents. They found that a power imbalance, social economic status (SES), and language and cultural barriers negatively impacted parental access to the special education process. The families in this study did not encounter SES, language, or cultural barriers. These families had significant social and cultural capital. Yet, access was still difficult for the non-educator parents because they lacked the educational jargon and professional knowledge to gain access to the school microsystem initially.

Mueller and Buckley (2014) found that when school staff’s use of special education jargon or the complexity of the IEP process intimidated parents, parents often reacted by limiting their participation in the IEP process. Additionally, Hoover-Dempsey and Sandler (1995) suggested that when parents perceived that they had less knowledge, they were inclined to be less involved with the school. However, Hoover-Dempsey and Sandler also indicated that, as part of the model of parental involvement, the parents' motivational beliefs about their role in their child’s education would impact their interactions with the school microsystem. The three non-educator parents’ motivational beliefs regarding their role in their children’s education included protecting and advocating for their children. This belief superseded their initial limited knowledge and led them to challenge the school's hierarchical role and demand access despite their limited knowledge. The parents’ motivational belief that their role was to protect their children overshadowed other components of the Hoover-Dempsey and Sandler model, such as life context or previous experiences. It was the driving force behind the parents’ advocacy, leading to all six families acquiring the necessary knowledge to become equal counterparts to the school microsystem. Fortunately, they all had the social and cultural capital needed to access the knowledge and to establish equality with the school microsystem.

Balancing and Navigating the Professionals

Similar to parents in other studies, the parents in this study described the importance of building goodwill with the teachers due to concern that school staff would take out parental frustrations on their children if the parents became too adversarial (Bray & Russell, 2016; Henderson et al., 2020; Love et al., 2017). Despite this concern, each parent in this study stated that they assumed goodwill on the part of the teachers. Leah, whose son Andre had behavioral needs, purposely sought a positive relationship with the teachers so that they would feel comfortable calling her when needed, drawing the family and school microsystem into closer overlap (Epstein, 2011).

Victoria emphasized the importance of teachers listening to parents and honoring their expertise, while Ann expressed anxiety about the upcoming school with all new teachers. She stated, “These are the big transition years, and we don't need, we don't need somebody we're teaching.”

Santamaria Graff et al. (2021) found that adversarial relationships occurred when teachers struggled to see families as experts, leading to turfism, where families experienced school professionals as claiming the school microsystem as the territorial space of the school professionals. Iris and Mark experienced turfism as they struggled to gain access to the special education process. Iris referenced becoming a “challenging adult” to navigate this obstacle to Laura’s access to special education. Don perceived turfism during Evan's special education eligibility process, so Sheila sought support from their significant educator. Kathy pushed back on turfism when the school tried to find John eligible for autism.

Turfism relates to the knowledge hierarchy embedded in the professional paradigm (Santamaria Graff et al., 2021). Freire (1970) referred to the idea that educators provided parents with information and knowledge as the banking concept. Leah was told, “No, no, it’s fine. He is going to hit his stride. Just wait it out. Just wait it out. And that’s what we kept getting told … umm … through second grade.” Leah recalled the following:

> I think they all just thought he would grow out of it. And I’m like, it’s not. And I think part of it is that they kept trying to tell me he’s too smart for one [an IEP], like, he’s too smart for these services. And I’m like, once I figured out, it’s not about his smarts but behavior … don’t let the schools tell you it’s about grades.

Leah had to push back on the school's knowledge with her own knowledge of her son to balance what the professionals thought about her son and gain access to the microsystem.

In their model, Hoover-Dempsey and Sandler (1995) suggested that parents' job skills impacted their ability to navigate the school microsystem. At first, Iris was reticent to push back on the professional knowledge when Laura's teacher said Laura was okay and that "She just hasn't *popped* yet." With time, Iris and Mark learned when to challenge professionals and when to navigate around them. Iris learned to use her problem-solving skills as a project manager to negotiate the IEP process. Iris stated the following:

> What I've found works really well is to reframe things as questions. And say, "Hey, I want to explore a topic. Help me understand. Right? Help me understand this thing." And then they explain it to me, and then you look for weaknesses in the logic. And then you come back. So, what you're saying is, and then that's where you put your spin and interpretation on it.

Iris and Mark had learned to avoid conflict and maintain a balanced exchange with the educators using Iris's job-related problem-solving skills.

Due to personal experiences, some teachers were more open to parental involvement and communication because they had experienced the IEP process or had similar issues with their children (Bezdek et al., 2010). In their model of parental involvement, Hoover-Dempsey and Sandler (1995) suggested that staff's personal experiences impacted their interactions with parents, making them more open to overlapping the school and family microsystems to benefit the child. Ann described how her middle school principal also had a child with autism, as did the advocate that Ann used. Ann shared that both professionals had a unique understanding of her family's challenges. When encountering turfism or rigid school microsystem boundaries, the families in this study were fortunate to have the social and cultural capital to navigate a balanced and equal relationship between the family and school microsystems.

Depth of a Parent's Unwavering Love

In their model, Hoover-Dempsey and Sandler (1995) described role construction as a primary mediator in how a parent interacted with the school. In each family in this study, the parents described their role as protecting and advocating for their child in the school setting. According to the Hoover-Dempsey and Sandler model, parents' sense of protection correlated to what the parents perceived as important, necessary, and expected in their role construction. For the families in this study, the mother often maintained frequent communication with the school, and the fathers attended the annual IEP, often in more of a supportive role. Buzard et al. (2023) found that educators tended to contact mothers more frequently than fathers, suggesting support for traditional gender roles through school-initiated contact. Herawati et al. (2020) found that fathers were usually more focused on providing for the family, while mothers were more responsible for the children's education and care. According to the Hoover-Dempsey and Sandler model, a mother constructs her role with the school based on the family's expectations and her internal expectations for herself as a mother. Each mother in this study expressed a fierce "mama bear," as Kathy described it. Researchers have found that while both parents have role expectations to provide for and protect their children, mothers often experienced more substantial expectations for school involvement based on gender norms, which was most likely why the mothers were the primary reporters in this study (Coyl-Sheperd &

Newland, 2013; Herawati et al., 2020; Lareau & Weininger, 2008). Each mother in this study appeared to have internalized and valued the role expectation of being responsible for the children's education.

While the mothers in this study touched upon self-blame, they may have replaced self-blame and possibly reconciled any remaining guilt by championing their children's strengths and abilities. Kausar et al. (2003) found that parents of children with disabilities credited the child's disability for increased personal growth and an increase in empathy, compassion, and hope in their own families. While some of the families described the financial and emotional toll their children's disabilities caused, they also emphasized that their other children became more caring, compassionate, and kind to their siblings and others with disabilities.

The Frostig Center in Pasadena, California did 20 years of research to determine what predicted a successful life outcome for children with learning disabilities (Raskind et al., 2003). They found that students with perseverance, goal setting, pro-activity, and the presence of effective support systems were most successful. The parents in this study modeled these attributes for their children. Iris and Mark described teaching Laura and Lisa to be proactive advocates for themselves and to be resilient. Sheila, Don, Kathy, and John Sr. described teaching Evan and John Jr. similar skills. As Laura, Lisa, Evan, and John developed these skills, they required less special education support each school year. Because the children were most likely developing the skills described by Raskind et al. (2003), the parents described more peace about their children's future.

Anna, Victoria, and Leah were more unsure of what the future held for their sons, but their determination and Christian faith led to their hopeful optimism and loving support. Often, parents of children with disabilities have higher rates of depressive symptoms and higher stress levels (Carroll, 2013; Singer, 2006). Ann had embedded herself in the autism community, creating a significant support community for herself in addition to the support of her family. She was actively involved in her church community. Victoria and her husband had been active in the Down's Syndrome Association since Randy was born, providing a solid social support system. Their family was also actively involved in their church community. The disability and church communities appeared to be a protective factor for these families' well-being. Ann and Victoria were both unsure as they considered what adulthood would look like for their sons or what acceptance of their role in their adult sons' lives would encompass. According to the researchers, social support would help them navigate this acceptance and future (Kauser et al., 2003; Santelli et al., 1997).

Leah, unfortunately, was more isolated, given the severity of Andre's needs. In addition, Leah worried that Andre would not be allowed to remain in school, which researchers validated was a significant concern (Quinn & Lee, 2007; Wynne et al., 2013). Wynne et al. (2013) found that staying in school, primarily through post-secondary education, contributed most strongly to the success of students with emotional and behavioral disorders. Researchers additionally found that Andre was more likely to be successful in high school if his parents, the school, and the mental health community staff effectively collaborated (Quinn & Lee, 2007; Wynne et al., 2013). Given the research findings, Leah's anxiety about Andre's high school career was warranted.

Kirksey et al. (2022) described how Bronfenbrenner and Ceci's updated bioecological (1994) model captured the impact of a disability on a child's microsystem

(Kirksey et al., 2022). For each family in this study, the child's disability resulted in multiple professionals interacting with the mesosystem. All of the families described additional mesosystemic interactions resulting from their children's disabilities. Bronfenbrenner (1986) emphasized that the family microsystem was the primary support for the developing child. When families effectively partner with the community, which includes the school and other providers, the child has more opportunities to reach their full potential. The children in these families were fortunate to have families that could build collaborative relationships effectively.

Research Question 2: How do parents of children who have participated for two or more years in the public-school special education process describe the impact of previous experiences and perceptions in the special education process on how they currently interact and collaborate with school staff?

The purpose of this study was to determine the impact of parents' previous experiences on their current interactions with school staff. Another way to frame the research question would be to examine the impact of the parents' chronosystem on their mesosystemic interaction with the school microsystem. Each of the parents spoke of their apprehension when starting a new school year when the school staff were all unknown. Ann referenced having to "teach" a new staff member, while Leah discussed building a trusting relationship with the high school teachers so the teachers would reach out to her when Andre was difficult. For Iris and Mark, their experience brought confidence in their ability to navigate each year's school staff and any "disinterested" professionals. Each school year was another stop on their long journey of their child's special education experience, and each school brought a new school microsystem to negotiate. If the family was fortunate, the school microsystem had familiar faces from previous years.

The Difference One Professional Can Make

Based on their previous school year experiences, each family described approaching the current school year with apprehension and intention. Iris and Mark, Sheila and Don, Kathy, and Leah stated that in previous school years, one of the teachers usually did not follow the IEP accommodations. Apprehension existed because the parents hoped but were not entirely sure that the teachers would cooperate when they followed up to ensure that the IEP was followed in all academic classes. While the parents reported that most teachers often did include accommodations, the parents started each year with apprehension of the possible conflict. Intention existed because the parents anticipated that at least one middle or high school teacher would not follow the IEP, so they purposefully monitored the implementation of their child's accommodations. The parents anticipated the non-compliance and anticipated the need to address it. Each parent described this yearly occurrence, but their monitoring of it resulted from their previous experiences.

Additionally, each parent started the year by evaluating if one of the educators might be a significant educator with whom they could connect. For example, Sheila said they had not found their person at the high school yet but were still looking for someone to connect with Evan. Leah hoped the orchestra teacher would build a relationship with Andre when he started high school this year. The parents of rising ninth graders, Leah, Iris and Mark, and Kathy, all discussed the importance of their children making connections at the high school because they had learned the importance of having an educator with whom they and their child could effectively communicate if problems arose. Based on her experience with the middle school case manager's mistakes regarding the IEP, Kathy was concerned that the case manager at the high school had not contacted her regarding the upcoming school year. Her previous experience with the middle school undermined her confidence in the high school staff. Ann, Kevin's mom, hoped that Kevin's new teacher would be a significant educator and not someone who was an obstacle as a new teacher. Victoria wished the school would share more information with her as she did not know what to do as her son turned 18. Each parent of a high school student in this study was looking for a significant high school-level educator but had not yet found one.

Considering that each of the children in this study will have to include a transition plan in their IEP, a significant educator would help the family trust that the transition plan consists of the necessary components for their children's success. A transition plan in an IEP addresses post-secondary education or training, career and employment, and independent living-related goals. The transition plan breaks long-term goals into short-term goals and may require accessing community and outside resources. For this reason, high school is a vital time for a family to connect with a significant educator, but no family has reported one in this study.

The Impact of Knowledge Gained on Navigating the Professionals

As the parents in this study navigated the special education journey, they gained knowledge of special education jargon and an understanding of the IEP process. With more experience and expertise, they learned their rights, options, and how to advocate for their children better than when they first entered special education. As a result, they shifted their approach to the special education parent-school partnership and how to balance and navigate the professionals.

For Iris and Mark, their previous experiences significantly shifted their current interactions with school staff. They no longer looked at the educators as experts. Iris stated, “I feel like I understand every section of the IEP now because I've spent a lot of time with it, but I don't really care about half of it.” Based on previous experiences, Iris and Mark focused on ensuring Laura and Lisa had the needed academic support and placements, such as team-taught or consult. They decided that services and placement mattered the most in the IEP, and much of the IEP was just “the paperwork and forms the teachers had to do.” Iris and Mark described learning how to ask teachers questions during the IEP to determine how their daughters were performing, but they also stated that they relied on their daughters more for information. Iris and Mark began the special education journey by asking the school staff for help with their daughters. When interacting with school staff now, they listen for potential problems and steer the conversation toward problem-solving. Their dynamic shifted from looking to the school staff for answers to looking to the school staff more as an obstacle course to navigate and problem-solve in their child’s educational journey. In gaining knowledge and experience, they reduced the inequality in access and used their job skills to balance the professionals.

Kathy’s previous experiences negatively impacted her trust in the high school staff. Kathy shared that her impression of the school district was that systemic procedures did not exist to protect parental rights based on her experience with the middle school. As a result, she was wary when the high school case manager did not make contact in the fall of the school year. When the high school case manager sent home the IEP draft this fall, it was completely filled out, including placement decisions and the meeting minutes, even though the meeting had not yet been held. Her distrust of the district's perceived lack of parental rights procedures based on her previous experiences exacerbated her reaction to this case manager's presumptuous draft, so she immediately involved the administration and told the school that they were predetermining her son's placement and violating her and her son's rights. Based on her past experiences, she was not inclined to "give grace" in the current situation. Instead, she reacted with an email citing her legal rights and demanding that the case manager remove the predetermination from the draft. Had the high school case manager reached out in August, she may have realized that Kathy had experienced mismanagement of the IEP at the middle school level and been more aware of planning the IEP this school year. Kathy had equality of knowledge, and her past experiences made her less inclined to "balance" the professionals by giving grace. Instead, she reacted more legalistically and from a place of distrust.

Based on her previous experiences, Sheila stated that she become more proactive in her advocacy. Evan was highly anxious and distressed during the first semester of ninth-grade finals because of the volume of material he had to know. In the second semester, Sheila asked the teachers in advance for their help with a study guide for the finals and found them accommodating. Based on her previous experiences, Sheila proactively monitors school staff to ensure that Evan's accommodations are consistently implemented and seeks additional support when needed. She has become more intentional and proactive.

Ann described being a baby in terms of her knowledge when she began the special education process, but today is a strong advocate in the autism community. Ann expressed anxiety about the upcoming school year with all new teachers. She stated, “These are the big transition years, and we don't need, we don't need somebody we're teaching.” Ann has learned to make herself available to the teachers so they will reach out to her and ask about Kevin. Ann does not wait for staff to contact her as she knows what questions may arise, so she seeks to build the relationship early in the school year, stating the following:

> I've always tried to establish a positive relationship with the teachers. You know, until, you know, make them know that, hey, I'm in this with you. I don't … You know, I'm here. Talk to me. Work with me. But that takes a lot of work.

Ann described establishing a positive relationship to avoid “having to be that parent. But I have had to go in and be that parent before.” Based on previous experiences, Ann first proactively seeks to establish a positive relationship. However, if needed, she will quickly become assertive of her legal rights or conflictual in advocating for her son because she has learned what most significantly affects change in the parent-school partnership, first relationships then legal advocacy.

As Andre began high school, Leah was concerned about her ability to affect change in the parent-school partnership. Every year, she told school staff that her son should not use a computer as he could not transition from it, triggering behavioral outbursts. Yet, each year, school staff said that this year would be different, resulting in Andre's behavioral outbursts triggered by his inability to transition from the computer.

Based on the high school's response to her concerns during the IEP meeting and previous experience with school staff, Leah anticipated difficulty at the high school stating:

> I say do the same things over and over again. And I already know that that's going to happen for high school because, I mean, when we called and had our IEP meeting for high school, it was a very just. Oh, yeah. Okay. Yeah, yeah. Okay. Okay. Yeah. We'll just keep it this way. And I'm like, great for this. Gonna be fun.

Her prior experiences led Leah to approach the high school partnership with anxiety, frustration, and dread, unbeknownst to Andre's new case manager. Leah struggled to acquire the needed knowledge as Andre's situation was complex. As a result, she still struggled to navigate and balance the professionals, fearing that Andre could face retaliation.

With knowledge and experience, the parents in this study became more adept at balancing and navigating the professionals in the special education process. Iris and Mark, as well as Sheila and Dan have become resources for other parents just beginning their special education journey. Through her advocacy group involvement, Ann helps many parents of younger children with disabilities learn how to navigate the special education process and the parent-school partnership. Their previous experiences impact not only their current experiences but other parents' current experiences as well.

Implications for Practice

When Congress reauthorized IDEA (2004), parents became the accountability agent for schools to ensure effective IEP development and implementation (Haines et al., 2017). Unfortunately, gaining the knowledge to become an equal participant was difficult even for this study's intelligent, proactive, and college-educated parents. As a solution, the research repeatedly returned to educators opening the school microsystem to parents to share knowledge. I asked Iris and Mark if it would have helped to have a third-party person explain the IEP process to them when Laura was first found eligible. They responded, “If the school system paid them, I would not trust them.” I asked them what they would suggest to help close the knowledge gap related to special education. They said they would have only trusted a parent advocacy group to give them information as any school contractor or employee would inherently be biased. Lawson (2003) referenced similar distrust of school professionals in the African American and Puerto Rican communities. Therefore, Iris and Mark’s suggestion of a parent advocacy group referral most likely has a more generalizable appeal to parents of different backgrounds.

Kathy suggested that school staff provide parents with a written brochure that explained the basics of the educational jargon and the process. Building on what Iris and Mark said, I wondered if a parent-friendly PowerPoint or video could walk parents through the RTI, evaluation, eligibility, and IEP process. Parents and educators would need to co-create the materials as educators may not realize what parents do and do not know. Lawson (2003) found that parents were more receptive to community leaders, so utilizing parent leaders in local communities to personalize the educational materials may be more effective in drawing the family and school microsystems into greater overlap (Epstein, 2011).

Building Empathy

Kervick (2017) found that families of children with disabilities were like case managers, balancing the mesosystemic interactions of the school and family microsystems and the medical and service provider microsystems. Despite researchers describing the challenges families of children with disabilities face, educators without personal experience with a disability often appeared school-centric and overlooked the chronosystem of the family experiences and the multiple microsystems interacting in their mesosystems (Bezdek et al., 2010; Cavendish & Connor, 2018; Koch, 2016). On the other hand, researchers found that when teachers conducted home visits and entered students' microsystems, their perspectives changed dramatically (Collier et al., 2015; Lin & Bates, 2010). Creating opportunities for preservice teachers and teachers to understand the family microsystem of a child with a disability could begin to soften the artificial boundaries between the school and family microsystem. While families may not always want a teacher to visit their home, preservice teachers and teachers could participate in a course where they must read case studies on parents' journeys through special education to gain empathy as part of understanding the parent-school relationship. In addition, families could share their stories with a class of teachers, impacting a group of teachers instead of just one teacher in a home visit setting. As a result, teachers may shift from the school-centric view of just seeing the parent through "this year's microsystem" to seeing the family through their larger chronosystem of multiple years of special education. Student achievement will benefit if school and family microsystems can achieve maximum overlap (Epstein, 2011).

A Shift Away From the School-Centric View

Mapp and Kuttner (2013) described the risk of parent engagement activities as becoming "one-way communication and random acts of engagement, such as poorly attended parent nights." Mapp and Kuttner described a dual-capacity framework for family-school partnerships that required the "4 Cs":

1. Capabilities: School staff need skills to build trusting relationships with families, while families need more information about how students learn and how the "system works."
2. Confidence: Both families and educators need to be comfortable and have a sense of self-efficacy working with each other's differences
3. Cognition: Both the educator and the family need to see value in a relationship with each other.
4. Connections: Access to social capital through family-teacher relationships, parent-parent relationships, and community agency connections.

As part of the Dual Capacity Framework, Mapp and Kuttner (2013) proposed that if these 4 Cs existed, then staff and families would create relationships that honored families' expertise and promoted true engagement. Mapp and Kuttner cited studies that built on the community's strengths, either through home visits or building parent connections. Mapp and Kuttner's model did not directly include the special education community or the special education parent-school partnership, but the ideas of this framework would strengthen this partnership. Turnbull et al. (2000) described educators and families creating power through relationships based on their synergistic knowledge and ability to learn from each other and share resources. Schools could encourage parents to access the materials created to understand the special education process to create more synergy or provide a parent advocate to help explain the process to parents.

The parent and school microsystems on the concept map for this study were drawn equally on the diagram. Due to unequal knowledge and access, the two microsystems did not begin this way. I would assert that only Kathy’s microsystem began as the concept map was originally drawn. Smaller family microsystems and larger school microsystems would have better represented the rest of the families in the more hierarchical structure often found in the research (Cohen & Mosek, 2019; Henderson et al., 2020; Kluth et al., 2007; Kurth et al., 2020; Lalvani, 2012). Friedman and Allen (2014) stated that a system grows through an exchange of energy between it and the environment, which for a family would include the school microsystem. For the family microsystem to grow, the school microsystem would have to maintain permeable boundaries as the family adapted to their environment. As parents gained knowledge and skills, components described by Hoover-Dempsey and Sandler (1995), the family actively shifted the family microsystem to a more equal standing with the school microsystem. Thus, while the concept map accurately reflects the components involved, it does not reflect the initial power structure and its interaction with those components as the families adapt and change.

The research often referenced a school-centric focus in the parent-school partnership (Lawson, 2003; Ramirez, 2003; Trainor, 2010). I propose the school reposition itself in the family’s chronosystem and reflect on its larger mesosystem before establishing the special education parent-school relationship. To do this, the case manager may want to ask the family at the start of the year what the family would like the school staff to know, which is like opening the boundaries of the school microsystem and honoring the family’s expertise. By taking this stance, the school would shift away from the school-centric, year-focused school microsystem to a more overlapping family-school microsystem at the start of the year (Epstein, 2011). This stance would also alleviate some of the anxiety and apprehension embedded in the families' stories as they described the upcoming school year.

Limitations

A limitation of this study is that only white, college-educated, middle-class, two-parent families were included as participants. In addition, these families resided in a metropolitan area in school districts with significant financial resources and over 90% high school graduation rates. In contrast, Ann described having no access to therapeutic resources or special advocates in her previous state. In a smaller school district, fewer placement and service options are available. Researchers indicated that lower socioeconomic as well as culturally and linguistically diverse families encountered more barriers to equal collaboration in the special education process (Bodvin et al., 2018; Geenan et al., 2005; Harry, 1992; Ishimaru et al., 2016; Lawson, 2003; Murry & Wiley, 2017; Ramirez, 2003). Perspectives from parents from rural areas from all socioeconomic backgrounds could provide additional valuable insights into the special education experience. Perspectives from parents of diverse cultural and socioeconomic backgrounds would give insights into how culture and language impact the parent-school relationship across multiple years. The Hoover Dempsey and Sandler (1995) model suggested that parents' perceived time and energy impacted their level of school involvement, so the perspective from single parents would also provide valuable insight. In addition, in their model, Hoover Dempsey-Sandler (1995) also suggested that parents' perceived level of knowledge impacted their level of involvement, so perspectives of parents with only a high school education or less would provide additional insight.

The schools in this study were all located in suburban areas in one state, which was also a limitation. Sampling schools from rural and urban areas would provide a more extensive variety of settings. Since the setting impacted the experiences the parents had, this variation may uncover new insights.

The mothers were the primary reporters in this study, which was also a possible limitation. Conducting research with fathers as the primary reporters or as co-reporters, like Sheila and Don, might also provide more insight. The study was bounded within the stories of the six families I interviewed and their children’s specific disabilities. While the families offered their unique perspectives and insights, their insights were bounded by their experiences and, therefore, cannot be generalized to the experiences of all parents. In this study, I only collected parents' perspectives and did not include educators’ perspectives. If possible, I would recommend further qualitative research that provides in-depth interviews with school staff and parents, specifically the mother and the father, in the parent-school partnership. While school staff may understand the parents’ perspectives, other conditions may exist that impact the staff interactions with parents that in-depth interviewing may uncover.

Recommendations for Future Research

Participants in this study were limited to white, middle-class, two-parent families whose children attended suburban schools as part of a metropolitan area school district. Future researchers should consider studying the perspectives of families with less social and cultural capital. Those families might include the following:

- families of varied socioeconomic status in rural areas
- families with language barriers
- families with diverse cultural backgrounds
- families with different racial backgrounds
- families living in poverty in rural areas and urban areas
- families living in urban areas
- single parent families
- families in the LGBTQ community
- families in small or poorly funded school districts

Researchers have studied the disconnect between schools and parents for years and have repeatedly found that parents valued feeling like the teachers cared about their children and families (Baxter et al., 1995; Harry, 2008; Collier et al., 2015; Jackson & Andipatin, 2021). The research has shown that this care and concern could transcend racial and cultural barriers (Bodvin et al., 2018; Geenan et al., 2005; Lawson, 2003; Ramirez, 2003). What that care and concern looked like was communicating with parents and granting them access to the school microsystem by establishing open communication, shared knowledge, and respect (Bodvin et al., 2018; Collier et al., 2015; Geenan et al., 2005; Harry, 1992; Ishimaru et al., 2016; Lawson, 2003; Murry & Wiley, 2017; Ramirez, 2003). Since we already know this does not happen when teachers struggle to have empathy, future research should focus on how to build empathy in teachers effectively (Bezdek et al., 2010; Bodvin et al., 2018; Henderson et al., 2020).

In their model, Hoover-Dempsey and Sandler (1995) include components leading to parental involvement, which I would suggest provide the family microsystem with more or less equality in relation to the school microsystem. Research regarding how changes to components in the Hoover-Dempsey model could impact the power dynamics between the family and school microsystem is another area for future study.

Conclusion

Parents of children who qualify for special education and have participated for two or more years in the public-school special education process described their experiences of the parent-school partnership as a long, winding road with some productive stretches and some rough patches. However, they were fortunate to have significant educators help them navigate the rough patches and unite the family and school microsystems for the maximum benefit of their children.

Educators must shift to a perspective that views the family in the chronosystem to recognize and incorporate the family's expertise and experience in the special education parent-school partnership. The risk of educators viewing the family through the lens of the “school year-specific” microsystem is to risk becoming an educator who is a significant educator in the families’ lives due to the negative impact on the family’s special education journey while also exacerbating the exhaustive nature of the special education process over multiple school years for the family. While Hoover-Dempsey and Sandler (1995) suggested that the components of their model predicated parental involvement, they may also dictate the level of equality the family microsystem maintains with the school microsystem, suggesting further research.

The parents’ education, socioeconomic level, and cultural background comprised their social and cultural capital and impacted their access to the school microsystem and its professional paradigm. Putting social and cultural capital aside, the depth of these parents' unwavering love and drive to protect and advocate for their children was profound and superseded their lack of skills, knowledge, time, or energy. Parental love was the most critical component, and it was missing from the Hoover-Dempsey and Sandler (1995) Model of Parental Involvement.

REFERENCES

Adams, D., Harris, A., & Jones, M. S. (2016). Teacher-parent collaboration for an inclusive classroom: Success for every child. *Malaysian Online Journal of Educational Sciences, 4*(3), 58–72. https://files.eric.ed.gov/fulltext/EJ1106456.pdf

Ahmed, S. R., Amer, M. M., & Killawi, M. (2017). The ecosystems perspective in social work: Implications for culturally competent practice with American Muslims. *Journal of Religion & Spirituality in Social Work: Social Thought, 36*(1-2), 48–72. https://doi.org/10.1080/15426432.2017.1311245

American Educational Research Association. (2009). *Standards for research conduct*. https://www.aera.net/Publications/Standards-for-Research-Conduct

Anthony, N., & Campbell, E. (2020). Promoting collaboration among special educators: Social workers and families impacted by autism spectrum disorders. *Advances in Neurodevelopmental Disorders, 4*, 319–324. https://doi.org/10.1007/s41252-020-00171-w

Auerbach, S. (2007). From moral supporters to struggling advocates: Reconceptualizing parent roles in education through the experience of working-class families of color. *Urban Education, 42*(3), 250–283. https://doi.org/10.1177/0042085907300433

Bailey, B. B., Hebbeler, K., Scarborough, A., Spiker, D., & Mallik, S. (2004). First experience with early interventions: A national perspective. *Pediatrics, 113*(4), 887–896. https://doi.org/10.1542/peds.113.4.887

Bailey, J. (2008). First steps in qualitative data analysis: Transcribing. *Family Practice, 25*(2), 127–131. https://doi.org/10.1093/fampra/cmn003

Bateman, D. F., & Cline, J. E. (2015). *A teacher's guide to special education*. ASCD.

Baum, A. C., & Swick, K. (2008). Dispositions toward families and family involvement: Supporting preservice teacher development. *Early Childhood Education Journal, 35*(6), 579–84. https://doi.org/10.1007/s10643-007-0229-9

Baxter, C., Cummins, R. A., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school. *International Journal of Disability, Development, and Education, 42*(2), 125–136. https://doi.org/10.1080/0156655950420204

Benson, P. (2015). Longitudinal effects of educational involvement on parent and family functioning among mothers of children with A.S.D. *Research in Autism Spectrum Disorders, 11*, 42–55. https://doi.org/10.1016/j.rasd.2014.11.011

Bezdek, J., Summers, J., & Turnbull, A. (2010). Professionals' attitudes on partnering with families of children and youth with disabilities. *Education and Training in Autism and Developmental Disabilities, 45*(3), 356–365. https://www.jstor.org/stable/23880110

Blackwell, W., & Blackwell, V. (2015). A longitudinal study of special education due process hearings in Massachusetts: Issues, representation, and student characteristics. *Sage Open, 5*(1), 1–11. https://doi.org/10.1177/2158244015577669

Blandin, A. (2017). The home/school connection and its role in narrowing the academic achievement gap: An ecological systems theoretical perspective. *Journal of Research on Christian Education, 26*(3), 271–292. https://doi.org/10.1080/10656219.2017.1386146

Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*(2), 167–184. https://doi.org/10.1177/001440290407000203

Bodvin, K., Verschueren, K., & Struyf, E. (2018). School counsellors' beliefs regarding collaboration with parents of students with special educational needs in Flanders: Parents as partners or opposites? *British Educational Research Journal, 44*(3), 419–439. https://doi.org/10.1002/berj.3333

Bonifacci, P., Storti, M., Tobia, V., & Suardi, A. (2016). Specific learning disorders: A look inside children's and parents' psychological well-being and relationships. *Journal of Learning Disabilities, 49*(5), 532–545. https://doi.org/10.1177/0022219414566681

Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of theory and research for the sociology of education* (pp. 241–258). Greenwood Press. https://home.iitk.ac.in/~amman/soc748/bourdieu_forms_of_capital.pdf

Bray, L. E., & Russell, J. L. (2016). Going off script: Structure and agency in individualized education program meetings. *American Journal of Education*, *122*(3), 367–398. https://www.jstor.org/stable/26542681

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental Psychology, 22*, 723–742. http://dx.doi.org/10.1037/0012-1649.22.6.723

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*(4), 568–586. https://doi.org/10.1037/0033-295X.101.4.568

Broomhead, K. E. (2018). Perceived responsibility for developing and maintaining home–school partnerships: The experiences of parents and practitioners. *British Journal of Special Education, 45*(4), 435–452. https://doi.org/10.1111/1467-8578.12242

Brown v. Board of Education, 347 U.S. 483 (1954).

Buffum, A., Mattos, M., & Weber, C. (2010). The why behind RTI: Interventions that work. *Educational Leadership, 68*(2), 10–16. https://www.ascd.org/el/articles/the-why-behind-rti

Burke, M. M., & Hodapp, R. M. (2014). Relating stress of mothers of children with developmental disabilities to family-school partnerships. *Intellectual and Developmental Disabilities, 52*(1), 13–23. https://doi.org/10.1352/1934-9556-52.1.13

Burke, M. M., Lee, C. E., & Rios, K. (2019). A pilot evaluation of an advocacy programme on knowledge, empowerment, family–school partnership and parent well-being. *Journal of Intellectual Disability Research, 63*(8), 969–980. https://doi.org/10.1111/jir.12613

Buzard, K., Gee, L. K., & Stoddard, O. (2023). Who you gonna call? Gender equality in external demands for parental involvement. *SSRN – Elsevier, 4456100,* 1–40, https://dx.doi.org/10.2139/ssrn.4456100

Carlson, R. G., Hock, R., George, M., Kumpiene, G., Yell, M., McCartney, E. D., Riddle, D., & Weist, M. D. (2020). Relational factors influencing parents' engagement in special education for high school youth with emotional/behavioral problems. *Behavioral Disorders, 45*(2), 103–116. https://doi.org/10.1177/0198742919883276

Carrea, V. I., Jones, H. J., Thomas, C. C., & Morsink, C. V. (2005). *Interactive teaming: Enhancing programs for students with special needs*. Pearson Merrill-Prentice Hall.

Carroll, D. W. (2013). *Families of children with developmental disabilities: Understanding stress and opportunities for growth.* American Psychological Association. https://doi.org/10.1037/14192-000

Cavendish, W., & Connor, D. (2018). Toward authentic IEPs and transition plans: Student, parent, and teacher perspectives. *Learning Disability Quarterly, 4*(1), 32–43. https://doi.org/10.1177/0731948716684680

Cavendish, W., Morris, C. T., Chapman, L. A., Ocasio-Stoutenberg, L., & Kibler, K. (2020). Teacher perceptions of implementation practices to support secondary students in special education. *Preventing School Failure: Alternative Education for Children and Youth*, *64*(1), 19–27. https://doi.org/10.1080/1045988X.2019.1628000

Chopp, D. (2012). School districts and families under the IDEA: Collaborative in theory, adversarial in fact. *Journal of the National Association of Administrative Law Judiciary*, *32*, 423–460. https://repository.law.umich.edu/articles/937/

Chun, H., & Duvall, E. (2019). A parental involvement and academic socialization model: A cultural approach. *School Psychology, 34*(5), 555–565. https://doi.org/10.1037/spq0000330

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research.* Jossey-Bass.

Coetzee, O., Adnams, C., & Swartz, L. (2018). A psychodynamic understanding of parental stress among parents of children with learning and developmental disability and behaviours that challenge. *Psychodynamic Practice, 24*(4), 334–34. https://doi.org/10.1080/14753634.2018.1526106

Cohen, A., & Mosek, A. (2019). “Power together”: Professionals and parents of children with disabilities creating productive partnerships. *Child & Family Social Work, 24*(4), 565–573. https://doi.org/10.1111/cfs.12637

Collier, M., Keefe, E. B., & Hirrel, L. A. (2015). Listening to parents' narratives: The value of authentic experiences with children with disabilities and their families. *School Community Journal, 25*(2), 221–242. https://eric.ed.gov/?id=EJ1085720

Cook, L., & Friend, M. (2010). The state of the art of collaboration on behalf of students with disabilities. *Journal of Educational and Psychological Consultation, 20*(1), 1–8. https://doi.org/10.1080/10474410903535398

Coyl-Shepherd, D. D., & Newland, L. A. (2013). Mothers' and fathers' couple and family contextual influences, parent involvement, and school-age child attachment. *Early Child Development & Care, 183*(3-4), 553–569. https://doi.org/10.1080/03004430.2012.711599

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Sage.

Crotty, M. (1998). *The Foundations of Social Research*. Sage.

Czapanskiy, K. S. (2014). Special kids, special parents, special education. *University of Michigan Journal of Law Reform, 47*(3), 733–790. https://doi.org/10.36646/mjlr.47.3.special

Education for All Handicapped Children Act, 94-142 (1975). https://www.govinfo.gov/app/details/STATUTE-89/STATUTE-89-Pg773

Education of the Handicapped Act Amendments of 1990, Pub. L. No. 101-476, 104 Stat. 1103 (1990).

Epstein, J. (1987). Parental involvement: What research says to administrators. *Education and Urban Society, 19*(2), 119–136. https://doi.org/10.1177/0013124587019002002

Epstein, J. (1992). *School and family partnerships.* (Report No. 6). Center of Families, Communities, Schools & Children's Learning. https://files.eric.ed.gov/fulltext/ED343715.pdf

Epstein, J. (2010). School/family/community partnerships: Caring for the children we share. *Phi Delta Kappan, 92*(3), 81–96. http://doi.org/10.1177/003172171009200326

Epstein, J. L. (2011). *School, family, and community partnerships: Preparing educators and improving schools* (2nd ed.). Routledge.

Epstein, J. L., Sanders, M. G., Sheldon, S. B., Simon, B. S., Salinas, K. C., Jansorn, N. R., Van Voorhis, F. L., Martin, C. S., Thomas, B. G., Greenfeld, M. D., Hutchins,

D. J., & Williams, K. J. (2018). *School, family, and community partnerships: Your handbook for action* (4th ed.). Corwin.

Every Student Succeeds Act, 20 U.S.C. § 6301 (2015). https://www.congress.gov/bill/114th-congress/senate-bill/1177

The Family Educational Rights and Privacy Act, 20 U.S.C. § 1232g (1974). https://www.govinfo.gov/app/details/USCODE-2022-title20/USCODE-2022-title20-chap31-subchapIII-part4-sec1232g

Fenton, P., Ocasio-Stoutenburg, L., & Harry, B. (2017). The power of parent engagement: Sociocultural considerations in the quest for equity. *Theory into Practice, 56*(3), 214–225. https://doi.org/10.1080/00405841.2017.1355686

Fish, W. W. (2006). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education, 127*(1), 56–68. https://eric.ed.gov/?id=EJ765801

Fish, W. W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure: Alternative Education for Children and Youth, 53*(1), 8–14. https://doi.org/10.3200/PSFL.53.1.8-14

Florida Problem Solving & Response to Intervention Project. (2021). *MTSS implementation components: Ensuring common language and understanding*. https://floridarti.usf.edu/resources/index.html

Fox, H. B., Tuckwiller, E. D., Kutscher, E. L., & Walter, H. L. (2020). What makes teachers well? A mixed methods study of special education teacher well-being. *Journal of Interdisciplinary Studies in Education, 9*(2), 223–248. https://files.eric.ed.gov/fulltext/EJ1294633.pdf

Francis, G. L., Blue-Banning, M., Haines, S. J., Turnbull, A. P., & Gross, J. (2016). Building “our school”: Parental perspectives for building trusting family-professional partnerships. *Preventing School Failure, 60*(4), 329–336. https://doi.org/10.1080/1045988X.2016.1164115

Freire, P. (2000). *Pedagogy of the oppressed* (M. B. Ramos, Trans.) (30th ed.). Continuum. (Original work published 1970)

Friedman, B., & Allen, K. (2014). Systems theory. In J. R. Brandell (Ed.), *Essentials of Clinical Social Work* (pp. 3–20). Sage. https://doi.org/10.4135/9781483398266

Friedman, B. A., Bobrowski, P. E., & Markow, D. (2007). Predictors of parents' satisfaction with their children's school. *Journal of Educational Administration, 45*(3), 278–288. https://doi.org/10.1108/09578230710747811.

Fu, W., Lu, S., Xiao, F., & Wang, M. (2020). A social-cultural analysis of the individual education plan practice in special education schools in China. *International Journal of Developmental Disabilities, 66*(1), 54–66. https://doi.org/10.1080/20473869.2018.1482853

Fulton County Schools. (2015, July 28). *Your rights as parents – regarding special education.* https://www.fultonschools.org/site/handlers/filedownload.ashx?moduleinstanceid=31879&dataid=69950&FileName=Parental%20Rights%20Regarding%20Special%20Education.pdf

Geenan, S., Powers, L. E., & Lopez-Vasquez, A. (2005). Barriers against and strategies for promoting the involvement of culturally diverse parents in school-based transition planning. *The Journal for Vocational Special Needs Education, 27*(3), 4–14. https://eric.ed.gov/?id=EJ854361

Georgia Department of Education. (2021). *Georgia's tiered system of supports for students*. https://www.gadoe.org/wholechild/Documents/MTSS/MTSS%20National%20Definition%20Fact%20Sheet.pdf

Georgia Department of Education. (2022). *Quick facts on Georgia education 2021-2022*. https://www.gadoe.org/External-Affairs-and-Policy/communications/Pages/Quick-Facts-on-Georgia-Education.aspx

Gibbs, B. G., Marsala, M., Gibby, A., Clark, M., Alder, C., Hurst, B., Steinacker, D., & Hutchison, B. (2021). "Involved is an interesting word": An empirical case for redefining school-based parental involvement as parental efficacy. *Social Sciences, 10*(5), 156. https://doi.org/10.3390/socsci10050156

Goodall, J. (2021). Parental engagement and deficit discourse: Absolving the system and solving parents. *Educational Review, 73*(10), 98–110. https://doi.org/10.1080/00131911.2018.1559801

Green, C. L., Walker, J. M. T., Hoover-Dempsey, K. V., & Sandler, H. M. (2007). Parents' motivations for involvement in children's education: An empirical test of a theoretical model of parental involvement. *Journal of Educational Psychology, 99*(3), 532–544. https://doi.org/10.1037/0022-0663.99.3.532

Grinyer, A., & Thomas, C. (2012). The value of interviewing on multiple occasions or longitudinally. In J. Gubrim, J. Holstein, A. Marvasti, & K. McKinney (Eds.), *The*

SAGE handbook of interview research: The complexity of the craft (2nd ed., pp. 219–230). Sage. https://dx.doi.org/10.4135/9781452218403

Haines, S. J., Francis, G. L., Tracy, G. M., Chun-Yu, C., Burke, M. M., Kyzar, K., & Turnbull, A. P. (2017). Reconceptualizing family-professional partnership for inclusive schools: A call to action. *Inclusion, 5*(4), 234–247. https://doi.org/10.1352/2326-6988-5.4.234

Hampden-Thompson, G., & Galindo, C. (2017). School-family relationships, school satisfaction and the academic achievement of young people. *Educational Review, 69*(2), 248–265. http://dx.doi.org/10.1080/00131911.2016.1207613

Handicapped Children's Protection Act of 1986, Pub. L. No. 99-372, 100 Stat. 796 (1986). https://www.congress.gov/99/statute/STATUTE-100/STATUTE-100-Pg796.pdf

Harry, B. (1992). *Cultural diversity, families, and the special education system: Communication and empowerment*. Teachers College Press.

Harry, B. (2008). Collaboration with culturally and linguistically diverse families: Ideal versus reality. *Exceptional Children, 74*(3), 372–388. Sage. https://doi.org/10.1177/001440290807400306

Heller, T., Harris, S. P., Gill, C. J., & Gould, R. (2019). *Disability in American life: An encyclopedia of concepts, policies, and controversies.* ABC-CLIO. https://www.gale.com/ebooks/9781440834233/disability-in-american-life-an-encyclopedia-of-concepts-policies-and-controversies

Henderson, L. J., Williams, J. L., & Bradshaw, C. P. (2020). Examining home-school dissonance as a barrier to parental involvement in middle school. *Preventing School Failure, 64*(3), 201–211. https://doi.org/10.1080/1045988X.2020.1719964

Herawati, T., Rizkillah, R., & Hernawati, N. (2020). Differences in father and mother involvement and the factors that influence it on early childhood education. *SEA-CECCEP, 1*(1), 17–31. http://seameo-ceccep.org/journal/index.php/eccep/article/view/7

Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision making. *British Journal of Special Education*, *33*(3), 148–157. https://doi.org/10.1111/j.1467-8578.2006.00430.x

Hill, N. E., & Taylor, L. C. (2004). Parental school involvement and children's academic achievement: Pragmatics and issues. *Current Directions in Psychological Science, 13*(4), 161–164. https://doi.org/10.1111/j.0963-7214.2004.00298.x

Hodge, N., & Runswick-Cole, K. (2008). Problematizing parent-professional partnerships in education. *Disability & Society, 23*(6), 637–647. https://doi.org/10.1080/09687590802328543

Hoover-Dempsey, K., & Sandler, H. (1995). Parental involvement in children's education: Why does it make a difference? *Teachers College Record*, *97*(2), 311–331. https://doi.org/10.1177/016146819509700202

Hoover-Dempsey, K. V., Walker, J. M., Sandler, H. M., Whetsel, D., Green, C. L., Wilkins, A. S., & Closson, K. (2005). Why do parents become involved?

Research findings and implications. *The Elementary School Journal, 106*(2), 105–130. https://doi.org/10.1086/499194

Hsiao, Y., Higgin, K., Pierce, T., Schafer Whitby, P. J., & Tandy, R. D. (2017). Parental stress, family quality of life, and family-teacher partnerships: Families of children with autism spectrum disorder. *Research in Developmental Disabilities, 70*, 152–162. https://doi.org/10.1016/j.ridd.2017.08.013

Ice, C. L., & Hoover-Dempsey, K. V. (2011). Linking parental motivations for involvement and student proximal achievement outcomes in homeschooling and public schooling settings. *Education and Urban Society*, *43*(3), 339–369. https://doi.org/10.1177/0013124510380418

Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Individuals With Disabilities Education Act Amendments of 1997, Pub. L. No. 105-17, 111 Stat. 37 (1997).

Ishimaru, A. M., Torres, K. E., Salvador, J. E., Lott, J., Williams, D. M. C., & Tran, C. (2016). Reinforcing deficit, journeying toward equity: Cultural brokering in family engagement initiatives. *American Educational Research Journal*, *53*(4), 850–882. https://doi.org/10.3102/0002831216657178

Jackson, K., & Andipatin, M. (2021). An exploration of the challenges fathers experience when parenting a child that presents with dyspraxia. *Qualitative Research Journal, 21*(4), 424–443. https://doi.org/10.1108/QRJ-09-2020-0103

Johnson-Bailey, J. (2002). Race matters: The unspoken variable in the teaching-learning transaction. *New Directions for Adult and Continuing Education, 2002*(93)*,* 39–50. https://doi.org/10.1002/ace.48

Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development, and Education, 47*(2*),* 119–136. https://doi.org/10.1080/713671106

Karande S., Kumbhare, N., Kulkarni, M., & Shah, N. (2009). Anxiety levels in mothers of children with specific learning disability. *Journal of Postgrad Medicine, 55*(3), 165–170. http://doi.org/10.4103/0022-3859.57388

Kassa, C. (2019). Commentary on "The sibling's perspective: experiences of having a sibling with a learning disability and behaviour described as challenging." *Tizard Learning Disability Review, 24*(3), 147–150. https://doi.org/10.1108/TLDR-04-2019-0017

Kausar, S., Jevne, R. F., & Sobsey, D. (2003). Hope in families of children with developmental disabilities. *Journal on Developmental Disabilities, 10*(1), 35–46. https://oadd.org/wp-content/uploads/2016/12/kauser_etal.pdf

Kervick, C. T. (2017). Parents are the experts: Understanding parent knowledge and the strategies they use to foster collaboration with special education teams. *Journal of the American Academy of Special Education Professionals, 12*(2), 62–82. https://files.eric.ed.gov/fulltext/EJ1164646.pdf

Kim, J. (2016). *Understanding narrative inquiry*. Sage.

Kirksey, J. J., Gottfried, M. A., & Freeman, J. A. (2022). Does parental involvement change after schools assign students an IEP? *Peabody Journal of Education, 97*(1), 18–31. https://doi.org/10.1080/0161956X.2022.2026717

Klarman, M. J. (2007). *Brown v. Board of Education and the civil rights movement*. Oxford University Press.

Kluth, P., Biklen, D., English-Sand, P., & Smukler, D. (2007). Going away to school: Stories of families who move to see inclusive educational experiences for their children with disabilities. *Journal of Disability Policy Studies, 18*(1), 43–56. https://doi.org/10.1177/10442073070180010501

Koch, K. A. (2016). The influence of parenting experience on special education teachers' pedagogy. *International Journal of Special Education, 31*(3), 1–19. https://eric.ed.gov/?id=EJ1120684

Kurth, J. A., Love, H., & Pirtle, J. (2020). Parent perspectives of their involvement in IEP development for children with autism. *Focus on Autism & Other Developmental Disabilities, 35*(1), 36–46. https://doi.org/10.1177/1088357619842858

Labov, W., & Waletzky, J. (1997). Narrative analysis: Oral versions of personal experience. *Journal of Narrative and Life History, 7*(1–4), 3–38. https://doi.org/10.1075/jnlh.7.02nar

Lake, J. F., & Billingsley, B. S. (2000). An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education, 21*(4), 240–251. https://eric.ed.gov/?id=EJ611318

Lalvani, P. (2012). Parents' participation in special education in the context of implicit educational ideologies and socioeconomic status. *Education and Training in Autism and Developmental Disabilities, 47*(4), 474–486. https://www.jstor.org/stable/23879640

Lareau, A., & Weininger, E. B. (2008). Time, work, and family life: Reconceptualizing gendered time patterns through the case of children's organized activities. *Sociological Forum, 23*(3), 419–454. https://doi.org/10.1111/j.1573-7861.2008.00085.x

Lawson, M. A. (2003). School-family relations in context. *Urban Education, 38*(1), 77–133. https://doi.org/10.1177/0042085902238687

Lee, J. S., & Bowen, N. K. (2006). Parental involvement and the achievement gap among elementary school children. *American Educational Research Journal, 43*(2), 193–218. https://doi.org/10.3102/00028312043002193

Lee, Y., & Park, H. J. (2016). Becoming a parent of a child with special needs: Perspectives from Korean mothers living in the United States. *International Journal of Disability, Development, and Education, 63*(6), 593–607. http://dx.doi.org/10.1080/1034912X.2016.1154139

Lilly, C. L., & Hoover-Dempsey, K. V. (2011). Linking parental motivations for involvement and student proximal achievement outcomes in homeschooling and public schooling settings. *Education and Urban Society, 43*(3), 339–369. https://doi.org/10.1177/0013124510380418

Lin, M., & Bates, A. (2010). Home visits: How do they affect teachers' beliefs about teaching and diversity? *Early Childhood Education Journal, 38*(3), 179–185. https://doi.org/10.1007/s10643-010-0393-1.

Lo, L. (2008). Chinese families' level of participation and experiences in IEP meetings. *Preventing School Failure, 53*(1), 21–27. https://doi.org/10.3200/PSFL.53.1.21-27

Love, H. R., Zagona, A. L., Kurth, J. A., & Miller, A. L. (2017). Parents' experiences in educational decision making for children and youth with disabilities. *Inclusion, 5*(3), 158–172. http://dx.doi.org/10.1352/2326-6988-5.3.158

Low, H. M., Lee, L. W., & Ahmad, A. C. (2020). Knowledge and attitudes of special education teachers towards the inclusion of students with autism spectrum disorder. *International Journal of Disability, Development, and Education, 67*(5), 497–514. https://doi.org/10.1080/1034912X.2019.1626005

Machin, D., & Mayr, A. (2012). *How to do critical discourse analysis: A multimodal introduction*. Sage.

Macleod, K., Causton, J. N., Radel, M., & Radel, P. (2017). Rethinking the individualized education plan process: Voices from the other side of the table. *Disability and Society, 32*(3), 381–400. http://dx.doi.org/10.1080/09687599.2017.1294048

Mapp, K. L., & Kuttner, P. J. (2013). *Partners in education: A dual capacity-building framework for family-school partnerships.* U.S. Department of Education. https://www2.ed.gov/documents/family-community/partners-education.pdf

Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research* (4th ed.). Sage.

Masten, A. (2018). Resilience theory and research on children and families: Past, present, and promise. *Journal of Family Theory & Review, 10*(1), 12–31. https://doi.org/10.1111/jftr.12255

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). Sage.

Maxwell, J. A., & Miller, B. A. (2008). Categorizing and connecting strategies in qualitative data analysis. In S. N. Hesse-Biber & P. Leavy (Eds.), *Handbook of emergent methods* (pp. 461–477). The Guilford Press.

Mayger, L., & Provinzano, K. (2022). Leadership for family and community engagement: A qualitative policy analysis of state principal evaluation processes. *Educational Administration Quarterly*, *58*(1), 141–177. Sage. https://doi.org/10.1177/0013161X211052501

Mazher, W. (2012). A Foucaultian critique of learning disability discourses: Personal narratives and science. *International Journal of Qualitative Studies in Education, 25*(6), 767–800. https//doi.org/10.1080/09518398.2011.569767

McCoach, D. B., Goldstein, J., Behuniak, P., Reis, S. M., Black, A. C., Sullivan, E. E., & Rambo, K. (2010). Examining the unexpected: Outlier analyses of factors affecting student achievement. *Journal of Advanced Academics, 21*(3), 426–468. https://files.eric.ed.gov/fulltext/EJ906112.pdf

McGee, G. W. (2004). Closing Illinois' achievement gap: Lessons from the "Golden Spike" high poverty, high-performing schools. *Journal of Education for Students Placed at Risk, 9*(2), 97–125. https://doi.org/10.1207/s15327671espr0902_2

McNeal, R. B. (2012). Checking in or checking out? Investigating the parent involvement reactive hypothesis. *The Journal of Educational Research, 105*(2), 79–89. https://doi.org/10.1080/00220671.2010.519410

Mereoiu, M., Abercrombie, S., & Murray, M. M. (2016). Structured intervention as a tool to shift views of parent-professional partnerships: Impact on attitudes toward the IEP. *Exceptionality Education International, 26(*1), 36–52. https://doi.org/10.5206/eei.v26i1.7734

Merriam, S. B. (2002). *Qualitative research in practice*. Jossey-Bass.

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation* (4th ed.). Jossey-Bass.

Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Sage.

Mishler, E. G. (1986). *Research interviewing: Context and narrative*. First Harvard University Press.

Mitchell, D., Morton, M., & Hornby, G. (2010). *Review of the literature on individual education plans: Report to the New Zealand Ministry of Education*. Ministry of Education. http://hdl.handle.net/10092/5766

More, C. M., Hart, J. E., & Cheatham, G. A. (2013). Language interpretation for diverse families: Considerations for special education teachers. *Intervention in School and Clinic, 49*, 113–120. https://eric.ed.gov/?id=EJ1019895

Mueller, T. G. (2015). Litigation and special education: The past, present, and future direction for resolving conflicts between parents and school districts. *Journal of Disability Policy Studies, 26*(3), 135–143. https://doi.org/10.1177/1044207314533382

Mueller, T. G., & Buckley, P. C. (2014). Fathers' experiences with the special education system: The overlooked voice. *Research and Practice for Persons with Severe Disabilities, 39*(2), 119–135. https://doi.org/10.1177/1540796914544548

Mueller, T. G., Massafra, A., Robinson, J., & Peterson, L. (2019). Simulated individualized education program meetings: Valuable pedagogy within a preservice special educator program. *Teacher Education and Special Education, 42*(3), 209–226. https://doi.org/10.1177/0888406418788920

Mueller, T. G., & Piantoni, S. (2013). Actions speak louder than words: How do special education administrators prevent and resolve conflict with families? *The Journal of Special Education Apprenticeship, 2(*2), 1–15. https://eric.ed.gov/?id=EJ1127777

Murphy, A. N., & Risser, H. J. (2022). Perceived parent needs in engaging with therapeutic supports for children with disabilities in school settings: An exploratory study. *Research in Developmental Disabilities, 123*, 1–11. https://doi.org/10.1016/j.ridd.2022.104183

Murry, A. T., & Wiley, J. (2017). Barriers and solutions: Direction for organizations that serve Native American parents of children in special education. *Journal of American Indian Education, 56*(3), 3–33. https://doi.org/10.5749/jamerindieduc.56.3.0003

Murtadha-Watts, K., & Stoughton, E. (2004). Critical cultural knowledge in special education: Reshaping the responsiveness of school leaders. *Focus on Exceptional Children, 37*(2), 1–8. https://doi.org/10.17161/foec.v37i2.6809

Musgrove, M. (2011). *A response to intervention (RTI) process cannot be used to delay-deny an evaluation for eligibility under the Individuals with Disabilities Education Act (IDEA*) [Policy brief]. U.S. Department of Education Office of

Special Education and Rehabilitative Services. https://sites.ed.gov/idea/files/osep11-07rtimemo.pdf

National Center for Education Statistics. (2021). *Students with disabilities*. Condition of Education. https://nces.ed.gov/programs/coe/indicator/cgg

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities, 117*(1), 48–66. https://doi.org/10.1352/1944-7558-117.1.48

Olivos, E. M., Gallagher, R. J., & Aquilar, J. (2010). Fostering collaboration with culturally and linguistically diverse families of children with moderate to severe disabilities. *Journal of Educational and Psychological Consultation, 20*(1), 28–40. https://doi.org/10.1080/10474410903535372

Osborne, A. G., & Russo, C. J. (2010). Attorney fees, school boards, and special education. *School Business Affairs, 76*(5), 36–38. https://files.eric.ed.gov/fulltext/EJ904679.pdf

Patton, M. Q. (2015). *Qualitative research & evaluation methods* (4th ed.). Sage.

Pennsylvania Association for Retarded Children v. Pennsylvania, 343 F. Supp. 279 (E.D. Pa. 1972). https://case-law.vlex.com/vid/pennsylvania-ass-n-ret-885252438

Polkinghorne, D. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education, 8*(1), 5–23. https://doi.org/10.1080/0951839950080103

Quinn, K. P., & Lee, V. (2007). The wraparound approach for students with emotional and behavioral disorders: Opportunities for school psychologists. *Psychology in the Schools, 44*(1), 101–111. https://doi.org/10.1002/pits.20209

Ramirez, A. Y. (2003). Dismay and disappointment: Parental involvement of Latino immigrant parents. *The Urban Review, 35*(2), 93–110. https://doi.org/10.1023/A:1023705511946

Raskind, M. H., Goldberg, R. J., Higgins, E. L., & Herman, K. L. (2003). *Life success for children with learning disabilities: A parent's guide*: Frostig Center. https://auspeld.org.au/wp-content/uploads/2013/02/LifeSuccessParentGuide.pdf

Ratcliff, N., & Hunt, G. (2009). Building teacher-family partnerships: The role of teacher preparation programs. *Education, 129*(3), 495–505. https://eric.ed.gov/?id=EJ871593

Ray, J. A., Pewitt-Kinder, J., & George, S. (2009). Partnering with families of children with special needs. *Young Children, 64*(5), 16–22. https://eric.ed.gov/?id=EJ868190

Reiman, J. W., Beck, L., Coppola, T., Engels, A., & Center for Appropriate Dispute Resolution in Special Education (CADRE). (2010). *Parents' experiences with the IEP process: Considerations for improving practice.* https://files.eric.ed.gov/fulltext/ED512611.pdf

Reynolds, R., & Howard, T. (2013). Sharing responsibility: A case for real parent-school partnerships. In M. B. Katz & M. Rose (Eds.), *Public education under siege* (pp. 201–206). University of Pennsylvania Press.

Riessman, C. K. (1993). *Narrative analysis*. Sage.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Sage.

Rios, K., Aleman-Tovar, J., & Burke, M. M. (2020). Special education experiences and stress among Latina mothers of children with autism spectrum disorder (ASD). *Research in Autism Spectrum Disorders, 73,* Article 101534. https://doi.org/10.1016/j.rasd.2020.101534

Roberts, C., & Hyatt, L. (2019). *The dissertation journey: A practical and comprehensive guide to planning, writing, and defending your dissertation* (3rd ed.). Corwin.

Rosetti, Z., Burke, M., Hughes, O., Schraml-Block, K., Rivera, J., Rios, K., Tovar, J., & Lee, J. (2021). Parent perceptions of the advocacy expectation in special education. *Exceptional Children, 87*(4) 438–457. https://doi.org/10.1177/0014402921994095

Ross, H. (2019). Supporting a child with dyslexia: How parents/carers engage with school-based support for their children. *British Journal of Special Education 46*(2), 136–156. https://doi.org/10.1111/1467-8578.12254

Rotatori, A. F., Obiakor, F. E., & Bakken, J. P. (2011). *History of special education*. Emerald Publishing Limited.

Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data* (3rd ed.). Sage.

Salas, L. (2004). Individualized educational plan (IEP) meetings and Mexican American parents: Let's talk about it. *Journal of Latinos and Education, 3*(3), 181–192. https://doi.org/10.1207/s1532771xjle0303_4

Saldana, J. (2016). *The coding manual for qualitative researchers*. Sage.

Santamaria Graff, C., Manlove, J., Stuckey, S., & Foley, M. (2021). Examining pre-service special education teachers' biases and evolving understandings about families through a family as faculty approach. *Preventing School Failure: Alternative Education for Children and Youth, 65*(1), 20–37. https://doi.org/10.1080/1045988X.2020.1811626

Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (1997). Parent to parent programs: A resource for parents and professionals. *Journal of Early Intervention. 21*(1), 73–83. https://doi.org/10.1177/105381519702100108

Schultz, S. (2022, December). *Differences between a 504 Plan and an Individualized Education Program (IEP)*. National Education Association. https://www.nea.org/professional-excellence/student-engagement/tools-tips/differences-between-504-plan-and-individualized-education-program-iep

Sears, J. A., Peters, B. L., Beidler, A. M. S., & Murawski, W. W. (2021). Using relationships to advocate with, for, and to families. *TEACHING Exceptional Children*, *53*(3), 194–204. https://doi.org/10.1177/0040059920982373

Seidman, I. (2013). *Interviewing as qualitative research*. Teachers College Press.

Seim, A. R., Jozefiak, T., Wichstrom, L., Lydersen, S., & Kayed, N. S. (2020). Reactive attachment disorder and disinhibited social engagement disorder in adolescence: Co-occurring psychopathology and psychosocial problems. *European Child and Adolescent Psychiatry, 31*, 85–98. https://doi.org/10.1007/s00787-020-01673-7

Sheldon, S. B., & Epstein, J. L. (2005). Involvement counts: Family and community partnerships and mathematics achievement. *Journal of Educational Research, 98*, 196–206. https://doi.org/10.3200/JOER.98.4.196-207

Shelton, L. G. (2019). *The Bronfenbrenner primer*. Routledge.

Singer, G. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal of Mental Retardation, 111*(3), 155–169. https://doi.org/10.1352/0895-8017(2006)111[155:MOCSOD]2.0.CO;2

Singh, S., & Keese, J. (2020). Applying systems-based thinking to build better IEP relationships: A case for relational coordination. *Support for Learning, 35*(3), 359–371. https://doi.org/10.1111/1467-9604.12315

Smith, T., & Sheridan, S. (2019). The effects of teacher training on teachers' family-engagement practices, attitudes, and knowledge: A meta-analysis. *Journal of Educational and Psychological Consultation, 29*(20), 128–157. https://doi.org/10.1080/10474412.2018.1460725

Stanger, N. R. G. (2011). Moving "eco" back into socio-ecological models: A proposal to reorient ecological literacy into human developmental models and school systems. *Human Ecology Review, 18*(2), 167–173. https://www.jstor.org/stable/24707472

Supporting Change and Reform in Preservice Teaching in North Carolina. (2022, December). *IEP process flowchart.* https://scriptnc.fpg.unc.edu/sites/scriptnc.fpg.unc.edu/files/resources/IEP-Process-Flowchart_0.pdf

Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the quality of family-professional partnerships in special education services. *Exceptional Children, 72*(1), 65–81. https://doi.org/10.1177/001440290507200104

The Center for Appropriate Dispute Resolution in Special Education. (2020). *IDEA dispute resolution summary for Georgia: 2009–2010 to 2019–2020*. CADRE: The Center for Appropriate Dispute Resolution in Special Education. https://www.cadreworks.org/resources/cadre-materials/state-part-b-dispute-resolution-data-summaries

The Public Interest Law Center. (2019). *Pennsylvania Association for Retarded Citizens (parc) v. Commonwealth of Pennsylvania: The Public Interest Law Center*. Public Interest Law Center. https://www.pubintlaw.org/cases-and-projects/pennsylvania-association-for-retarded-citizens-parc-v-commonwealth-of-pennsylvania/

The University of Kansas. (2021, October 18). *Timeline of the individuals with disabilities education act (IDEA)*. https://educationonline.ku.edu/community/idea-timeline

Trainor, A. A. (2010). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly, 41*(3), 245–263. https://www.jstor.org/stable/40890868

Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with A.S.D. *School Mental Health, 5,* 3–14. https://doi.org/10.1007/s12310-012-9102-0

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family professional partnership models: Collective empowerment as the model for the early 21st century. In S. J. Measels & J. P. Shonkoff (Eds.), *Handbook of early* *childhood intervention* (pp. 630–650). Cambridge University Press. https://doi.org/10.1017/CBO9780511529320.029

Turnbull, A. P., Turnbull, R., Erwin, E. J., Soodak, L. C., & Shogren, K. A. (2011). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust.* Pearson Education.

Ungvarsky, J. (2022). Fundamental attribution error (social psychology). In *Salem Press Encyclopedia*.

Universal Teacher. (n.d.). *Transferability in qualitative research*. https://universalteacher.com/1/transferability-in-qualitative-research/

U.S. Department of Education. (2020, November 24). *A history of the Individuals with Disabilities Education Act*. Individuals with Disabilities Education Act. https://sites.ed.gov/idea/IDEA-History#1980s,1980s-90s

U.S. Department of Education. (2022, October 1). *Implementing RTI Using Title I, Title III, and CEIS Funds* [Policy brief]. https://www2.ed.gov/programs/titleiparta/rtifiles/rti.pdf

Valle, J. (2009). *What mothers say about special education*. Palgrave MacMillan.

Valle, J. (2011). Down the rabbit hole: A commentary about the research on parents and special education. *Learning Disability Quarterly, 34*(3), 183–190. https://doi.org/10.1177%2F0731948711417555

Wanat, C. (2010). Challenges balancing collaboration and independence in home-school relationships: Analysis of parents' perceptions in one district. *The School Community Journal, 20*(1), 159–186. https://files.eric.ed.gov/fulltext/EJ891837.pdf

Wang, P., Michaels, C. A., & Day, M. S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism & Developmental Disorders, 41*, 783–795. http://dx.doi.org/10.1007/s10803-010-1099-3

Weiss, H. B., Kreider, H., Lopez, M. E., & Chatman-Nelson, C. M. (2014). *Preparing educators to engage families: Case studies using an ecological framework.* Sage.

Wilkinson, D. & Birmingham, P. (2003). *Using research instruments: A guide for researchers*. Routledge.

Wingate, S. E., Postlewaite, R. R., Mena, R. M., Neely-Barnes, S. L., & Elswick, S. E. (2018). Parent knowledge of and experiences with response to intervention. *Children & Schools, 40*(3), 163–172. https://doi.org/10.1093/cs/cdy010

Wynne, M. E., Ausikaitis, A. E., & Satchwell, M. (2013). Adult outcomes for children and adolescents with EBD: Understanding parents' perspectives. *Sage Open, 3*(1). https://doi.org/10.1177/2158244013483133

Yell, M. (2019). *The law and special education*. Pearson.

Zagona, A. L., Miller, A. L., Kurth, J. A., & Love, H. R. (2019). Parent perspectives on special education services: How do schools implement team decisions? *School Community Journal, 29*(2), 105–128. https://files.eric.ed.gov/fulltext/EJ1236582.pdf

Zeitlin, V. M., & Curcic, S. (2014). Parental voices on Individualized Education Programs: "Oh, IEP meeting tomorrow? Rum tonight!" *Disability & Society, 29*(3), 373–387. https://doi.org/10.1080/09687599.2013.776493

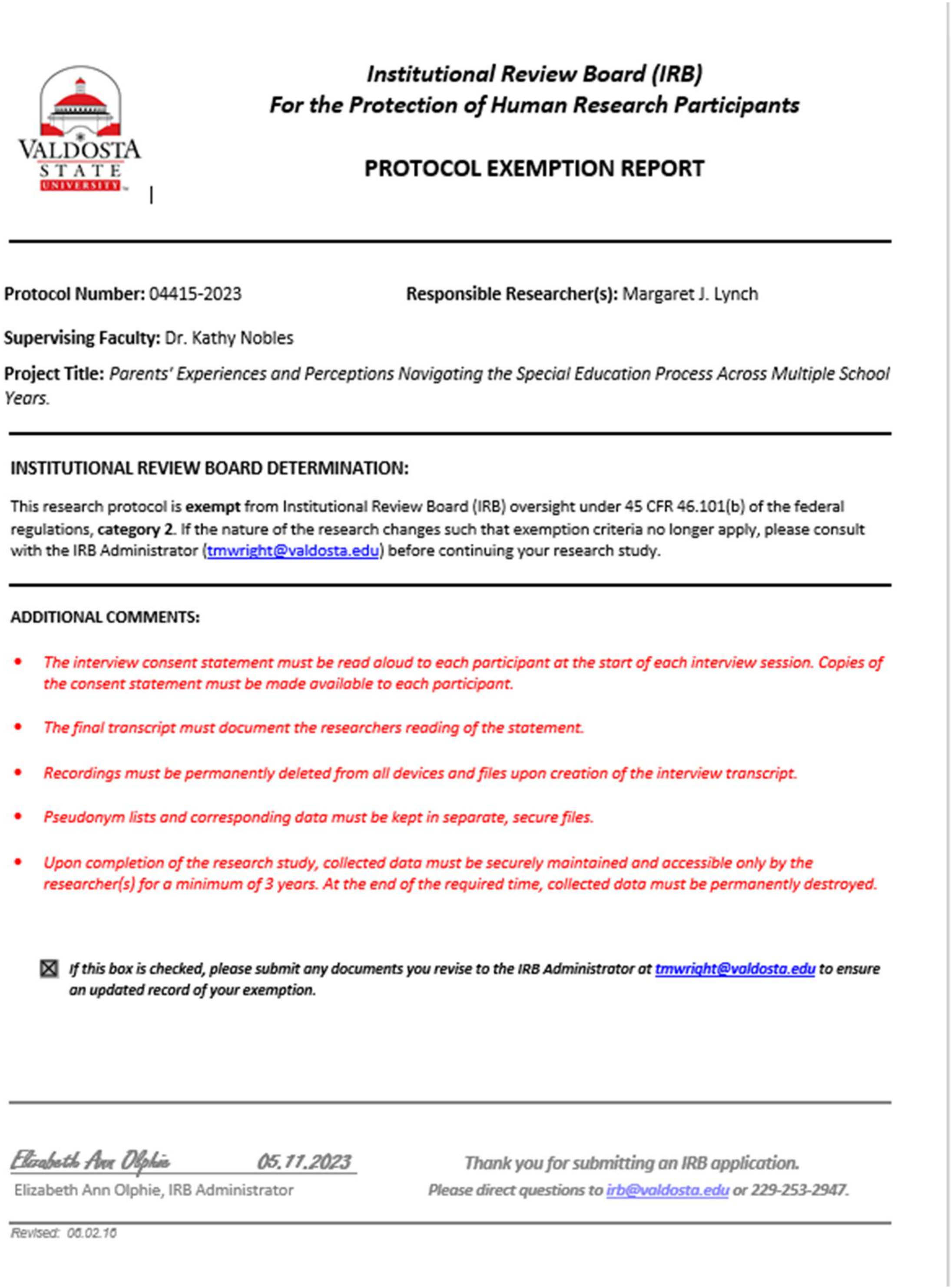
Zhang, D., Hsu, H. Y., Kwok, O., Benz, M., & Bowman-Perrott, L. (2011). The impact of basic-level parent engagements on student achievement: Patterns associated with race/ethnicity and socioeconomic status (SES). *Journal of Disability Policy Studies*, *22*(1), 28–39. https://doi.org/10.1177/1044207310394447

Zhou, J., Gao, S., Sun, T., Gao, W., Fu, W., Ying, Z., & Mao, W. (2022). Sleep quality, anxiety, somatic symptoms, and features of brain structure in parents of children with disabilities. *Social Behavior and Personality: An International Journal, 50*(6), 96–109. https://doi.org/10.2224/sbp.11557

Appendix A:

Institutional Review Board Exemption

Institutional Review Board Exemption



Institutional Review Board (IRB)
For the Protection of Human Research Participants

PROTOCOL EXEMPTION REPORT

Protocol Number: 04415-2023 **Responsible Researcher(s):** Margaret J. Lynch

Supervising Faculty: Dr. Kathy Nobles

Project Title: *Parents' Experiences and Perceptions Navigating the Special Education Process Across Multiple School Years.*

INSTITUTIONAL REVIEW BOARD DETERMINATION:

This research protocol is **exempt** from Institutional Review Board (IRB) oversight under 45 CFR 46.101(b) of the federal regulations, **category 2**. If the nature of the research changes such that exemption criteria no longer apply, please consult with the IRB Administrator (tmwright@valdosta.edu) before continuing your research study.

ADDITIONAL COMMENTS:

- *The interview consent statement must be read aloud to each participant at the start of each interview session. Copies of the consent statement must be made available to each participant.*
- *The final transcript must document the researchers reading of the statement.*
- *Recordings must be permanently deleted from all devices and files upon creation of the interview transcript.*
- *Pseudonym lists and corresponding data must be kept in separate, secure files.*
- *Upon completion of the research study, collected data must be securely maintained and accessible only by the researcher(s) for a minimum of 3 years. At the end of the required time, collected data must be permanently destroyed.*

☒ ***If this box is checked, please submit any documents you revise to the IRB Administrator at tmwright@valdosta.edu to ensure an updated record of your exemption.***

Elizabeth Ann Olphie 05.11.2023
Elizabeth Ann Olphie, IRB Administrator

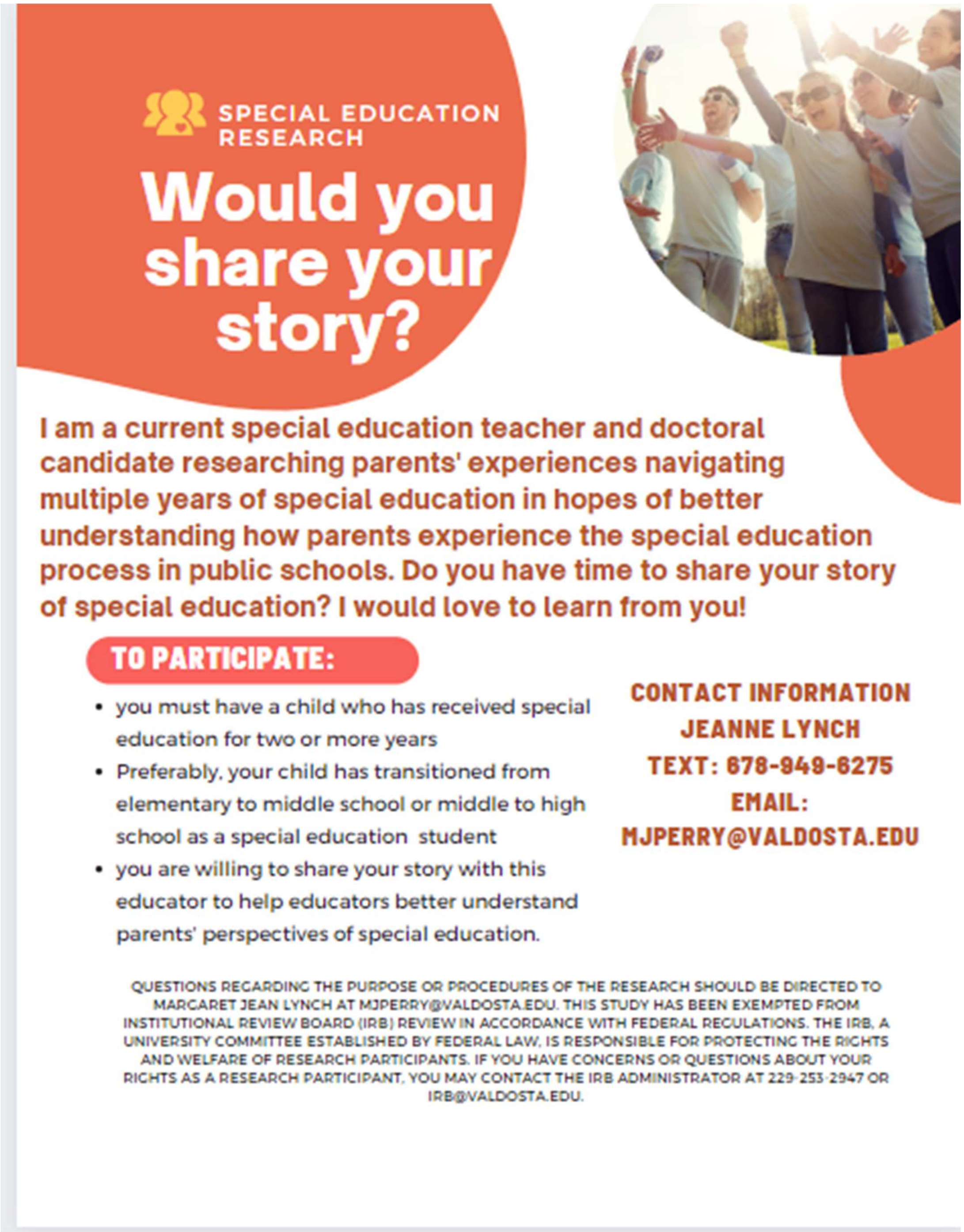
Thank you for submitting an IRB application.
Please direct questions to irb@valdosta.edu or 229-253-2947.

Revised: 06.02.16

Appendix B:

Recruitment Flyer

Recruitment Flyer



SPECIAL EDUCATION RESEARCH

Would you share your story?

I am a current special education teacher and doctoral candidate researching parents' experiences navigating multiple years of special education in hopes of better understanding how parents experience the special education process in public schools. Do you have time to share your story of special education? I would love to learn from you!

TO PARTICIPATE:

- you must have a child who has received special education for two or more years
- Preferably, your child has transitioned from elementary to middle school or middle to high school as a special education student
- you are willing to share your story with this educator to help educators better understand parents' perspectives of special education.

CONTACT INFORMATION
JEANNE LYNCH
TEXT: 678-949-6275
EMAIL:
MJPERRY@VALDOSTA.EDU

QUESTIONS REGARDING THE PURPOSE OR PROCEDURES OF THE RESEARCH SHOULD BE DIRECTED TO MARGARET JEAN LYNCH AT MJPERRY@VALDOSTA.EDU. THIS STUDY HAS BEEN EXEMPTED FROM INSTITUTIONAL REVIEW BOARD (IRB) REVIEW IN ACCORDANCE WITH FEDERAL REGULATIONS. THE IRB, A UNIVERSITY COMMITTEE ESTABLISHED BY FEDERAL LAW, IS RESPONSIBLE FOR PROTECTING THE RIGHTS AND WELFARE OF RESEARCH PARTICIPANTS. IF YOU HAVE CONCERNS OR QUESTIONS ABOUT YOUR RIGHTS AS A RESEARCH PARTICIPANT, YOU MAY CONTACT THE IRB ADMINISTRATOR AT 229-253-2947 OR IRB@VALDOSTA.EDU.

Appendix C:

Consent Form

Consent Form

VALDOSTA STATE UNIVERSITY
Consent to Participate in Research

You are being asked to participate in an interview as part of a research study entitled "Parents' Experiences and Perceptions Navigating the Special Education Process Across Multiple School Years," conducted by Margaret Jean Lynch, a *student* in the Curriculum and Instruction department at Valdosta State University. The purpose of the study is to explore how parents of children who qualify for special education and have participated for two or more years in the public-school special education process describe their experiences in the special education parent-school partnership. You will receive no direct benefits from participating in this research study. However, your responses may help us learn more about parents' perspectives on navigating the special education process. There are no foreseeable risks involved in participating in this study other than those encountered daily. Participation should take approximately 4 hours in total. The interviews will be audio-recorded to capture your concerns, opinions, and ideas. Once the interview recording has been transcribed, the recording will be deleted from recording devices. This research study and your participation will be kept confidential. Your identifiable information will be replaced with a pseudonym in publications or presentations. No one, including the researcher, will associate your responses with your identity. Your participation is voluntary. You may choose not to participate, to stop responding at any time, or to skip questions you do not want to answer. You must be at least 18 years of age to participate in this study. Your participation in the interview serves as your voluntary agreement to participate in this research project and your certification that you are 18 years of age or older.

Questions regarding the purpose or procedures of the research should be directed to Margaret Jean Lynch at mjperry@valdosta.edu. This study has been exempted from Institutional Review Board (IRB) review in accordance with Federal regulations. The IRB, a university committee established by Federal law, is responsible for protecting the rights and welfare of research participants. If you have concerns or questions about your rights as a research participant, you may contact the IRB Administrator at 229-253-2947 or irb@valdosta.edu.

Procedures: If you agree to participate, you will participate in three interviews in the next 1-2 months. The first interview will focus on previous school experiences in the parent-school special education partnership and provide a context for how your child became eligible for special education. The second interview will focus on your recent experience with the parent-school special education partnership. The third and final interview will be an opportunity to reflect on your experiences and share what you have learned in your years of experience, as well as an opportunity for this researcher to clarify or follow up on ideas from the first two interviews. Interviews will be conducted virtually or in person, based on participants' preferences. Each interview will last about 90 minutes. Interviews will occur at a mutually agreed location, including a virtual meeting, a public location, or the participants' homes. The researcher will coordinate the days and times using the preferred contact method from the contact form. Interviews will take place after 3 pm Monday through Friday as this researcher is a current educator unless the time of interviews is delayed until the summer. In the summer, times may be more flexible. On the weekends, the researcher will accommodate the participants' schedules. Your total time is estimated at 4 hours, including all three interviews.

Appendix D:

Conversational Interview Guide Approach

Conversational Interview Guide Approach

IMPORTANT NOTE: Using a conversational approach in conjunction with an interview guide is the most effective way to build rapport while clarifying the interview's purpose (Patton, 2015). To effectively explore participants' experiences of the special education process, I will use a conversational interview guide approach to avoid influencing the flow of conversation with my interests, biases, or assumptions. Too much questioning by me will affect what participants choose to share and the credibility of the interview process by skewing the content toward my agenda. Given the emergent nature of qualitative research and my intent to allow participants to reconstruct their experiences of the special education process, the following questions will only be guides.

Interview Guide #1

This introduction will not be stated verbatim to avoid a stilted and artificial presentation of my interest. The following written introduction is meant to relay the intent of my introduction and not the exact verbiage.

Introduction

> Thank you for meeting with me today. I am so excited to hear about you and your child and how you have experienced the special education process. I want to thank you and let you know how much I appreciate your time and cooperation. The information in this interview will remain confidential, and I expect the interview to last about 90 minutes. (***Verify all consent forms have been signed***)
>
> **REMINDER**: As a reminder, I will audio-record this conversation so that I can be sure to reflect your responses accurately. Do you have any questions before we begin?
>
> **MY BACKGROUND**: To start, let me share a little about myself. I have been a special education teacher for 14 years, a former social worker, and a mother of five children, all of whom navigated school in their own individual way. I was drawn to this topic because I have seen how different the school experience can be for different families. I feel that it is essential to learn the perspectives of parents with students receiving special education to help teachers be more empathetic and responsive to families.

Guiding questions

While the first questions will be asked, the rest of these exact questions may not all be asked not to interrupt the natural flow of conversation. If the participant organically provides the information as part of their responses, the question will not be asked directly to avoid redundancy and the appearance of not listening. The questions provide a similar starting point and guide for this researcher to use with each participant.

1. I would love to know more about your child. How would you describe them? (If prompt needed, what three words describe your child-then ask more about each word)
2. What are your child's greatest qualities or strengths?
3. When did you first recognize that your child learned or processed the world differently?
4. How would you describe the school experience before special education services?
5. Thinking back, how would you describe how you and your child first became involved in the special education process?
6. What do you remember about the eligibility process for special education?
    a. Since your child has been identified as a special education student, how many Individualized Education Plan (IEP) meetings have you been a part of?
7. How would you describe the initial IEP meeting?
        i. In this meeting, how would you describe your role and other members' roles?
        ii. Does any memory or feeling stand out in regard to this meeting?
        iii. How was your child described during this first meeting?
        iv. If your child has been in the IEP meetings, how would you describe their experience?
8. When you think about past school years, how would you describe the staff's knowledge of your child's disability?
9. How would you describe your relationship with general and special education teachers in past years?
    a. Describe a time when you had to discuss a concern with the general or special education teacher.
    b. If I say the words "power and IEP," what ideas do you have in response?
10. When you think about past school years, how would you describe your knowledge of the process and your effectiveness in making a change regarding your child's education when needed?
11. How would you describe your own experience of school?
    a. If you have other children, how would you describe their experience of school?
12. What has worked well in your relationship with the school in the past or previous school years?
13. What has been a challenge in your relationship with the school in the past or previous school years?
14. When you think about past experiences with your child and special education, is there any other information you would like to add?

Interview Guide #2

The following written introduction is meant to relay the intent of my introduction and not the exact verbiage.

> Thank you for meeting with me again. The information in this interview will remain confidential, and I expect the interview to last about 90 minutes. As a reminder, I will audio-record this conversation to understand your responses accurately. Do you have any questions before we begin?
>
> Before we start, do you have any questions for me or anything you have thought about since our last meeting?

Guiding topics

While the first questions will be asked, the rest of these exact questions may not all be asked so as not to interrupt the natural flow of conversation. If the participant organically provides the information as part of their responses, the question will not be asked verbatim to avoid redundancy and the appearance of not listening. The questions provide a similar starting point and guide for this researcher to use with each participant.

1. In our last meeting, we talked more about the past. Today, I was wondering if you could share how you would describe your and your child's experiences this school year.
2. When you think about your own knowledge and skills to navigate special education, how would you describe them today versus when you began this process?
3. What is your understanding of the IEP and its components such as the services, goals, objectives, and accommodations?
4. Do you get regular progress reports on the IEP goals and if so, what are your thoughts about them in terms of how helpful they are to you as a parent?
5. How do you think your child's education is different from a student that is not in special education?
6. What do you expect from the IEP process and the special education teachers?
7. When you think about your role concerning school, how would you describe it? Has it changed over time?
8. How has the experience of being a parent of a child with a disability in special education changed your perspective on the role of the school?
9. Have you felt the need to access outside resources to better serve your child's needs?
10. What does collaboration mean to you? How would you describe your collaboration with the school staff?
11. How would you describe the impact of your past experiences in the special education process on how you currently interact with the school staff involved in the special education process?
12. If you could speak to new teachers, what would you want them to know about how parents experience the special education process?
13. What would you want to say if you could speak freely to your child's teachers?
14. How would you describe it when you have had to advocate for your child this year?
15. What has worked well in your relationship with the school this year?

16. What has been a challenge in your relationship with the school this year?

Follow-up: Interview Guide #3

The following written introduction is meant to relay the intent of my introduction and not the exact verbiage.

> Thank you for meeting with me again. As you know, the information in this interview will remain confidential, and I expect the interview to last about 90 minutes. As a reminder, I will audio-record this conversation so that I can be sure to understand your responses accurately. Do you have any questions before we begin?

1. When you reflect on your experiences of your child's education, including the parent-school partnership in special education, what has it meant for you? (Seidman, 2013)
2. When you reflect on your past and present experiences of special education, what advice would you give to a parent just starting the special education process, or what have you learned?
3. Beyond what you would want them to know, is there anything else that you want to share with educators about your experience of the special education process?
4. If you could change or improve anything about your school experiences regarding special education, what would it be?
5. Much of this Interview will include follow-up questions generated from my review and analysis of interviews 1 and 2 for each participant.

In addition, during the third Interview, Merriam and Tisdell (2016) recommended member checking the information and tentative interpretations by asking follow-up questions and clarifying with the participants. To be able to ask follow-up questions, I will code and analyze the participant's first two interviews prior to conducting the third Interview (Merriam and Tisdell, 2016). After reviewing and reflecting on the transcripts, this interview will clarify or further explore participants' responses as part of gathering more detailed and thicker descriptions. In clarifying, I will be member-checking to ensure we have a shared meaning of how they make meaning of their experiences.

Appendix E:

Interview Summary Form

Interview Summary Form

Participant Code (school number, Pseudonym):

____

Phone: ____________________ Email: _____________________________________

Date Interview Scheduled: _____________________ Time: _____________________

Date Interview Conducted: _____________________

Circle contact type: virtual, phone, in-person

Time Interview Began: ________________________ Ended: ____________________

Interview Return Date: ____

1) What key issues or themes struck me today in this contact?

2) What non-verbal language was noted or important?

3) Did I notice my own biases or assumptions emerge? If so, what?

4) Anything else that I saw as salient, interesting, or important?

5) **What new or remaining target questions do I have in considering the next contact with this site?**

Appendix F:

Participant Contact Form

Participant Contact Form

Parent Name/Pseudonym____

Parent level of Education____

Phone: ____________________ Email: _______________________________________

Circle preferred contact method: phone/email/text: Permission to email transcript: Y/N

Child’s Name______________________

Age and Grade________________

School name and number code: ___________________________________

Child's area of special education eligibility? _________________

# of other children in the home____________________________

Date and time of Interview #1____

Date and time of Interview #2____

Date and time of Interview #3____

CONTACT LOG

DATE	TIME	CONTENT/SUBJECT