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Strategies That Mothers of Children Who Are Deafblind Employ to Foster Collaboration Within Individualized Education Program Teams

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STRATEGIES THAT MOTHERS OF CHILDREN WHO ARE
DEAFBLIND EMPLOY TO FOSTER COLLABORATION
WITHIN INDIVIDUALIZED EDUCATION
PROGRAM TEAMS

A Dissertation Submitted in Partial Fulfillment
of the requirements of the Degree of
Doctor of Philosophy

Lanya Lynn McKittrick

College of Education and Behavioral Sciences
School of Special Education

May 2019

This Dissertation by: Lanya Lynn McKittrick

Entitled: *Strategies that Mothers of Children Who are Deafblind Employ to Foster Collaboration within Individualized Education Program Teams.*

has been approved as meeting the requirements for the Degree of Doctor of Philosophy in the College of Education and Behavioral Sciences in the School of Special Education.

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ABSTRACT

McKittrick, Lanya Lynn. *Strategies that mothers of children who are deafblind employ to foster collaboration within individualized education program teams.* Published Doctor of Philosophy dissertation, University of Northern Colorado, 2019.

Although active parent involvement is mandated as part of the Individuals with Disabilities Education Act (IDEA), parents continue to report dissatisfaction with IEP meetings. Despite increases in parent participation policy since the adoption of IDEA, the parent-professional partnership originally envisioned by lawmakers is arguably not consistent with practice. This is evident for families of all children who represent the thirteen disability categories covered under the auspice of IDEA; however, because of its uniqueness, this study focuses on families of children who are deafblind. Deafblindness is a low-incidence disability with a heterogenous population. Parents of children who are deafblind have unique challenges before, during, and after Individualized Education Program (IEP) meetings. Often there is a lack of professional knowledge about deafblindness, thereby requiring families to gain and share knowledge. Because parent knowledge and advocacy are essential roles, there is need to understand better how parents advocate and share knowledge during the IEP meeting. This study focused on parent-initiated strategies used to increase IEP team collaboration and to address their child's needs. Currently, there is a lack of research on IEP strategies initiated by parents

of children who are deafblind. Further, there is sparse research on families of children who are deafblind overall. Thus, this study begins to fill a gap in the research literature.

The purpose of this phenomenological qualitative study was to explore the strategies that parents of children who are deafblind use in fostering a collaborative relationship with their children's IEP teams. To do that, it was necessary to first gain an understanding of what leads parents to develop such advocacy strategies, and how parents view collaboration. Fourteen mothers of children who are deafblind were interviewed about the unique and essential perspectives that mothers have concerning IEP team meetings and collaboration. Open-ended interview questions were used to collect in-depth information as mothers shared their experiences of attending IEP meetings, with the goal of identifying themes regarding their experiences working with IEP teams. Participants were also asked to provide written responses to interview reflection questions. The researcher also journaled through the research process. The following questions were posed:

Q1   What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Q2   How do parents define collaboration with their IEP teams?

Q3   What knowledge and strategies do parents use in IEP meetings to promote collaboration?

The results from this study revealed valuable insights into the various and vital roles that parents play on their child's IEP teams, including case management, advocacy, and knowledge sharing. Three categories emerged from the data: (a) problems parents experience that lead them to develop advocacy strategies, (b) valued family-school collaboration, and (c) advocacy strategies used by families. The problems parents

experience fell into two distinct themes: (a) challenges associated with the deafblind population in schools and, (b) challenges with the IEP process.

Mothers of children who are deafblind shared insight on how they use collaborative strategies to build strong relationships with IEP team members. During discussions about relationship building, participants shared examples of how they use the collaboration principles of trust, respect, communication, advocacy, equality, commitment, and competence (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Not only did the mothers in this study indicate that these principles were important, but participants also encouraged professional team members to follow them. Because of the unique needs associated with deafblindness, collaboration between team members who are serving the child is vital to student success. Partnership comes in the form of problem-solving and knowledge sharing and in understanding the impacts of dual sensory loss. Knowledge sharing is reportedly tricky because often, families are the ones most knowledgeable about deafblindness and certainly of their child, yet families sometimes become frustrated because they wish that someone on the team would bring knowledge and ideas back to them.

The last category identified how participants advocate and share knowledge through positive, collaborative strategies. Advocacy strategies fell into the following three themes: (a) advocacy through action, (b) advocacy through knowledge, and (c) advocacy through student involvement. There are many roles that mothers play in educational planning including: (a) knowledge sharing, (b) advocacy, and (c) case management. Participants outlined advocacy through action strategies that fell into two categories: (a) direct strategies (e.g. meeting management strategies) and (b) leadership skills (e.g. consensus building, positive approach).

This study adds to the scant literature on families of children who are deafblind. The results provide meaningful insight into parent IEP experiences, paying careful attention to the much-neglected area of deafblindness. Participants shared strategies they use when playing these roles. These strategies can be shared with other families to help more families build collaborative relationships with IEP teams. The leadership skills and strategies mentioned in this study also provide families with ideas about how to advocate and share knowledge using a firm, but positive approach. Educators can benefit from reading this study to better understand the leadership role that families play in the IEP meeting and what strategies parents use to build consensus to get their child's needs met. Families and educators can benefit from better understanding of the strategies that mothers employ to increase collaboration and to get their child's needs met. Results from this study may not be representative because of the small sample size and because the deafblind etiology breakdown is more highly weighted toward families who have children with Usher syndrome.

Keywords: deafblindness, deaf-blind, dual sensory loss, family-professional partnership, collaboration, advocacy

ACKNOWLEDGEMENTS

DEDICATION

This is dedicated to the families and professionals that tirelessly work collaboratively for the common goal of educating children who are deafblind. I am so appreciative of the networking and support that fellow families and professionals have provided me as I walked this journey as a mom and researcher. I also dedicate this to my family, especially Conner and Dalton. Conner and Dalton have taught me so much about living each day to the fullest potential. They have been so gracious to share their personal stories with me and have helped me grow as a mom and person. Without my family's love and support this would not have been possible.

TABLE OF CONTENTS

CHAPTER

LIST OF TABLES

TABLE

LIST OF FIGURES

FIGURE

CHAPTER I

INTRODUCTION TO THE STUDY

Today, we are having a special Individualized Education Program meeting for my 10-year-old son. At home, I have seen him struggle this year, and I do not know why. I am upset because I do not have all the answers. Are his struggles because he is missing some of the information at school due to his dual sensory loss? Is it that he needs extra support in academics or perhaps that we are missing that he has other needs that are not related to deafblindness? I have been up all night trying to figure out how to get the IEP team to understand what is going on. The morning of the IEP meeting, I decide to bring my son to the meeting so that he can share how he is feeling. On the car ride, I explain to him that I am here to support him but that I need him to be honest with his team about what is going on in the classroom and at home.

I walk into the district office. I had hoped to have this meeting at our house so that it would be on "our turf," but it wouldn't work with schedules. I feel less comfortable in this environment because it feels impersonal. We continue into the stark conference room where the entire team is already seated. Have they had a pre-meeting without us? I feel the inequality of power.

The reason for this meeting is that I have asked the IEP team for a tutor. I know that what I am asking for is a stretch. His case manager informs me that he does not qualify for a tutor because he is making sufficient academic progress. Although I am not surprised by her response, I am hurt. Even though he has a supportive IEP team, they are not advocating for him. It's up to me now. My stomach is upset. I feel anxious. My son is watching my next move. I take a deep breath to calm myself. I am careful with my next words and actions.

I make a choice to advocate for my son by clearly and calmly explaining his need for a teacher of the deaf (TOD). The case manager addresses the rest of the team and asks their opinion. Everyone is silent. I look over at our district audiologist with a pleading look. He bravely tells the case manager that he agrees with me and that there is research to support what I am saying.

The case manager looks at my son, and says to him, "Don't worry. I do not yet have the knowledge to help you. I need to get some more information and background so that I can make things better for you. I promise I will do

everything to help you. I am sorry that you have been struggling and that we do not currently have what you need."

The next day they received approval for the district to hire an itinerant TOD to work with my son. The case manager called to thank me for advocating for my sons needs and for helping her to better understand how to help him. She also acknowledged his bravery at being there to advocate for his needs.

Personal Reflection

I am a mother of two children, ages 19 and 10, who are deafblind. The vignette I shared is of a recent Individualized Education Program (IEP) meeting for my son. I used to believe there would be no conflict if the team worked well together. But, meetings can easily turn emotional, especially if a family sees their child struggling. Thankfully, the meeting I described ended well, and my son is now doing well, but that meeting was stressful. If I would have let it turn emotional, it may not have ended with the same positive result. I have been fortunate over the years to get my son's needs met with IEP teams. Instead of looking for educators to create a positive, collaborative environment in IEP meetings, I assume mutual responsibility to ensure meetings are collaborative and that my son's needs get met.

I have had mostly positive IEP meetings over the years, but there were times when IEP teams did not understand my children's needs, and it was up to me to advocate. I had to fight for what my kids needed, which usually involved educating the teams about deafblindness and the unique needs associated with this low-incidence disability. I gained knowledge about deafblindness by doing research and would share that knowledge with IEP team members because often I was the only one on the team with knowledge about deafblindness. I discovered advocacy strategies by talking with other parents who had similar experiences. Most of the time, the IEP process felt rushed and impersonal.

However, I learned that a negative attitude or conflict approach did not get me anywhere. If I showed frustration and anger at the meeting, it usually led to conflict.

I learned that I could better advocate for my children's needs by employing positive strategies to improve collaboration. I learned how to compose myself in meetings. I would always be prepared with research to support my position. I would bring my sons with me to meetings and have them tell the team directly how their year was going. I would take steps to ensure that the meeting was meaningful to me. I always tried to be considerate of the team and to understand their viewpoints. I always checked in with everyone before the meeting to thank them and to see if there was anything we needed to discuss.

Because of my personal experiences, I became interested in finding ways to improve collaboration in IEP meetings. I found that past research was focused on either the conflict and family dissatisfaction itself or on strategies that educators can employ to improve collaboration. I found no studies that documented family-initiated strategies used to improve collaboration and to get their children's needs met. This study documents family-initiated strategies that lead to increased IEP team collaboration in hopes that these findings will lead to a more collaborative IEP team environment.

Significance of the Study

In 1975 the Education for All Handicapped Children's Act (EAHCA), hereafter referred to as the Individuals with Disabilities Education Act (IDEA), was passed to help ensure that students with disabilities would receive a free and appropriate public education (FAPE) just like their typically developing peers. Since 1975, there have been several amendments to IDEA, the most recent being in 2004. These amendments include additional provisions for parent involvement in the Individual Education Program (IEP)

process. Although parent involvement is an essential element of IDEA, parents still do not always feel like equal members of their child's IEP teams (Fish, 2008). IEP meeting practices still fall short of the partnership envisioned by IDEA (Martin, Marshall, & Sale, 2004). In an effort to acknowledge the diversity of families, the terms "parent" and "family" are used interchangeably in this study. Further definition of these terms is discussed in the Definition of Terms section of this paper. Additionally, because all of the study participants were mothers, I refer to them as such.

When parents feel like equal members of IEP teams, they report higher levels of satisfaction with IEP meetings (Childre & Chambers, 2005). Collaboration has been shown to improve the relationship between professionals and parents (Blue-Banning et al., 2004; Hedeen, Moses, & Peter, 2011). In 2004, Blue-Banning and colleagues, identified seven indicators of partnership: (a) communication, (b) commitment, (c) equality, (d) competence, (e) respect, (f) trust, and (g) advocacy. Successfully implementing these seven principles of partnership has been shown to lead to increased collaboration (Kyzar, Brady, Summers, Haines, & Turnbull, 2016; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). Much of the past research has focused on family dissatisfaction with the IEP process and the benefits of educators implementing the seven principles of partnership (Blue-Banning et al., 2004; Kyzar et al., 2016; Tucker, 2009).

Many parents describe the IEP process as stressful and non-collaborative, which can lead to dissatisfaction (Childre & Chambers, 2005; Esquivel, Ryan, & Bonner, 2008; Fish, 2008). Parents report that their participation in IEP meetings is often passive and that they feel like they do not have equal input during meetings (Childre & Chambers, 2005; Garriott, Wandry, & Snyder, 2000). Parents express concerns about the IEP process itself and report that meetings feel impersonal and too procedural (Hedeen et al.,

2011; Zeitlin & Curcic, 2014). Lack of knowledge of special education law and IEP team use of educational jargon can add to parent frustration (Fish, 2008; Zeitlin & Curcic, 2014).

When there are disagreements between parents and IEP teams, parents may find it necessary to advocate for their children so their individualized needs can be met (Trainor, 2010). Initially, parents do not often have the knowledge of special education law, their child's disability, and advocacy (Wang, Mannan, Poston, Turnbull, & Summers, 2004). Often, parents gain that knowledge over time by doing extensive research and networking with other families (Dammeyer, 2010). Families of children who are deafblind have additional challenges due to the heterogeneity of the population. Further, because deafblindness is a low-incidence disability, often the people who are the most knowledgeable about deafblindness on the team are the family members, which can lead to frustration for families (Correa-Torres & Bowen, 2016).

Parents may first try to resolve conflicts amicably. If the dispute cannot be resolved amicably, parents may try to achieve a mutually agreeable outcome by: (a) involving an advocate (Burke & Hodapp, 2016), (b) holding a facilitated IEP (Mueller & Vick, 2018), (c) requesting a resolution session (Mueller, 2009), or (d) using a mediator (Feinberg, Beyer, & Moses, 2002). If the IEP team is still not able to resolve the conflict, it could lead to due process (Lake & Billingsley, 2000; Mueller, 2015). Due process provisions are a safeguard for parents as part of IDEA, creating a court procedure using a hearing officer and previous case law to resolve any disputes about a child's education (Mueller & Carranza, 2011). Due process can be very costly, emotionally and financially (Special Education Expenditure Project [SEEP], 2003). In a study about special education dispute resolution, the average cost of due process hearings was $95,000 in 1999 and

2000 (SEEP, 2003), and some due process cases reached more than double that cost (Daggett, 2004). Because of the emotional and financial cost and the negative impact on relationships, it is advantageous to try to resolve the conflict without the use of due process.

Statement of Problem

There is a plethora of documented research that demonstrates parents are dissatisfied with the IEP meeting process (Fish, 2008; Mueller, Singer, & Draper, 2008; Zeitlin & Curcic, 2014). Specifically, parents report that IEP meetings are often impersonal and emotional and that it is their perception that their voices are often not heard (Zeitlin & Curcic, 2014). This dilemma is further exacerbated for parents of children who are deafblind. Because deafblindness is a low-incidence disability and because children who are deafblind have unique needs in the classroom, there are additional challenges when parents advocate for their child's needs (Ferrell, Bruce, & Luckner, 2014). For example, one major issue is that parents of children who are deafblind often struggle to get appropriate services for their children because of the lack of IEP team knowledge of deafblindness (Correa-Torres & Bowen, 2016; Kyzar & Summers, 2014; McInnes, 1999), thereby, contributing to the challenges within the field of deafblindness. Additionally, past research suggests that parent-school communication is vital for the team serving a child that is deafblind, and when that is lacking it may lead to conflict (Correa-Torres, Bowen, Mueller, & McKittrick, 2018).

Previous research has focused on documenting problems with IEP meetings and the resulting aftermath, including: team dissatisfaction, conflict, and due process requests (Lake & Billingsley, 2000; Mueller et al., 2008; Turnbull & Turnbull, 2015). Consequently, in response to this dilemma, parents have provided suggestions to

educators about how satisfaction can be improved during IEP meetings (Fish, 2008; Zeitlin & Curcic, 2014). Parents in these past studies suggested ways that educators could make the IEP process more collaborative such as having pre-planning meetings (Zeitlin & Curcic, 2014). There is also research about formal conflict prevention strategies such as the use of advocates and facilitated IEPs (Mueller et al., 2008; Mueller & Vick, 2018). There is a gap in research identifying family-initiated strategies to increase collaboration in IEP teams.

This study focused on strategies that *parents* of children who are deafblind employ to foster collaboration with their children's IEP teams as they advocate for their children, past experiences that led them to develop advocacy strategies, and parent views of collaboration. The goal of the study was to broaden the focus beyond known documented conflict prevention strategies such as the use of advocates or facilitated IEPs. This study focused on the unique needs of families of children who are deafblind. Because, student outcomes may suffer if the IEP team cannot agree on how to serve children best, the entire team can benefit from additional strategies to work collaboratively. The primary goal is to ensure the IEP meeting stays student-focused.

Purpose of the Study

Previous research has identified problems with the IEP meetings and focused on the resulting parent dissatisfaction and conflict (Fish, 2008; Mueller et al., 2008). Not all parents, however, have been dissatisfied with their IEP meetings. Some have been satisfied with their meetings and have had positive IEP experiences (Mueller & McKittrick, 2019). Some parents, like myself, have had both positive and negative IEP meetings. Others have experienced conflict, while exploring strategies used to resolve the conflict without the use of due process. Use of formal dispute resolution strategies may

be necessary if disagreements cannot be resolved in other ways. Many parents, however, have disagreements with IEP teams and resolve the conflict with the intent to meet their child's needs without using formal dispute resolution strategies. There is a need to better understand what past experiences lead mothers of children who are deafblind to develop advocacy strategies.

Parents play an important role on the IEP team because they know their child best. More research needs to be done from the perspective of parents, specifically focusing on strategies that parents employ to foster collaboration with their IEP teams. Indeed, research points out that parents play an essential role as an advocate for their children (Burke & Hodapp, 2016), but there is a need to better understand those advocacy activities. We have 40 years of research on the causes of conflict, and parents still report dissatisfaction with the IEP process. IEP teams can benefit from better understanding the strategies that parents employ to increase collaboration and to get their child's needs met. This study focused on parent-initiated strategies that improve collaboration and reduce conflict in IEP teams. This study paid particular attention to families of children who are deafblind because these families have unique challenges in IEP meetings because often times, these families are the most knowledgeable about deafblindness on the IEP team.

The purpose of this phenomenological qualitative study was to explore the roles that parents of children who are deafblind play in fostering a collaborative relationship with their children's IEP teams. There is a lack of research on collaboration strategies initiated by parents. There is also sparse research on families of children who are deafblind. In this study, mothers of children who are deafblind were interviewed about the unique and essential perspectives that they have concerning IEP team collaboration. Open-ended interview questions were used to collect in-depth information as parents

shared their experiences of attending IEP meetings, with the goal of identifying themes regarding strategies mothers use to collaborate with IEP teams. After the interviews, participants were also asked to provide written responses to related reflection questions. I also journaled throughout the research process.

Research Questions

To better understand the role that parents and caregivers of children who are deafblind play in fostering a collaborative relationship with their children's IEP teams, the following questions were posed:

Q1   What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Q2   How do parents define collaboration with their IEP teams?

Q3   What knowledge and strategies do parents use in IEP meetings to promote collaboration?

Definitions of Terms

The following terms are defined for use in this study.

Advocacy: Advocacy is defined as "speaking out and taking action in pursuit of a cause" (Turnbull et al., 2015, p. 178). In an educational context, advocacy refers to speaking out on behalf of a student. An advocate prevents problems, documents problems, forms alliances, creates win-win solutions, and is alert for opportunities to advance the concerns of students (Turnbull et al., 2015). Advocacy is one of the seven principles of partnership that may lead to increased parent satisfaction (Blue-Banning et al., 2004). Both family and educator advocacy are essential in the context of special education when addressing the needs of a student.

Collaboration: Collaboration in the IEP process was first mandated in 1975 as part of
what is now known as IDEA (Epstein, 1992). Collaboration is a process of shared
decision making or to "work jointly with others or together especially in an
intellectual endeavor" (Webster, 2019). Cook and Friend (2010) defined
collaboration as having mutual goals, shared responsibility for critical decisions,
and shared accountability for outcomes (Hedeen et al., 2011).

Conflict (in special education IEPs): Conflict involving IEPs include problems that may
arise between parents and schools when creating, documenting, and implementing
the IEP (Mueller, 2015).

Deafblindness: The IDEA (2004a) defines deafblindness as "concomitant hearing and
visual impairments, the combination of which causes severe communication and
other developmental and educational needs that cannot be accommodated in
special education programs solely for children with deafness or children with
blindness" (Sec. 300.8[c][2]). The number of students who are deafblind is small,
making this the lowest incidence disability in IDEA. There can be a significant
amount of variability in the hearing and vision of children who are considered
deafblind, and many of these children have needs in addition to deafblindness. A
diagnosis of deafblindness can have a profound impact on the entire family
(Correa-Torres & Bowen, 2016).

Family: The use of the term "parent" is too narrow in the discussions about partnerships
with educational teams. The term "family" means "two or more people who
regard themselves as family and who perform some functions that families
typically perform" (Turnbull et al., 2015, p. 30). In this definition of family, it is
less about the relationship by blood or marriage and more about the functions that

family members play (Turnbull et al., 2015). The term "family" could mean caregivers, extended families such as grandparents, or siblings. For the sake of ease, I used the term "parent" in this study, but this term is to be used interchangeably with the term family.

Family-professional partnership: Family-professional partnerships refer to families and educational and related service professionals working together to enhance and support student outcomes. Partnerships involve relationships between families (not just the parents), educators, and counselors. Family-professional partnerships benefit students, families, and professionals by bringing together multiple perspectives and resources (Turnbull et al., 2015). Families and professionals' partner in all school settings, but partnership is especially important in special education when teams work together to determine and meet the individualized needs of students as part of the IEP process.

Free and appropriate public education (FAPE): The IDEA states that each child who has a disability and needs special education will be afforded and have access to no-cost appropriate public education that is individualized to meet their needs (IDEA, 2004a).

Individuals with Disabilities Education Act (IDEA): The Individuals with Disabilities Education Act (IDEA) is a federal law that requires schools to serve the educational needs of eligible students with disabilities (www.understood.com). The original law, the Education for All Handicap Children's Act, was enacted in 1975. Since then, there have been several amendments, the most recent in 2004.

Individualized education program (IEP): Every public-school student who receives

special education and related services is required to have an IEP. An IEP is an

individualized document. The IEP creates an opportunity for teachers, parents,

school administrators, related services personnel, and students (when appropriate)

to work together to improve educational results for children with disabilities. The

IEP is the cornerstone of quality education for each child with a disability.

(Küpper, 2000, p. 1). The IEP team may consist of general educators, special

educators, service providers who may work with the child, the family, and the

student.

List of Acronyms

CRRRE   Culturally responsive relational reflexive ethics

EAHCA   Education for All Handicap Children Act

FAPE   Free and Appropriate Education

IDEA   Individuals with Disabilities Education Act

IEP   Individualized Education Program

NCDB   National Center on Deaf-Blindness (formerly known as National

Consortium on Deaf-Blindness)

CHAPTER II

REVIEW OF LITERATURE

Before the enactment of the Education for All Handicapped Children's Act (EAHCA) of 1975, now known as the Individuals with Disabilities Education Act (IDEA, 1975), students with disabilities were often segregated and living in group homes. Katsiyannis, Yell, and Bradley (2001) reported that these students were excluded from the education system and their outcomes were typically poor. Students were often institutionalized, devalued, and treated as if they were unable to learn (Turnbull & Turnbull, 2015). Advocacy in the 1950s and 1960s by family advocacy groups who wanted better opportunities for students with disabilities led to the passing of the IDEA in 1975. The IDEA guaranteed that students with disabilities would receive a free and appropriate public education (FAPE). Several amendments to the IDEA have helped to provide FAPE to students with disabilities and to give rights to parents. Even after the enactment of IDEA in 1975, parents continued to report that they were not included in education decision making regarding their children with disabilities. Consequently, Congress later added more provisions to IDEA to ensure parents could meaningfully participate in their children's education (IDEA, 1997). In 2004, the IDEA was reauthorized again and critical components related to parent involvement included parent rights related to due process procedures, parent participation in Individualized Education

Program (IEP) planning, and collaboration and shared decision making related to evaluation, placement, and service implementation (Katsiyannis et al., 2001).

There are six foundational principles of IDEA: (a) free and appropriate education, (b) appropriate evaluation, (c) individualized education program, (d) least restrictive environment, (e) procedural safeguards, and (f) parent involvement (IDEA, 2004a). Although parent involvement is one of the six foundational principles of IDEA and collaboration with parents is stressed as part of the IDEA, parents often still do not feel they are equal partners of the IEP teams (Lake & Billingsley, 2000). The practice of parent involvement still falls short of the vision of IDEA.

In this chapter I start by discussing issues related to the education of students who are deafblind and the impact of dual sensory loss on the development of learning. I then discuss the gap between policy and practice related to parent involvement. The literature on the importance of family-professional partnerships, barriers to collaboration, and the resulting conflict will also be addressed. Literature on families who have children who are deafblind is almost non-existent. In a search of 11 literature databases, only five peer-reviewed, English-language articles have been published since 2009 about families of children who are deafblind. In an expanded search of studies of families who have children with developmental disabilities, the findings were still sparse. In a review of the literature by Kyzar, Turnbull, Summers, and Gómez (2012), 14 studies were published between 1993 and 2009. Kyzar and Summers (2014) expanded this search and found 22 additional studies between 2009 and 2013. Not all of these studies were deemed relevant to this study but past literature on knowledge and advocacy for families of children who are deafblind will be discussed.

Educating Students who are Deafblind

When most people think of deafblindness, they think of Helen Keller and her relationship with her teacher, Anne Sullivan. Although the story of Helen Keller is inspiring and most people know the stories of her education by watching movies and reading books, the population of those who are deafblind is much more heterogeneous. Historically, students who are deafblind were educated in specialized schools and institutions, however, there is a continued trend for students who are deafblind to now be educated in in their neighborhood schools (Nelson & Bruce, 2016). Etiologies have shifted to being primarily attributed to illness, to prematurity, and now mostly to syndromes (Nelson & Bruce, 2016). To understand the unique challenges that families of children who are deafblind might experience, it is important to comprehend deafblindness, the impact of dual sensory loss on learning, and the services students who are deafblind receive in schools. In this section I provide general information about deafblindness, and then shift to discuss issues related to education such as services and placement, teacher competencies, and personnel preparation.

Overview of Deafblindness

Many people believe that deafblindness refers to a total inability to see or hear however deafblindness is a condition in which there is some combination of hearing and vision loss, but not always profound deafness or total blindness (Miles, 2008). The IDEA (2004a) defines deafblindness as:

> Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and education needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. (Sec. 300.8[c][2])

In addition to the IDEA definition, states may also have their own definitions of deafblindness, which leads to confusion in regard to providing accurate reporting of students needing and/or receiving services (Riggio & McLetchie, 2008). Regardless of the definition used, the effects of deafblindness cannot be determined simply by adding up the impacts of the hearing and vision loss (Nelson & Bruce, 2016). Many argue that "concurrent losses of vision and hearing constitutes a unique disability" (Nelson & Bruce, 2016, p. 2). The IDEA (2004a) definition addresses the combined hearing and visual impacts but impacts of this unique disability continue to be misunderstood.

The population of students who are deafblind is heterogeneous and the effects vary for each person (Nelson & Bruce, 2016). According to the National Center on Deaf-Blindness' (NCDB) 2017 child count, only 1% of the youth population has profound hearing loss and is totally blind; the remainder of the population have some residual hearing and/or vision (National Center on Deaf-Blindness, 2018). The NCDB's 2017 child count reported that just under 80% of children and youth with deafblindness were identified as having low vision, being legally blind, or having a documented functional vision loss in 2017. Only a total of approximately 5% of the deafblind youth population is totally blind. In the same NCDB child count report, the documented degree of hearing loss was more evenly distributed from mild to profound. According to National Center on Deaf-Blindness (2018), these documented degrees of hearing and vision loss have remained stable in recent years. More than 87% of those students who are deafblind have other disabilities in addition to vision and hearing loss (National Center on Deaf-Blindness, 2018).

According to Everson (1995) deafblindness falls into the following categories: (a) congenital deafblindness, (b) adventitious deafblindness, (c) congenital deafness-adventitious blindness, and (d) congenital blindness-adventitious deafness. Congenital deafblindness refers to vision and hearing loss that occurs early in life whereas adventitious deafblindness refers to vision and hearing loss that do not experience dual sensory loss until later in life. CHARGE syndrome, discussed later, is an example of congenital deafblindness. Adventitious deafblindness can be severe and progressive; the vision and hearing loss often occurs at different times. An example of adventitious deafblindness is traumatic brain injuries. Those with deafness-adventitious blindness are born with a degree of hearing loss but lose vision over time, such as in Usher syndrome. Congenital blindness-adventitious deafness is similar but refers to individuals who are born with vision loss but lose their hearing over time (Everson, 1995).

There are over 70 different etiologies of deafblindness including syndromes (e.g. Usher syndrome), multiple congenital anomalies (e.g. CHARGE syndrome), prematurity, congenital prenatal dysfunction (e.g. Rubella), and post-natal causes (e.g. stroke or head injury) (Heller, Kennedy, & Cooper, 1994). Some etiologies have fewer than five cases nationally. Usher syndrome and CHARGE syndrome are the two most common of syndromes associated with deafblindness (National Center on Deaf-Blindness, 2018). Usher syndrome is a condition that affects hearing, vision, and sometimes a person's balance. The major symptoms of Usher syndrome are deafness or hearing loss and an eye disorder called retinitis pigmentosa. There are three main types of Usher syndrome and there is heterogeneity between types, some causing more severe onset than others (Boughman, Vernon, & Shaver, 1983). CHARGE syndrome, another syndromic cause of deafblindness, refers to a specific set of birth defects that typically causes difficulty with

hearing, vision, and balance. Those with CHARGE syndrome have a unique set of presenting features, with varying degrees. Many with CHARGE have decreased cognitive abilities, however 30-50% have average intelligence. The lifespan for those with CHARGE syndrome can be normal however, a large number are considered medically fragile (CHARGE Syndrome Fact Sheet, n.d.).

Due to the varying age of onset, degree of vision and hearing loss progression, and possibility of additional disabilities, students who are deafblind experience different educational impacts. A majority of students who are deafblind have some residual hearing and vision that can be used to access classroom information. Some students who are deafblind have more severe communication impacts and complex medical and academic needs. Some students who are deafblind have the goal to attend college, whereas others will need lifelong support (Riggio, 2009).

Incidence of Deafblindness

Recent data from the National Center on Deaf-Blindness census indicate that there were about 10,000 children and youth identified as having deafblindness and eligible to receive services between December 1, 2016 and December 1, 2017 (National Center on Deaf-Blindness, 2018). This report included children who have other disabilities in addition to deafblindness. The Office of Special Education Program (OSEP) also completes a child count each year, based upon student IEP disability category. OSEP's census data for Fall 2017 only showed 1,306 children who have IEP's that classify them as deafblind (National Center for Education Statistics, 2017), significantly lower than the NCDB count in the same year. Funding for deafblind student services is based upon OSEP census data, which is grossly understated.

The ability to provide high quality services to students who are deafblind depends on the ability to correctly identify students (Riggio & McLetchie, 2008). Many school districts fail to correctly identify students who are deafblind on their IEP's, this is due to lack of understanding of deafblindness, different state definitions for deafblindness, and presence of additional disabilities among other reasons. As a result, these students many not receive the support they need (Riggio & McLetchie, 2008). To help ensure that IDEA requirements are met, the OSEP provides funding for the State Deafblind Projects and the National Center on Deaf-Blindness (NCDB). Each state has a deafblind project that supports families and school districts in supporting infants and youth that are deafblind. Working with families, services providers, state deafblind projects, federal agencies, and professionals, NCDB provides technical assistance on a national level (Riggio & McLetchie, 2008).

Services and Educational Placement
for Students with Deafblindness

Dual sensory vision and hearing loss can create complex and unique challenges for a student who is deafblind and their families (McLetchie & MacFarland, 1995). According to the NCDB census, in the academic year 2017 through 2018, 14.2% of deafblind school age students were taught in inclusive classrooms at least 80% of the day, and over 60% were educated in inclusive settings at least some of the day (National Center for Educational Statistics, 2017), making it imperative that professionals have the knowledge and skills to serve these children in an inclusive setting. It is promising to note that the number of preschool students served in general education classrooms doubled from 15% to 30% in the last decade (National Center on Deaf-Blindness, 2018), however, that just means that we need to be able to serve this growing number of families. Families

need access to information, services and high levels of support, when making educational choices for their children (Correa-Torres & Bowen, 2016).

The Individuals with Disabilities Education Act (2004a) requires that adequate services and placement options be available to students with disabilities. Choosing an appropriate program is one of the most difficult things to do for a student who is deafblind because even the smallest change in services and placement can be significant (Riggio & McLetchie, 2008). Because each student is impacted differently, services and supports should be tailored to meet the individual needs of the student. Hearing and vision loss changes over time, meaning educational impacts will likely also change over time. The IEP team needs to consider the impact of the dual sensory loss on academics, incidental learning, communication, and social relationships. A student's ability to safely move within their environment is also something that should be considered by the IEP team (Riggio & McLetchie, 2008).

There are common challenges in serving the needs of students who are deafblind. One challenge is that dual sensory loss can contribute to students sense of isolation, therefore it is important for the educational team to consider how to provide appropriate access to their surroundings. Children need to be able to have communication access to the world around them. Services should be delivered by team of knowledgeable professionals who can create communication and learning opportunities for students. To do this, professionals need to recognize that students who are deafblind communicate using many methods. When determining the educational placement and services, it is crucial that the student's communication abilities be considered. Educators should understand and use communication modes that are most natural for the students they serve (Riggio & McLetchie, 2008).

It is crucial that a professional who has specific training on deafblindness be on the IEP team (Ferrell et al., 2014). Teams should include professionals knowledgeable on deafblindness when providing services, support, and training to team. Most students who are deafblind benefit from one-on-one support (Riggio & McLetchie, 2008). The following should be considered when determining if a student would benefit from this level of support: learning style, preferences, age, visual and auditory functioning, communication abilities, student's experiential history, additional disabilities, and prior education (Riggio & McLetchie, 2008, p. 50). Services to help a student establish a consistent communication strategy are provided primarily by speech and language pathologists, special education teachers, audiologists, interveners, teachers of the deaf, and vision teachers. Related services may also include assistive technology, interpreting, and orientation and mobility services (Riggio & McLetchie, 2008).

Interveners are trained paraprofessionals who have knowledge in deafblindness (National Center on Deaf-Blindness, 2012). Interveners help a child who is deafblind to access information, the environment, communication, and conceptual learning. Since the 1970's, efforts have been underway to establish a role of interveners for students who are deafblind and by 2004 a national task force developed National Intervener Competencies (Alsop, Blaha, & Kloos, 2000; Zambone & Alsop, 2009). These competencies were used to create intervener training. In 2012, the National Center on Deaf-Blindness (NCDB) put out recommendations for improving intervener services. This report discussed the importance of this role on the service team. In the Center's 2017 child count, only 713 children and youth were reported as receiving intervener services. Although this was an increase over previous years and it is encouraging to see that these children and youth are receiving intervener services, it is discouraging that this accounts for only 7% of the

population. It is important to note that interveners are not recognized in every state, and some students may be receiving support from a paraprofessional who is not specifically trained on deafblindness. For many students who are deafblind, an intervener is a vital member of the IEP team, because of their knowledge and skills of deafblindness. An intervener is a way to provide one-on-one support for the student.

Teacher Competencies and
Personnel Preparation

As mentioned before, students who are deafblind are often served by a large IEP team, however, the team members' knowledge of deafblindness may still be limited (Malloy & Killoran, 2007). To ensure quality services, someone who has expertise in deafblindness should be supporting the student's full access to learning (Riggio & McLetchie, 2008). As previously stated, slow progress has been made in creating the interveners model of serving children who are deafblind. Although we now have competencies developed for interveners and training is available, there still remains a shortage of educational personnel with knowledge of deafblindness.

According to Bruce (2007) inclusion has changed the role of teachers, forcing teachers to have additional knowledge and skills to support the needs of the students in their classrooms. Bruce (2007) indicated that even with these changing roles, general educator teacher preparation programs have not adequately added content to meet these needs. To meet the changing student needs, teacher preparation programs need to provide more training in how collaborate with families, other educational team members, and outside service organizations (Silberman, Bruce, & Nelson, 2004).

The field of deafblindness faces an ongoing challenge with teacher preparation programs (Bruce, 2007). In a survey of 205 professionals working with students who are

deafblind, Correa-Torres & Bowen (2018) reported that only 36% of the participants had received training in deafblindness in their teacher preparation program. The majority of participants in this study (62%) reported that their school district provided them with opportunities to improve their knowledge and skills when working with students who are deafblind. Lack of time for collaboration was also mentioned as a challenge for professionals in this study. Relatedly, teachers in this study also reported a need to find time to do long range planning with outside service and educational agencies (Correa-Torres & Bowen, 2018).

To ensure quality services are provided to students who are deafblind, leaders in the field of deafblindness set out to develop educational standards and core competencies for professionals working with students who are deafblind. As part of this large initiative, a team working on the Perkins National Deafblind Training Project identified competencies needed by the deafblind specialist and educational team members. These competencies include: (a) deafblindness, (b) personal identity, (c) concept development, (d) communication, (e) hearing-vision, (f) orientation and mobility, (g) environment and materials, and (h) professional issues (McLetchie & Riggio, 1997). Teacher preparation programs have also attempted to meet the need for more specialized deafblind education by infusing the deafblind competencies into coursework for teachers of the visually impaired or teachers of the deaf (Parker & Nelson, 2016). Although there has been significant progress in the last 15 years, there is a strong need for more educators who are trained in the area of deafblindness. In 2007, Bruce reported that funding was declining for programs which train personnel to serve students with low incidence disabilities such as deafblindness. The situation remains the same today. Although there is a lack qualified

personnel to serve students who are deafblind, there are still few university programs that prepare teachers in the field of deafblindness (Bruce, 2007).

Students who are deafblind are a "unique population with unique needs for learning, communication, and environmental access" (Parker & Nelson, 2016, p. 1). Due to the previously mentioned staffing and personnel preparation challenges, many students who are deafblind receive their services from teachers of the visually impaired or teachers of the deaf, who many not be adequately prepared to understand the unique needs of this student population. Although much progress has been made in the area of professional deafblind competencies and intervener training, most students are not served by a professional who is trained in deafblindness (Parker & Nelson, 2016). Special education teachers must meet the highly qualified definition specified in IDEA (2004a), however, teachers of students who are deafblind often times do not. Because of the professional lack of deafblind knowledge, families are forced to become experts. As a result, families are often the most knowledgeable about deafblindness on the team. Parents of children who are deafblind, in a study of IEP conflict, reported that lack of professional team member knowledge of deafblindness contributed to their IEP conflict (Correa-Torres et al., 2018).

Family Engagement: Policy vs. Practice

Parent roles in educational planning and implementation have increased since IDEA went into effect in 1975. The focus of the IDEA was broadened to recognize the importance of family members in educational decision-making (IDEA, 2004a). However, implementation of this legislative requirement of IDEA has been slow (Martin et al., 2004). A report by the United States Department of Education's Elementary and Secondary Education in 2008 found that family engagement is the weakest area of IDEA

compliance (Wang et al., 2004). The partnership envisioned by IDEA is still not consistent with practice (Haines et al., 2017; Lake & Billingsley, 2000; Mueller et al., 2008). Parents still report dissatisfaction with IEP meetings (Zeitlin & Curcic, 2014). In a recent study of 14 parents of children who are deafblind, participants reported IEP dissatisfaction due to: (a) feelings that their student's unique needs were not being met, (b) poor communication between families and the rest of the IEP teams, (c) lack of administrative support, (d) IEP procedural violations, and (e) not agreeing with educational placement decisions (Correa-Torres et al., 2018)

The parent participation required by IDEA can be organized into the following broad categories: (a) one-way communication, (b) student-level decision making and planning, (c) information access, and (d) systems-level decision making and planning. Two examples of one-way communication are parent's right to receive prior notice from the local educational agency (LEA) regarding any change or action taken in the identification, evaluation, or placement of a child, and the LEA requirement to give parents a copy of the Parents' Rights. Information access gives parents the right to review all educational documents related to their child. Systems-level decision making makes opportunities available to parents to be involved in state-policy-level discussions as part of a state advisory panel. The most active parent participation occurs in regard to student-level decision making and planning. Through the *FEDC Issue Brief*, the IDEA (2012) provides provisions for parent participation in IEP meetings, being an integral part of the IEP team, and providing meaningful feedback on educational decisions.

The IDEA (2004a) requires that services and placement options be available to students with disabilities. This goal cannot be realized unless the student has full access to the curriculum and educational environment (Riggio & McLetchie, 2008). Services

and must be well implemented and coordinated in a collaborative way (Riggio &

McLetchie, 2008). A student who is deafblind, because of the dual sensory loss, does not

have access to the curriculum and environment without appropriate services and supports

by professionals that are knowledgeable about deafblindness. Unfortunately, there

continues to be a shortage of qualified personnel in the field of deafblindness (Parker &

Nelson, 2016), therefore this vision is often not realized in practice, causing frustrations

for families (Correa-Torres et al., 2018).

Family-Professional Partnerships

In a special education context, family-professional partnership refers to a

collaborative relationship between family members, typically parents or guardians, of

children with disabilities and educational professionals, including teachers, counselors,

service providers, and administrators to make decisions to improve student outcomes

(Turnbull et al., 2015). Family-professional partnerships are a key component of support

for families as they work with IEP teams to meet the educational needs of their children

with disabilities (Haines et al., 2017). Partnerships are necessary so that students can

receive a fair and appropriate education (Newman, 2005). Student achievement has been

shown to improve when parents feel they are equal partners in IEP teams (Henderson &

Mapp, 2002). Several factors influence whether positive partnerships are possible,

including the quality of current and past relationships, whether family members trust the

other members of the team, whether parents believe their children's needs are being met,

and whether parents believe professionals genuinely care about and know their child

(Nelson, Summers, & Turnbull, 2004).

Collaboration is critical for a successful partnership (Blue-Banning et al., 2004;

Hedeen et al., 2011). Cook and Friend (2010) defined collaboration as having mutual

goals, shared responsibility for critical decisions, and shared accountability for outcomes (Hedeen et al., 2011). In the context of educational planning, collaboration can help a team collectively work toward the mutual goal of supporting the student.

Parents and professionals can both benefit from working together collaboratively to support individualized student needs (Blue-Banning et al., 2004; Hedeen et al., 2011). Due to the unique needs, general education teachers have found collaborative teaming essential to successful inclusion for students who are deafblind (Ferrell et al., 2014). Collaborative teaming should include all professionals serving the student and the family (Ferrell et al., 2014). Increased family involvement is also essential and leads to better student outcomes in the areas of school engagement, academic performance, social adjustment, and independence (Newman, 2005).

Several family-professional partnership principles have been established. The landmark study by Blue-Banning et al. (2004) provided six interrelated themes that are indicators of collaborative family-professional partnerships: (a) communication, (b) commitment, (c) equality, (d) competence, (e) respect, and (f) trust. In this qualitative study, researchers conducted 33 focus groups of parents and 32 individual interviews with non-English speaking parents and their service providers. Participants were asked about indicators of professional behavior that they saw as indicative of a collaborative partnership. Turnbull et al. (2015) later added a seventh indicator of collaborative family-professional partnerships: advocacy. Research indicates that successfully implementing these seven principles leads to increased collaboration and strong family-professional partnership (Kyzar et al., 2016). In the next section, each of the seven principles are discussed, using supportive literature.

Communication

Effective communication refers to both quantity and quality of communication in family-professional partnerships; however, parents often concentrate on the quality aspect of this partnership dimension (Blue-Banning et al., 2004). Parent participants in Blue-Banning and colleagues (2004) study reported the importance of positive, understandable, and respectful communication. Participants also reported that communication provides a vehicle for team members to establish trust, show respect, and confer equity with parents. Relatedly, Turnbull and colleagues (2015) proposed five actions as necessary for effective communication, these include: (a) being friendly, (b) listening, (c) being clear, (d) being honest, and (e) providing and coordinating information gathering.

In a qualitative study where 20 parents were interviewed about parent satisfaction, participants reported that better communication would enhance their satisfaction with IEP meetings (Zeitlin & Curcic, 2014). For these parents, better communication meant having communication with teachers about how things are going, and planning and problem solving together. Participants in Latham's (2002) qualitative study of 20 parents indicated that communication improved over time, primarily because they were the ones ensuring that communication was happening. Even though communication was reportedly better, participants stated that they wanted "more communication, clearer communication, and more frequent communication" (p. 92). Parents indicated that they often felt like they were communicated to "too late" (p. 151) and would appreciate more timely information and feedback. Parents felt like they left IEP meetings without the information they needed on special education law and to make educational decisions. Participants in this study suggested that parent support groups or the creation of parent manuals might be ways for parents to gain the necessary knowledge to advocate for their children.

One strategy for managing communication throughout the year is for team members to create an individualized communication plan for each family (Turnbull et al., 2015). This strategy can help eliminate any misunderstandings about communication. A communication plan addresses: (a) how families prefer to be communicated with (e.g. text, phone, or in person), (b) how frequently they want to be communicated with, and (c) what types of things do they want to hear about. Other strategies are to: (a) check in with families before the IEP meeting and frequently during the year, (b) send draft IEP documents in advance, (c) have IEP pre-planning meetings when appropriate, (d) ensure families have all the information they need to make decisions, (e) respond quickly to parent communications, even if to say you do not yet have the answers, (f) be honest even when there is bad news, and (g) actively listen to families concerns (Turnbull et al., 2015).

Because of the unique and individualized needs of a child who is deafblind, there can be many members of a student's IEP team, which can pose communication challenges that may make collaboration difficult (Riggio & McLetchie, 2008). One challenge for parents and professionals is to how to ensure that children who are deafblind are included in the flow of the family and community (Miles, 2008). Students who are deafblind may respond differently than other children. With collaboration and good communication, parents and professionals are able to work on mutual goals to help children be included in their schools, family, and community (Miles, 2008). Another challenge is that families are often the most familiar with the communication abilities of their child and sharing information with their child's teams about communication is critical to student growth (Correa-Torres et al., 2018; Ferrell et al., 2014). The Deafblind Educational Service Guidelines state that personnel working with students who are

deafblind should: (a) ensure parents are confident that they have the information they need to make decisions and, (b) provide a supportive environment where parents can communicate strengths, needs, concerns, and priorities.

Commitment

Commitment in the context of family-professional partnerships refers to parents believing that team members are dedicated to the educational wellbeing of their children (Blue-Banning et al., 2004). Parents in Blue-Banning et al. 's (2004) study indicated that they want team members to approach work with their child as "more than a job" (p. 175) and expect team members to understand the unique needs of their children. Parents reported the importance of the team going above and beyond to meet the needs of their children (Francis, Hill, Blue-Banning, Turnbull, & Haines, 2016).

Parents appreciate when team members are flexible in meeting times, and they want professionals to be committed to working with their child (Nelson et al., 2004). Professionals can demonstrate commitment by being sensitive to emotional needs and by being accessible to family members (Turnbull et al., 2015). Strategies that can be used to show commitment include: (a) scheduling meetings during times that work for the family, (b) ensuring all team members are at meetings and "are present," (c) giving families ways to get ahold of you outside of school hours, and (d) following through on IEP goals (Turnbull et al., 2015). As previously mentioned, parents want to know their child's team is committed however, they understand there needs to be boundaries to ensure work-life balance for the IEP team (Turnbull et al., 2015).

Equality

Equality refers to shared power in decision making and IEP implementation (Turnbull et al., 2015). Inviting parents to IEP meetings does not necessarily translate to

equality at those meetings (Martin et al., 2006). Equality also refers to being flexible and providing creative options whenever possible (Turnbull et al., 2015). In a quantitative survey of 1,056 parents, participants reported that although parents are invited to IEP meetings, they felt their opinions did not matter (Burke & Hodapp, 2016). Parents reported that decisions are made before the meetings, IEP documents are created in advance without their input, meetings are a formality, and parents are excluded from crucial conversations (Burke & Hodapp, 2016; Fish, 2008). In meetings, equality can be shown by being willing to explore all options, validating other members' thoughts and suggestions, and empowering others (Blue-Banning et al., 2004). Strategies to help increase a family's feeling of equality are: (a) finding ways to empower students and families in educational planning, (b) being flexible in approach and creative in finding solutions, (c) providing options for families, and (d) providing a meeting environment that makes families feel comfortable (Turnbull et al., 2015).

Competency

In social cognition research, respect was found to depend on the level of counselors' professional competence (Fiske, Cuddy, & Glick, 2007). In an educational context, if parents believe education team members are competent, they may show more respect for them. Professional competency refers to knowing how to provide an appropriate education to students, setting high expectations for the student, and continually helping them to learn (Turnbull et al., 2015). Competency can take the form of formal professional development or through interactions with parents and students (Turnbull et al., 2015). Parents appreciate when team members keep current in their field, have high expectations of their children, and make things happen (Lake & Billingsley, 2000). For professionals who work with students who are deafblind, competency also

means having knowledge of deafblindness and the unique needs of the child (Riggio & McLetchie, 2008).

Competency entails valuing the knowledge that parents and other team members hold that will help the team meet individual student needs (Wang et al., 2004). If a professional does not have the answer, parents appreciate when professionals are honest about it and then find the answer by asking parents or by seeking additional resources (Turnbull et al., 2015). Competency also requires team members to listen to students as they self-advocate for their needs. Strategies to promote competency are: (a) making sure that you understand the student needs and seeking out knowledge from the family and others, (b) if you do not know the answer be honest about it, (c) seeking out professional development opportunities, (d) developing realistic, but high expectations for the student and, (e) ensuring students are set up for success (Turnbull et al., 2015).

Competency in deafblindness is extremely important for professionals working with students who are deafblind. Most of these professionals likely have never worked with a student who is deafblind or received training on deafblindness in their teacher preparation programs (Riggio & McLetchie, 2008). Unfortunately, the nature and extent of the deafblindness is often misunderstood by those who serve the child (Malloy & Killoran, 2007). For inclusion to be successful, teachers need to creatively integrate information from various sources to meet the needs of an individual student, making collaboration essential (Ferrell et al., 2014; McLetchie & MacFarland, 1995).

Respect

Respect for family-professional partnerships means that team members will treat each other with esteem during all interactions, both formal and informal (Turnbull et al., 2015). Part of respect is honoring cultural diversity, affirming student strengths (and not

focusing on student weaknesses), and treating students and parents with dignity (Turnbull et al., 2015). For parents to believe educational team members respect them, parents must also think the team values their child as a person, rather than just understanding them through their disability (Blue-Banning et al., 2004). In regard to IEP meetings, respect means that the team encourages and respects parents' decisions and priorities (Wang et al., 2004). Strategies to show respect include: (a) maintaining good eye contact, (b) considering seating arrangements in meetings, (c) invite families to share about their culture, (d) choosing curriculum content that is appropriate and culturally responsive, and (e) knowing how the family prefers to be greeted (e.g. formal or informal) (Turnbull et al., 2015).

Trust

Trust is an overarching theme with the other six principles of partnership (Turnbull et al., 2015). Trust needs to be in place for collaborative family-professional partnerships to be successful (Blue-Banning et al., 2004). Trust is seen to be the foundation of effective partnerships because how educational professionals carry out the other partnership principles influences the extent to which parents trust educational team members (Turnbull et al., 2015). Parents reported that when they trust professionals, parents spend less energy on advocacy and progress monitoring (Stoner & Angell, 2006). Loss of trust can also lead to litigation. In a review of 85 special education law cases, parents commonly reported a lack of communication from IEP teams, which caused a breakdown of trust (Curtis, 2005).

Rodriguez, Blatz, and Elbaum (2014) found that parent trust in schools varied. If trust is lost, it can cause problems that lead to conflict between team members and parents (Rodriguez et al., 2014). Participants in Rodriguez et al.'s (2014) study suggested

that educators can improve trust by implementing agreed-upon accommodations and services, by providing regular updates on IEP progress, by explaining procedural safeguards, and by involving parents in placement decisions.

In a similar study of 24 parents, trust was also an overarching theme where parents responded negatively when asked about trust (Stoner et al., 2005). Participants in this study reported that they have trust in teachers if they are authentically caring, communication is good, and they feel like teachers are knowledgeable. Once trust is lost, parents said they become more watchful and diligent in advocating for services for their children. This meant coming into IEP meetings prepared to demand and negotiate for services.

Parents in Stoner and Angell (2006) study on parent engagement, reported that they had low trust in professions. Parents in this study reported that trust increased when they "perceived these professionals as competent, having the best interests of children at the center of their decisions, and keeping their word" (p. 184). Stoner and Angell (2006) reported that when problems exist, parents spend less time in the role of supporter and more time negotiating for services, making sure things get done, and advocating for their children.

In a study by Lake and Billingsley (2000), it was revealed during interviews with parents, school professionals, and mediators that trust was one of the several factors that escalate or de-escalate the conflict. One of the findings was that if trust was intact, parents were able to tolerate more negative experiences without it leading to conflict, giving professionals the "benefit of the doubt" (p. 248). When trust was lost, parents reported less satisfaction and were unable to accept the IEP teams "good faith efforts" (p.

248). Once trust was lost, parents reported turning to out-of-district placements, changes in schools, mediation or due process (Lake & Billingsley, 2000).

As previously mentioned, trust is an overarching theme with the other partnership principles. Trust can be built in partnerships by: (a) communication - exchanging information openly and honestly, (b) competency – being skilled in educating the student, (c) respect – honoring family values, (d) commitment – going above and beyond, (e) equality – using shared decision making, and (f) advocacy – advocating for the family and child (Turnbull et al., 2015).

For students who are deafblind, trust is at the core of all their interactions, because they rely on others to safely access the world around them (van Dijk, 2001). Best practice is to help students build trusting relationships (Riggio, 2009). Trust is also critically important between the families and the educational teams serving the student who is deafblind. Because of the uniqueness of how students are impacted, communication and trust are the core of the collaborative relationship (Correa-Torres et al., 2018; Riggio & McLetchie, 2008).

Advocacy

Advocacy is defined as "speaking out and taking action in pursuit of a cause" (Turnbull et al., 2015, p. 178). In an educational context, advocacy refers to speaking out on behalf of a student. If parents believe educational professionals are committed advocates for their children, they will likely be more satisfied with the partnership than if they feel professionals are not committed advocates (Blue-Banning et al., 2004; Wang et al., 2004). An effective advocate prevents problems, documents problems, forms alliances, creates win-win solutions, and is alert for opportunities to advocate (Turnbull et al., 2015). Burke (2013) discussed how advocacy is problem oriented. For problems to be

solved, the issue needs first to be identified so that resources can be gathered to solve the problem (Burke, 2013). Professional advocacy is vital to parents because it demonstrates commitment (Turnbull et al., 2015). Ways for professionals to demonstrate advocacy include: (a) putting yourself in the other person's shoes, (b) clearly documenting and addressing problems as soon as they happen, (c) providing evidence about the nature and extent of a problem, (d) having an "all in this together" attitude, and (d) making sure the student knows what is in their IEP and finding ways for the student to be involved in educational planning (Turnbull et al., 2015).

Parents, professionals, and students all are essential advocates in the educational process. Because parent advocacy is one documented way for parents to get their child's needs met in the IEP meeting, parent advocacy will be discussed later in this chapter within the context of parent knowledge. Student advocacy is not addressed in this review of the literature.

Parent Dissatisfaction with the Individualized Education Program Process

Parents often report having low satisfaction with the IEP process, most of which relates to lack of effective collaboration (Childre & Chambers, 2005; Esquivel et al., 2008; Fish, 2008; Rosenbaum, 2001). There is extensive research in which parents reported that being invited to participate in their child's education is not enough; they want to be equal decision makers (Blue-Banning et al., 2004; Hedeen et al., 2011; Mapp & Kuttner, 2013; Turnbull et al., 2015). As previously stated, many argue the intent of IDEA is to promote active parent participation. Although parent participation is reportedly high, parents often report that their participation in IEP meetings is passive and that their input is not valued or heard (Childre & Chambers, 2005; Esquivel et al.,

2008; Fish, 2008; Garriott et al., 2000). Parents report that IEP meetings are stressful, that they do not feel like equal members of the IEP team, and that their voices are not heard (Mueller, 2017).

Over four decades of research show that there are challenges to parents participating in IEP meetings (Esquivel et al., 2008; Goldstein, Strickland, Turnbull, & Curry, 1980; Zeitlin & Curcic, 2014). Parents have expressed concerns about the IEP process itself (Hedeen et al., 2011). Zeitlin and Curcic (2014) interviewed 20 parents about their IEP experiences and found a power imbalance in meetings, which forced parents to take a passive role, meaning that their feedback is not meaningfully incorporated into the decision-making process (Zeitlin & Curcic, 2014). Parents reported frustration that IEPs are often developed before the meeting, which contributes to them having a passive role in meetings and believing their input is not valued (Childre & Chambers, 2005; Esquivel et al., 2008; Fish, 2008). Similarly, Martin et al. (2006) analyzed 109 IEP meetings and concluded that parents contributed to IEP meetings at a much lower rate than educators (15% vs. 51%), indicating that little progress had been made in the last 30 years.

Lack of parent knowledge about the special education system was found to lead to frustration, which is often exacerbated by the use of educational jargon (Fish, 2008). In Zeitlin and Curcic's (2014) study, parents reported that they felt the IEP process was impersonal, emotional, and deficit-based, focusing on children's shortcomings rather than their strengths. Parents stated that, because of the excessive paperwork, the focus of meetings feels procedural and less collaborative. Sometimes meetings can seem to go well, but then parents become dissatisfied when there is no follow through on the IEP

(Rosenbaum, 2001). The lack of professional accountability is also frustrating to parents, especially when it leads to a lack of student progress on IEP goals.

Parent Suggestions to Improve Collaboration

Research in the last decade has focused on parent dissatisfaction with the IEP process and the resulting conflict (Zeitlin & Curcic, 2014). Parent participants, as part of these past studies, have provided suggestions for educators on how to increase parent satisfaction and improve the IEP process. For instance, participants in Zeitlin and Curcic's (2014) study offered recommendations about how to improve the IEP process itself to make the IEP document more meaningful. Suggestions to improve the IEP process included: (a) enhanced communication in regard to problem solving and decision making and (b) ensuring parents have an active role in meetings and that parents are supported, understood, and valued. Parents in this study wished the IEP document was parent-friendly, simple, with jargon-free language, with a focus on student strengths instead of deficits (Zeitlin & Curcic, 2014).

Parent views of the IEP meetings can be quite complicated. Esquivel et al. (2008) found that their past and current relationships with professionals' impact how parents feel about the meetings. Childre and Chambers (2005) found that some parents did not see any shortcomings in the IEP process because, based upon past meeting experiences, they have low expectations for the meetings. For other parents, they have only had positive or negative meetings. In Esquivel and colleagues' (2008) study of parent perceptions of IEP meetings, participants provided suggestions for educators to improve their experiences. Suggestions included involving parents in IEP meeting pre-planning and conveying knowledge of both student strengths and deficits (Esquivel et al., 2008). Parents in Zeitlin and Curcic's (2014) study had similar recommendations to improve their experience.

Parents reported that better communication and increased collaboration would enhance their satisfaction with IEP meetings (Zeitlin & Curcic, 2014).

Simply put, parents want to feel respected. Strategies for showing respect include: (a) calling parents by their last names unless told otherwise, (b) being on time for meetings, (c) acknowledging the efforts of parents, and (d) always showing common courtesy (Blue-Banning et al., 2004). Parents reported that team member empathy and compassion help parents to feel respected (Turnbull & Turnbull, 2015). If the IEP team is able to work collaboratively to meet the unique and individualized needs of the student, conflict is less likely to occur, and satisfaction with IEP meetings tends to be higher (Zeitlin & Curcic, 2014).

Conflict in Special Education

If an IEP team is not able to work collaboratively and if educators are unable to effectively partner with parents in a way in which parents believe their children's needs are being met, parents may have negative experiences in IEP meetings. If these negative experiences continue and mutual progress toward student outcomes cannot be made, conflict is likely to occur between parents and professionals, which can lead to litigation (Lake & Billingsley, 2000).

Although research is limited, several key factors can escalate or de-escalate conflict between families and professionals (Feinberg et al., 2002; Lake & Billingsley, 2000). In a study by Lake and Billingsley (2000), interviews with parents, school professionals, and mediators revealed several factors that are not mutually exclusive and may operate simultaneously to escalate or de-escalate the conflict. These factors include (a) conflicting views of a child's needs, (b) service delivery, (c) constraints, (d) valuation,

(e) reciprocal power, (f) knowledge, (g) communication, and (h) trust (Lake & Billingsley, 2000).

The IDEA (2004a) states that parents should be involved in the IEP development process. However, that is not always the case, or their involvement is limited or passive (Bateman & Linden, 2006; Yell, 2006). The focus of an IEP meeting is on the individual needs of a student, which means that the meeting should be student-centered. When conflict occurs in IEP teams, it often results in focus of the IEP meeting shifting away from the student to unproductive topics that lead to disagreements (Childre & Chambers, 2005). As previously stated, families of children who are deafblind are often the ones that bring the most knowledge of deafblindness to IEP teams. The knowledge of deafblindness and thorough understanding of how dual sensory loss is impacting the individual student is essential for the team to create meaningful IEP goals.

Feinberg et al. (2002) described three types of special education conflict: design conflict, delivery conflict, and conflict caused by relationship problems. Design conflicts occur when IEP team members have different understandings about appropriate services. Conflicts can also arise because of divergent views of how to implement the IEP. Relationship problems can also turn into conflict, and lack of trust, breakdowns in communication, and cultural differences can all contribute to relationship problems.

Causes of Litigation Related to the Individualized Education Program

Conflict with educators can lead parents to file for a due process hearing, mediation, or formal complaint. Resolving disputes using due process can be costly for both parents and districts (Christle & Yell, 2010). In the 1999-2000 academic year, $146.5 million was reportedly spent in the United States on mediation and due process

(SEEP, 2003). More recent data have not yet been reported. In a 2006 descriptive study of due process cases, Hill (2006) found a substantial increase in IEP litigation even though the district usually prevails. The goal of Hill's 2006 study was to identify reasons for IEP litigation. From a thorough review of 127 cases, Hill concluded that if schools make a good faith effort to educate students with disabilities and respond professionally, they will usually prevail in disputes (Hill, 2006, p. 566).

Meanwhile, a majority of IEP-related litigation has involved procedural violations (Etscheidt, 2003; Hill, 2006). The IDEA states that every student should be afforded a free and appropriate education. Even if an IEP is procedurally correct, it will not meet the standards set out in IDEA if it does not result in a student achieving educational benefit (Christle & Yell, 2010). A common procedural violation is not involving general educators in IEP development (Bateman & Linden, 2006; Yell, 2006). Another is not making placement decisions based upon the IEP (Christle & Yell, 2010). Although the IDEA states that parents must be fully involved in the IEP development process, but that is not always the case (IDEA, 2004b; Bateman & Linden, 2006; Lake, 2002; Yell, 2006). Mueller and Carranza (2011) reported that the most common areas of IEP dispute are placement (25%), IEP appropriateness (24%), assessment and evaluation (12%), and eligibility (11%). Problems in these commonly disputed areas often result in substantive and procedural violations of the IEP (Mueller & Carranza, 2011).

A substantive violation can occur if the IEP does not meet the student's unique needs (Bateman & Linden, 2006; Yell, 2006). An IEP may not have measurable goals, and the IEP team may not be collecting enough data to show that the student is making appropriate educational progress (Bateman & Linden, 2006; Christle & Yell, 2010; Yell, 2006). Or, there may be a lack of agreement between present levels and annual goals

(Epstein, Patton, Polloway, & Foley, 1992) or not enough goals altogether (Nickles, Cronis, Justen, & Smith, 1992). Lake (2002) noted that IEP teams should individualize goals and avoid predetermined goals.

Transition is another source of litigation in special education law (Romberg, 2011). The IDEA (2004a) mandates student involvement in the transition process, and there are signs of a lack of student involvement in the IEP transition process. Powers et al. (2005) found that, overall, transition plans were low quality. The most common IEP procedural violation was transition goals missing from the IEP (Epstein, 1992; Powers et al., 2005). Powers et al. (2005) found, in a review of 399 IEP transition documents, that transition goals were missing from 24% of IEPs sampled.

Parent Advocacy and Knowledge

Parents are essential educational advocates for their children (Burke & Hodapp, 2016). Throughout history, parent advocacy has played a significant role in making inclusion possible for students with disabilities. Wolfensberger (1977), in early disability rights literature, described advocacy as acting on behalf of someone else to make that person's strengths, preferences, and needs to be known. Some argue that advocacy is what was meant by the term *parent participation* in IDEA, whereas others say that partnership was what was envisioned (Turnbull & Turnbull, 1982). As parents gain the skills and knowledge of special education and advocacy, they discover strategies to use to get their children's needs met in IEP meetings. There are scant practitioner articles about these strategies, and no articles based on research. This study fills that gap in research by looking at strategies that parents use while advocating for their children's needs in school.

Parent advocacy can be complicated because there are many reasons for advocacy efforts. As previously mentioned, advocacy is one of the seven principles of partnership

that helps build a trusting partnership (Blue-Banning et al., 2004). If family satisfaction with the partnership is low, parents see advocacy as an obligation and a means to improve services (Wang et al., 2004). Parents who felt they needed to engage in high levels of advocacy reported having less satisfaction with the partnership with IEP teams (Burke & Hodapp, 2016). Conversely, if parents believed that partnerships are effective, advocacy may be less important to them (Burke & Hodapp, 2016; Wang et al., 2004). Parents often wished they did not have to fight for services or gather information that educational teams were not providing (Wang et al., 2004). In the 2004 study by Blue-Banning et al., parents reported increased stress if they felt like they needed to participate in advocacy activities related to improving services (Blue-Banning et al., 2004; Wang et al., 2004).

When parents are asked about their role and knowledge, they typically start with describing that they are the most knowledgeable person about "their child" and the disability (Shepherd, Kervick, & Morris, 2017). Kervick and colleagues have studied the multiple and complex ways that parents share knowledge with IEP teams (Kervick, 2017; Shepherd et al., 2017). When a student has more complex needs and when an IEP team is large, parents often play the role of "case manager," bringing all the information about the student together (Kervick, 2017). Parents often approach educational planning with intuition about their children's needs, and parents have reported that advocacy based upon intuition is not always successful because it is based more on gut instinct (Trainor, 2010). Another approach to advocacy is for parents to become "disability experts," which may help the parents who believe professionals are not giving them the information they need to make good choices for their children (Trainor, 2010). Parents who employ a "disability expert" approach to advocacy are often connected to other parents who have children who have similar disabilities (Trainor, 2010). The connections with other parents help

some parents approach advocacy as a "strategist" (Trainor, 2010). In Trainor's (2010)

study, parents who were considered strategists reportedly strengthened their knowledge

of special education by combining it with the knowledge gained from other parents who

have shared experiences. Strategists are often very knowledgeable about special

education law and are clear on what their role is within the IEP team (Trainor, 2010).

These strategist parents garner support and strength from connecting with other parents

(Kervick, 2017). Parents also play an active role in providing intervention to their

children and have a role of "interventionist" (Shepherd et al., 2017). In early intervention,

parents were expected to and gained knowledge to provide intervention services. For

many parents, they continue to provide intervention and support in grade school and

beyond, during the hours when their child is not at school (Shepherd et al., 2017). On the

one hand, by providing interventions and support, the parent is able to have more

knowledge to share with the IEP team about interventions to try. On the other hand,

frustration can occur if a family feels like the team is not versed in the literature and

"cutting-edge" interventions (Shepherd et al., 2017). One parent stated the ideal situation

as "parent and professional knowledge being intertwined and how a professional's

knowledge is the extension of the family's knowledge" (Shepherd et al., 2017, p. 89).

It can be emotional for parents to share knowledge and advocate for their

children. Depending on the level of advocacy efforts, stress can take an emotional toll on

parents (Kervick, 2017). Parents are expected to know how to advocate for their children,

but they may not have the necessary knowledge of their legal rights or the competence

needed to advocate for their children's needs (Mueller, 2017). One of the goals of subpart

E of the IDEA regarding procedural safeguards was to provide information to parents

about their rights (IDEA, 2004b). Parents are to receive copies of the procedural

safeguards at least annually, and at specified times; however, these safeguards are not written using parent-friendly language.

Parents reported that they typically self-educate about special education because the IEP teams do not provide the knowledge they need (Gorman, 2001; Mueller & Buckley, 2014). Parents may gain that knowledge by talking with other parents who have been through similar experiences. Parents may also learn about special education law and parental rights from their state's Parent Training and Information Centers (PTICs). To make matters more challenging for parents, the system of special education is confusing, full of jargon and rules and procedures that are unknown to parents. This lack of knowledge leads to parents feeling powerless and undervalued at meetings.

To complicate things more, parent knowledge and advocacy are often not valued by IEP teams (Kervick, 2017). Educators can see advocacy as positive or threatening. Colker (2015) found that educators sometimes label parents who are too assertive in their advocacy efforts as pushy or crazy. This type of advocacy can create a barrier between IEP team members and hinder progress in IEP meetings. In the context of parent advocacy, one way to increase equality in meetings is for team members to value the knowledge that parents bring to the table (Kervick, 2017). Also, parents do not expect team members to have all the answers (Blue-Banning et al., 2004). Parents indicated that they appreciate competent professionals who are not afraid to admit what they do not know but are committed to researching answers (Lake & Billingsley, 2000).

Conclusion

The kind of active parent participation forwarded by the IDEA is still not being realized in practice. Parents and families continue to report that IEP meetings are stressful and unproductive, resulting in parent dissatisfaction. If parents are dissatisfied and

stressed resulting in unproductive conversations at meetings, conflict can occur. Conflict can lead to more stress and can be emotional for all team members. Resolving conflict in using formal dispute resolution procedures can be financially and emotionally costly. Therefore, it is to IEP teams' benefit to try to resolve the conflict outside of due process. There are decades of research about parent dissatisfaction and conflict in special education. During the last decade, parents have given suggestions for strategies for educators to improve the process. It is important, however, to also look at strategies that parents employ during IEP meetings to advocate, resolve disagreements, and get their children's individual needs met. Educators and parents alike can learn much from understanding how parents help foster collaboration in IEP teams to keep the focus on children's needs. Parents of children who are deafblind have unique perspectives on collaboration due to the heterogeneous nature of deafblindness. The field of deafblindness is facing staffing and personnel preparation challenges. As a result, many students who are deafblind receive their services from teachers of the visually impaired or teachers of the deaf, who many not have expertise in deafblindness and serving this population. Because of the professional lack of deafblind knowledge, families are forced to become experts. These parents may experience challenges related to collaboration with large IEP teams and the lack of professional knowledge of deafblindness and individualized student needs.

CHAPTER III

RESEARCH METHOD

Introduction

I am a mother of two children who are deafblind due to Usher syndrome. Perceptions about Individualized Education Program (IEP) team collaboration have been shaped by my personal experiences advocating and working with IEP teams to get appropriate services. I have attended over 25 IEP meetings and have, over the years of attending IEP meetings, developed strategies for fostering collaboration with IEP teams. In doing so, my children received the services they needed to achieve positive student outcomes. The idea for this study came about because of my personal experiences as a parent in IEP meetings.

Past research focused on the source of conflict, reasons for dissatisfaction, and suggestions that parents have for educators to increase collaboration. The goal of this study was to explore parent-initiated strategies for preventing conflict and improving collaboration within IEP teams. The focus of this study was on families of children who are deafblind. This population was chosen because of the unique challenges that these families face due to the low-incidence nature of deafblindness and the individualized needs these children have. Children who are deafblind need support from someone who understands the impact of dual sensory loss, not just singular training in deafness or vision (McInnes, 1999).

The purpose of this phenomenological qualitative study was to explore the roles that parents of children who are deafblind play in fostering a collaborative relationship with their child's IEP teams. The phenomenon of interest was the strategies that parents use in IEP meetings to improve collaboration. The study focused on strategies that parents employ to foster collaboration with their children's IEP teams as they advocate for their children, the past experiences that lead parents to develop advocacy strategies, and parent views of collaboration. The goal of the study was to broaden the focus beyond known documented conflict prevention strategies such as the use of advocates or FIEPs. To address the need to understand the roles that mothers of children who are deafblind play in fostering a collaborative relationship with their children's IEP teams, I collected data, in the form of interviews and participant reflections, from mothers to learn about the unique and important perspective that they have concerning IEP team collaboration. The following questions were posed:

Q1   What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Q2   How do parents define collaboration with their IEP teams?

Q3   What knowledge and strategies do parents use in IEP meetings to promote collaboration?

Theoretical Framework

Culturally responsive relational reflexive ethics (CRRRE) served as the theoretical framework for the study (Lahman, 2017). This framework is based upon the premise that researchers should reflexively consider how their "experiences, discipline training, personal spiritual or religious beliefs, and the ethical culture of the communities they research impact the way they conduct themselves during human research" (Lahman, 2017, p. 2). I chose this theory as the foundation of my study to acknowledge that I have

experienced the phenomenon being studied. Because of my role as a fellow mother, I treated parent participants like I would like to be treated, as a person first. This relationship with fellow parents is extremely important to me. The best that I strive for in my personal life is what I strove for when researching this topic (Lahman, 2017).

I moved beyond what is mandated by procedural ethics to achieve aspirational ethics. Aspiration is "a strong desire to achieve something high or great" and aspirational ethics is a standard higher than what is necessary in order to be in compliance (Lahman, 2017). In CRRRE theory, the researcher pays attention to the idea of "other" and who "other" is. In this study, I was careful not to assume that others have had the same experiences that I have. I did not make any assumptions as to whether another mother was similar or like me; they may have had conflicting perspectives. As is common in the CRRRE framework, I treated each participant with respect, like I would like to be treated, and did not make assumptions.

The researcher/participant relationship is based upon caring ethics, emphasized by reciprocal relationships, recognition, and responsiveness. Although the research process brought me together with other families to share thoughts, feelings, and histories, this opened the door for vulnerabilities, and the power differential needs to be acknowledged (Lahman, 2017). As is common in CRRRE, throughout the research process, I reflexively journaled about my bias. I used professional judgement throughout the process to protect the relationships between researcher and participants, with the goal of giving authentic voice to participant experiences. I offered to share personal stories with participants at a later date but did so with great care to not influence the findings. These measures are discussed in more detail in the credibility section.

Research Genre: Phenomenology

Due to the nature of the research questions, a phenomenological research approach was chosen. In phenomenological research, the goal is to understand participants' subjective better, lived experiences and perspectives related to the phenomenon of interest (i.e., IEP meetings) as it has been experienced by participants (Moustakas, 1994). Phenomenology allowed me, as a mother of children who are deafblind, to suspend past knowledge and experience, to better understand a phenomenon at a deeper level (Creswell & Poth, 2018). To accomplish this goal, a trusting rapport was established with participants. A qualitative methodology allowed me to build a respectful, trusting rapport with participants by engaging in dialogue to explore the phenomenon of interest (IEP meetings).

In phenomenological research, interviews are the primary source of data, although documents and observations may also be included (Terrell, 2016). For this study, primary data collection took place through semi-structured open-ended qualitative interviews (Appendix A); however, other data sources included participant reflections and researcher journals. Each participant was asked to reflect on their IEP experiences and submit a written reflection after their interview (Appendix B). I journaled about my observations after the interviews and during coding, and those journals were reviewed and referred to during the data analysis phase.

Methodology

Participants

Fourteen mothers of children who are deafblind from twelve different states composed the sample for the study. Half of the participants in this study help other families work with their IEP teams so, although the sample size was 14, the depth of their

experience working with IEP teams extends beyond their personal experiences. Two of the families had two children who are deafblind. Eight families had children with Usher syndrome, 4 had children with CHARGE syndrome, and 2 families had children who are deafblind due to other causes. Because I am a mother of children with Usher syndrome, I received a higher percentage of Usher syndrome respondents because it was easier for me to reach those parents. As a result, the percentage of Usher syndrome respondents (57.1%) was higher than the national child count percentage of 12.9% according to the National Center on Deafblindness' 2017 Child Count (National Center on Deaf-Blindness, 2018), making this a limitation of this study that will be discussed further in the limitations section. The percentage breakdown in etiology allowed for the study to have a diverse sample, with children of various abilities. Ten of the 14 children (71.4%) had additional needs in addition to deafblindness, which is slightly lower than the national child count statistic of 87% of children having additional needs (National Center on Deaf-Blindness, 2018). Four children were under the age of 10, 8 children were between the ages of 10 and 18, and 4 children were over the age of 18. All children were currently being served or had been served on IEPs. Two families had other children who have IEPs for something other than deafblindness. Although I was recruiting all parents, all participants were mothers. Participants had a high level of education: seven had graduate degrees, six had undergraduate degrees, and one had some college. These education levels are not representative of all parents of children who are deafblind (See Table 1).

Table 1

Demographics

Participant	Parent Education	State	Child Deafblind Etiology	Educational Placement	Child Additional Disability	Deafblind Child Ages(s)
1	Bachelor Degree	WA	CHARGE	Public/Gen Ed	Y	6
2	Master Degree	MI	Usher	Public/Gen Ed	N	7
3	Master Degree	AK	Usher	Public/Gen Ed	N	9
4	Master Degree	CA	Usher	Public/Gen Ed	Y	19
5	Juris Doctorate	MO	Usher	Public/Gen Ed	N	5
6	Bachelor Degree	NC	CHARGE	Public/Self-contained	Y	22
7	Juris Doctorate	MN	Other	Private/Gen Ed	Y	17
8	College	SC	Other	Public/Self-contained	Y	19
9	Master Degree	WA	CHARGE	Public/Self-Contained	Y	13
10	Master Degree	NJ	Usher	Public/Gen Ed	Y	14, 16
11	Master Degree	IL	Usher	Public/Gen Ed	Y	15
12	Bachelor Degree	MS	CHARGE	Public/Self-contained	Y	15
13	Bachelor Degree	MN	Usher	Public/Specialized School	Y	17, 25
14	Bachelor Degree	NY	Usher	Public/Gen Ed	N	15

Because the purpose of the study was to investigate strategies that parents use to increase collaboration with IEP teams as an alternative to due process, inclusionary criteria deliberately required participants to have had both negative and positive IEP meeting experiences. Based on these requirements, participants met the following inclusionary criteria: (a) have at least one child who is deafblind who receives special education services or has exited special education services and is achieving positive student outcomes as determined by the family; (b) have attended at least five IEP meetings; (c) have experienced some conflict with their IEP teams and overcome some or all of those disagreements without the use of due process; (d) have attended a meeting that required specific parent-initiated strategies to resolve the conflict; and (e) has had IEP experiences that have resulted in needing to have meetings that lasted longer that previous meetings and/or multiple meetings to address the issues.

For purposes of this study, participants were asked to self-report if they had a child who was diagnosed as deafblind. The IDEA (2004a) defines deafblindness as:

> Concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and education needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. (Sec. 300.8[c][2])

The National Center on Deaf-Blindness (National Center on Deaf-Blindness, 2018) census indicated there were 10,000 children and youth as of December 1, 2017 on their child count. This count included children who have other disabilities in addition to deafblindness. OSEP's census data, collected by using disability category on the IEP, shows a much lower number of 1,306, due to misclassification.

During initial recruitment, I was looking for parents who had children who were deafblind between the ages of 10 and 18. Because of the low-incidence of deafblindness,

I was not able to recruit enough participants that fit the inclusionary criteria. I had several potential participants reach out to me indicating interest, but they did not meet the age criteria. Some of these potential participants had just transitioned their children to elementary school and others had children who had graduated high school or otherwise were too old to be served by IDEA. I spoke with two of these potential participants and realized that, although these parents did not have children between the ages of 10 and 18, these parents had been to multiple IEP meetings, mentored others, and had strategies they use in meetings. When I told one mother of a child over 18 that she did not meet the recruitment criteria because I wanted parents who had a good memory of the strategies, she said to me "Does a mom ever forget? I remember everything like it were yesterday." To obtain the desired sample size, I, then, removed age restrictions.

During the initial recruitment, I purposefully excluded parents who had been involved in due process because I had assumed these parents would not have collaborative strategies. I removed this criterion if, upon talking with the mother, they indicated they had extensive experience resolving conflict without the use of due process. I found that many mother had, early on, gone to mediation or filed a state complaint; then years later, they developed strategies to avoid due process. I allowed those mothers to be part of the study. Any mother with unresolved conflict, however, was excluded from participating in this study. I ensured that parents met study criteria by asking potential participants to fill out a short questionnaire (Appendix C). The questionnaire asked parents to identify source(s) of IEP conflict and helped collect basic demographic information. It is important to note that although I was recruiting all parents or caregivers, all 24 potential participants were mothers, and all 14 participants were mothers. This will be discussed further in the limitations section.

Recruitment. To obtain a national response, the primary method of participant recruitment was on social media. Because I am a mother of children who are deafblind I used personal experiences to identify the most effective way to recruit parents. I considered where I would go if I were interested in participating in a similar study. Based on my experience, parents who have questions regarding IEPs post them on Facebook groups.

Recruitment notices were posted on various Facebook groups for parents and caregivers to children who are deafblind, including but not limited to, the following groups: (a) Parents of Blind and Visually Impaired Children; (b) Hands and Voices Deaf and Hard of Hearing Plus and Hands and Voices; (c) Parents of Children with Cochlear Implants; (d) Usher syndrome (of America) support group; and (e) Usher Syndrome Parents. I did not have direct access to the CHARGE Syndrome Facebook group, but a fellow parent posted the notice there. When posting notices, I disclosed the fact that I was a fellow parent and a researcher. Because I am a mother of two children who are deafblind due to Usher syndrome, I also posted the flyer on my personal Facebook page and asked fellow parents who have children who are deafblind to share it with their friends. A sample of the recruitment post is included in Appendix D.

In addition to Facebook postings, I contacted national organizations who serve families who have children who are deafblind. The National Family Association of Deafblind sent notice to their parent membership (2,520 followers). I contacted the National Center on Deaf-Blindness, and they sent notice of the study out to the state deaf-blind technical assistance projects. There are 53 federally funded deafblind technical assistance projects across the United States and United States territories. The directors of the deafblind technical assistance projects were asked to email information about the

study to the parents of children who are deafblind in their states. Lastly, as a mother of two children who have Usher syndrome, I have access to the Google group for the Usher Syndrome Coalition, so I posted the flyer and notice about my study to this group. To reduce bias, I ensured that I did not have a close personal relationship with any of the participants. Although I had met some of the participants, I did not have knowledge of their IEP experiences, and all participants were "arms-length." I recruited 24 potential participants using these sampling methods, of which I interviewed 14.

Purposeful sampling. Because social media was the primary method of recruitment, a purposeful sampling method was chosen. Social media provided me the opportunity to communicate directly with potential participants using a communication method they were already using to share ideas with other parents (Salmons, 2016). Purposeful sampling is a technique widely used in qualitative research (Patton, 2002). This sampling technique allowed me to identify and select individuals who had extensive knowledge or experience with a phenomenon of interest (Creswell & Plano Clark, 2011). Purposeful sampling enabled me to consider a participant's availability and willingness to participate (Bernard, 2002).

Data Collection

Before data collection, Institutional Review Board (IRB) approval was obtained from the University of Northern Colorado to proceed with this research study. The IRB application included disclosure of proposed methods, safeguards for participant awareness and consent, research purpose, and background. After obtaining IRB approval, all ethical standards were maintained. A copy of the IRB approval letter dated November 16, 2018 can be found on Appendix E.

Potential participants were asked to email if they were interested in learning more about the study. I first asked prospective participants to verify they met criteria for inclusion with a quick screening. Participants filled out a short questionnaire using Google Forms (Appendix C) to ensure that they met the inclusionary criteria. The questionnaire asked parents to briefly discuss any past and current sources of conflict and allowed me to collect basic demographic information. Once I verified that a participant met the criteria, I emailed them to schedule a telephone interview. Phone interviews were used for convenience due to family schedules and other logistical issues. Consent forms were sent to participants in advance, and they were signed and received back before the interviews (Appendix F).

Researcher as an instrument. An important aspect of qualitative research is that the researcher acts as the data collection instrument, as all data flow through the researcher, and are, thus, subject to the potential influence of bias. To mitigate this, and allow as much context to the reader, it is crucial that any such biases be disclosed.

Every effort was made to ensure objectivity; however, bias undoubtedly develops the way the data are viewed and understood. To mitigate bias, interview and reflection questions were open-ended and not leading. I personally completed all interviews, and participants were told that I am a mother of children who are deafblind. Care was taken not to let bias influence data collection. Before starting every interview, I told participants that, although a fellow mother, I was not able to share my personal experiences during the interview. I told participants that this additional sharing needed to happen in a follow-up call.

Interviews. The primary source of data was phone interviews with mothers of children who are deafblind. All phone interviews were audio-recorded with the participant's explicit permission, indicated by signature on the informed consent form and by verbal consent during the phone calls. All participants were interviewed one time, and the interviews took between 25 and 60 minutes. No follow-up interviews were necessary to clarify any of the data. Participants were given details concerning the nature and purpose of the study and interview protocol in advance.

The interview protocol (Appendix A) followed a semi-structured format, where interview questions precede an array of potential follow-up or probing questions asked throughout the interview (Merriam & Tisdell, 2016). As is typical of this type of interview structure, questions were open-ended, and all the questions were flexibly worded (Merriam & Tisdell, 2016). In line with the semi-structured format of the interviews, participants responded to the series of pre-constructed questions, but were allowed to stray from the questions if they wished to share relevant information that could not be anticipated. The interview protocol (Appendix A) was created to allow participant responses to flow directly into the research questions and incorporated factors from a review of the literature and personal experiences to draw as much valuable information as possible. The interview protocol was developed based both on my past experience as a parent and based upon a review of the literature. Piloting procedures for the interview protocol incorporated the feedback from a mother who met the study eligibility criteria; this was intended to ensure the validity of the interview protocol. This mother is considered a parent leader in deafblindness and has had experience working with other families to help improve IEP meeting outcomes. Based upon the feedback I received during the pilot interview, I reordered and consolidated some of the questions,

so the interview had better flow. Although her feedback was considered, the parent interviewed during the pilot interview was not one of the study participants.

The interview protocol (Appendix A) was divided into three major sections: (a) demographics, (b) IEP experiences, and (c) resolving conflict/improving collaboration. The questions in the demographic section asked details about the child and family. These questions were asked in the Google survey prior to the interview. This allowed me to have background on the family prior to the interview. The section of interview questions related to IEP experiences was intended to answer Research Questions 1, 2, and 3 and focus on the knowledge, skills, and strategies that parents bring to IEP meetings and the family role in working with the IEP teams. The section of interview questions related to conflict and improving collaboration was to understand past conflict and what strategies were used to resolve the dispute without due process, which is related to Research Questions 2 and 3. If the mother described the IEP challenges in detail when answering other questions, I did not drill down further about the source of conflict. My goal was to focus on strategies and not the details of past conflict.

Participant reflections. Research indicates that a study is more likely to be supported when participants are involved (Patton, 2015); therefore, I wanted to find a way for the participants to be involved besides the interviews. To accomplish this goal, immediately after the interview, participants were emailed and asked to reflect on the interview by responding by email to reflection prompts (Appendix B). Participants were asked to return the reflection within 48 hours of the interview; that way the interview was fresh in their mind. If a written reflection was not convenient for the participant, I offered to schedule a follow-up interview to discuss reflections. No follow-up interviews were scheduled. In the reflection, participants were asked if any of their answers surprised

them (i.e., made them think differently about the issue) and to give advice to parents and educators. Because data collection took place around the holidays, I was not always able to get the reflections back within 48 hours of the interview. I had to remind participants two to three times to respond, but I ultimately received back all reflections.

Researcher journals. I maintained a journal for every interview, because dynamics between researcher and participant impact the collection of data, and because I am a fellow mother who has experienced this phenomenon, I journaled after every interview. The journal entries focused on the dynamics between me and the participants. I wrote about my feelings after each interview and about any participant emotions were felt in the interviews. At the start of each interview, I disclosed that, because of my bias, I was not able share any personal background during that meeting. If something came up that sparked a personal memory, I told participants that we could schedule another time to talk. Journaling was a way for me to make my past assumptions, history, and values known. Bias was mitigated using journaling because it made the potential bias more transparent (Ortlipp, 2008). I kept a journal during the coding process about any bias, any questions I had about coding, and any thoughts I had about the process. The journals were helpful during the analysis process. I referred to the journals frequently as I worked with the peer reviewer. When coding, I noted any uncertainty I had about any of the coding so I could go over these codes specifically with the peer reviewer.

Data Analysis

Thematic analysis was the method of coding and thematization and resulted in a series of common themes representative of the sample's shared experience (Braun & Clarke, 2006). Each recorded interview was transcribed verbatim by an outside transcription company. The transcriptions were reviewed by me for accuracy and

analyzed using thematic analysis. Participant reflections and researcher journals were coded and analyzed using this same method. To increase credibility, a peer reviewer assisted in the coding process. The peer coding process is discussed in more detail in the credibility section.

Thematic analysis is a very flexible approach to identifying, analyzing, and reporting patterns within data (Braun & Clarke, 2006). Unlike other methods of analysis, thematic analysis is not wed to any pre-existing theoretical framework and, therefore, can be used within different frameworks. The process of thematic analysis began by becoming familiar with the data, which occurred during data collection. I read the transcripts multiple times until immersion and patterns seemed to emerge. During this process, I listened to the audio recordings against the transcripts to ensure accuracy and to gain more familiarity with the data (Braun & Clarke, 2006).

With the help of the peer reviewer, for Phase 2, I generated a list of initial codes, based upon what was interesting to me when familiarizing myself with the data and based upon detailed coding of the first two interviews (Braun & Clarke, 2006). The coding of the first two interviews was done manually in Microsoft Word because the peer coder had easy access to that software program. The peer reviewer and I both independently coded the first two interviews and then met virtually to discuss the coding. The remaining data were then independently coded and organized into meaningful groups (Tuckett, 2005) using the NVivo qualitative software program. The coding of the two initial interviews were then imported into NVivo. NVivo is a software from QSR International that helps analyze and manage qualitative data. The process of coding and organizing the data involved working systematically through the data, giving full and equal attention to each data item.

Phase 3 of analysis involved searching for themes within the coded data. This step entailed collating codes into potential themes, by gathering data that were relevant to that potential theme. Visual data maps were used to sort the codes into themes and subthemes. Any data that departed from these main themes were placed into a theme called *miscellaneous* for future analysis. At the end of this phase, themes were preliminary; ultimately, some needed to be combined, refined, separated, or discarded. This analysis was done with the help of the peer reviewer. During Phase 4, with the peer reviewer, I reviewed preliminary themes and refined them into a list of final themes, taking care that there should be a clear and identifiable distinction between themes. Phase 5 of data analysis entailed defining and naming the themes. During this process, I considered how each theme fit into the broader overall story being told by the data (Braun & Clarke, 2006).

Lastly, for Phase 6, the analysis was written up to ensure that it would convince the reader of the merit and validity of the analysis. As part of the write-up, I selected quotes and vivid examples to illustrate the themes. These excerpts in support of each theme helped to ensure that participant voices were heard and to support the validity of the findings. The write-up presented a fluid argument concerning the research questions (Braun & Clarke, 2006).

Credibility and Trustworthiness

The process of data collection for phenomenological research required that I maintain an open mind with as little influence of bias as possible (Terrell, 2016). I was an important instrument for data collection, analysis, and interpretation. Data collection was easier, and the data is richer because I have experienced the phenomenon; however, sufficient methods to mitigate bias needed to be implemented.

One of the most important components of qualitative research is the establishment of credibility, explicitly addressing any threats to the internal validity of the investigation (Patton, 2002). A common and concerning threat to the internal validity of qualitative research can include data analysis bias. Because my background is as a mother who has had positive and negative IEP experiences, there was an increased risk for bias. To enhance the credibility and establish the trustworthiness of this study, four credibility measures were employed: triangulation, bracketing, peer reviewing, and member checks.

Triangulation. Triangulation is a credibility measure that entails the researcher collecting and examining multiple sources of data (i.e., interviews and documents) to build a coherent justification for themes (Creswell, 2014). Triangulation can also include the use of multiple investigators, such as several researchers or peer reviewers (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). For this study, I triangulated by collecting multiple sources of data: interviews, participant reflections, and researcher journals. A peer reviewer was also used to increase credibility in coding and analysis. The peer review process is discussed further below.

Bracketing. As is common in phenomenology, data were collected using epoché (bracketing) whereby data is collected with an open mind so that data are not contaminated with personal opinions or preconceptions (Terrell, 2016). Because of the potential bias and my past experiences with the phenomenon of study (i.e., IEP meetings), the use of bracketing allowed for a reduced potential for effects of researcher bias. Bracketing, or epoché, is useful when biases are easily identified and can be expressed in a way that is as comprehensive as possible. Bracketing is a concept in which the researcher puts their personal experiences aside to take a fresh perspective of the phenomenon (Creswell & Poth, 2018). To bracket personal perceptions and experiences,

I needed to acknowledge each potential personal bias, which allowed me to easily remind myself of my thoughts so that efforts to ignore biases could be more focused (Terrell, 2016). By similarly listing these biases in plain view, I provided context for readers and future researchers (Terrell, 2016).

Peer reviewing. Peer reviewing is the process of having someone familiar with the topic, but who is impartial, examine the methodology, transcripts, data analysis, and research findings and to play devil's advocate (Creswell & Miller, 2000; Terrell, 2016). For this study, peer feedback helped ensure the validity and credibility of the work (Terrell, 2016). A peer that was familiar with qualitative research and the topic of interest served in this role for this study.

To increase the reliability of the coding, the peer reviewer and I both independently coded the first two transcripts and created a list of codes. Both the peer reviewer and I reviewed codes together to ensure agreement. This process was to ensure there was agreement on the coding methods and overall data analysis. After the peer reviewer and I agreed on codes, I coded all of the remaining transcripts using the open coding procedure. I worked with the peer reviewer to determine and finalize themes. The peer reviewer reviewed findings over the phone to help ensure credibility and trustworthiness (Brantlinger et al., 2005).

Member checking. Each participant had the opportunity to perform member checking but was not required to take part in the task. Member checking is a process wherein participants are highly involved in the validity of the data, having the opportunity to review the findings for accuracy and provide feedback if they feel that one or more aspects of their experience were not accurate (Creswell & Miller, 2000). Member checking was especially important due to the phenomenological nature of the study, as

the result of the research should result in a story about the experience of collaborating

with IEP teams, and care was taken to ensure that the story is accurately documented.

Individual transcripts and preliminary themes were sent to participants to both ensure that

the transcripts were accurate, that participants agreed with initial responses, and that my

interpretation of the findings was valid. I showed the final findings report to participants

and asked if they believed that it accurately represented their input (Terrell, 2016). Three

participants responded to the findings and indicated they were an accurate reflection.

There were no changes to the transcripts or findings based on transcript review or

member checking. One participant elaborated on the issue of "difficult transitions" to ask

that I make sure to mention transitions due to staff changes, and I added that additional

detail in the findings section.

Ethical considerations. Recording each of the interviews allowed me to report

the interview information correctly, and all the transcripts of the interviews remain

confidential. When not in use, all audio recordings and transcripts remained on a

password-protected computer during the course of the study. All identifiable data,

including audio recordings and consent forms, will be destroyed by shredding or

permanent deletion (as applicable) three years after the study is completed. Participant

names were not used when sharing interview excerpts; where necessary, participants

were referred to by a pseudonym of their choosing. Only the peer reviewer and I had

access to data.

Participants were given an informed consent to sign and return before study

participation. The informed consent disclosed any risks and how they would be

addressed. The possible risks in this study were minimal. Participants were at a slight

increased risk of experiencing some psychological discomfort because it may have

reminded them of feelings of past conflict. For that reason, I chose to focus questions more on strategies and less on the conflict itself. Referrals to counseling services would have been provided, if needed; however, no one requested counseling services. While the most care possible was taken in keeping participants' information confidential, there was no way to guarantee absolute confidentiality. In response to this, I de-identified data as quickly as possible and retained a separate file linking participants' actual names to their pseudonyms. Storage on a device not connected to the internet also heightened the data's security, and data were only stored on an internet-connected device when actively being used.

Conclusion

Parents play an essential role on IEP teams. Because resolving conflict using due process is emotional and costly for parents, parents find other ways to get their child's needs met by IEP teams. Research has shown that if parents believe that they are equal partners of a collaborative IEP team, they have increased satisfaction. Unfortunately, however, IEP meetings are often fraught with conflict. If the conflict cannot be resolved, parents find they have no choice but to consider costly and emotional due process options. The purpose of this phenomenological qualitative study was to explore the roles that parents and caregivers of children who are deafblind play in fostering a collaborative relationship with their child's IEP teams. Using qualitative semi-structured interviews, mothers of children who are deafblind were asked about the strategies they employ to resolve conflict and increase collaboration, past experiences that led them to develop advocacy strategies, and their views on collaboration. The themes identified through the analysis of participant responses to the research questions adds to the sparse research literature that exists concerning strategies used by parents to foster collaboration and

reduce conflict. The analysis of participant responses provides IEP teams and families with strategies for improving collaboration.

CHAPTER IV

RESULTS

The purpose of this phenomenological qualitative study was to explore the role

that parents of children who are deafblind play in fostering a collaborative relationship

with their children's IEP teams. Fourteen mothers of children who are deafblind were

interviewed about their IEP experiences. Open-ended interview questions were used to

collect in-depth information as mothers shared their experiences of attending IEP

meetings, with the goal of identifying themes regarding collaboration within IEP teams.

To address the need to understand the roles that mothers of children who are deafblind

play when fostering a collaborative relationship with their children's IEP teams, the

following research questions were posed:

Q1　What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Q2　How do parents define collaboration with their IEP teams?

Q3　What knowledge and strategies do parents use in IEP meetings to promote collaboration?

This chapter presents the key findings obtained from interviews with participating

parents, all mothers. Three categories emerged from the data: (a) problems parents

experience that lead them to develop advocacy strategies, (b) valued family-school

collaboration, and (c) advocacy strategies used by families. These three categories

directly relate to the research questions. Although the primary goal of the study was to

identify parent-initiated strategies used to foster collaboration with their child's IEP

teams, it was also vital to understand past experiences that lead parents to develop these

strategies and to understand parent views of collaboration. The types of advocacy

strategies that participants in this study reportedly used were a result of their past

experiences and these collaborative values (See Figure 1). Participant past experiences

and views of collaboration serve as building blocks to thoroughly understanding the

advocacy strategies that mothers developed.
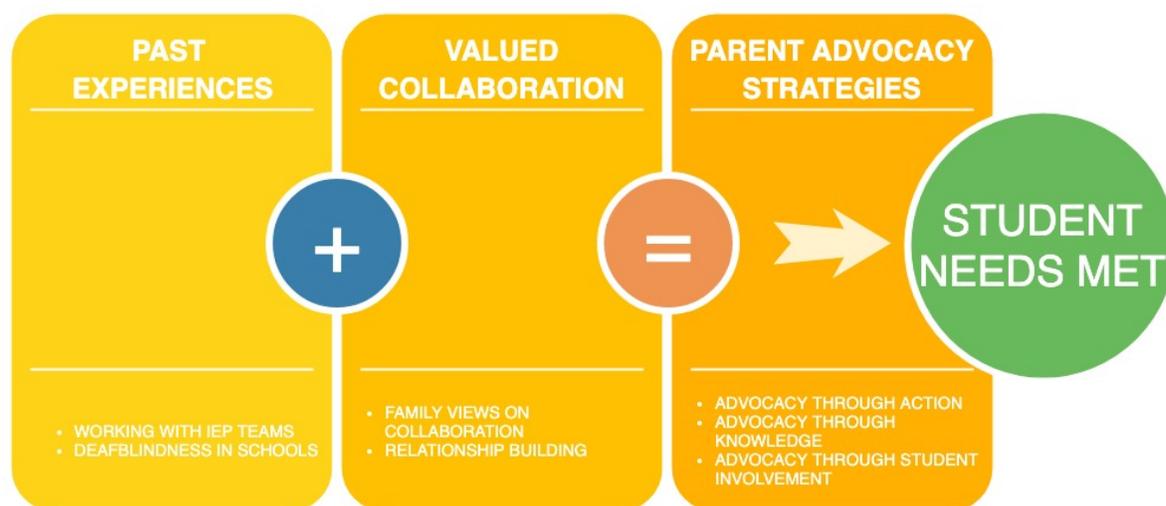
Figure 1. Category Mapping

Following is a discussion of the categories, and the related themes and subthemes with

details that support and explain each using, thick descriptions, and illustrative quotes.

Problems Parents Experience that Lead them
to Develop Advocacy Strategies

To answer research question 1, *What experiences lead parents to develop and use*

collaborative skills with their child's IEP team?, it is necessary to understand the

challenges parents have faced. Participants in this study identified problems they have

experienced that led them to develop advocacy strategies. These problems fell into two

major themes: (a) challenges associated with the deafblind population in schools, and (b)

challenges with the IEP process. Both of these challenges will be discussed in detail with associated subthemes. As previously stated, these past challenges contribute to mothers developing advocacy strategies as a way to get their child's needs met without using due process. Additionally, a few of the participants had previously exercised their rights through due process and, because of that past experience, developed strategies to avoid due process in the future. Following is a discussion of the past experiences that led participants to develop advocacy strategies.

Challenges Associated with the Deafblind Population in Schools

Although specific problems varied, all participants indicated that challenges related to deafblindness were some of the biggest struggles they experienced. The related challenges include: (a) professionals misunderstanding student needs, (b) lack of professional expertise, (c) parent need to push for vision or other services due to professional lack of understanding, (d) professionals not understanding and valuing different communication methods, (e) students being unable to communicate their needs directly, (f) collaborating within a large team of service providers, (g) lack of access to families with similar experiences, and (h) emotional impact of advocacy on families.

Professionals misunderstanding student needs. A majority of the participants' stated that their primary challenge is when teams misunderstand their child's needs. Because of the dual sensory loss, student needs may be complex and can result in disagreements in determining a child's least restrictive environment and how inclusion will be possible for that individual child. One mother of a child with Usher syndrome outlined the complexity,

There was a mindset when we started that if you need a lot of support, you had better be in a special education class and if you don't need support, then you go to mainstream, and I'm like, "That's not the way. You can have mainstream with support. Full inclusion." So, I was fighting that fight before anybody here was saying it, but then when they did make the switch and said everyone is fully included, they still weren't providing the support that went along with it. I think that's the hard thing is keeping it individualized but keeping it in a way that you can manage for 12,000 in the district, 1200 on an IEP, or whatever.

One participant shared a story about how her son was doing well at the Perkins School for the Blind, but the district wanted to move him back into district. I heard other stories about teams wanting to place children in very loud classes or in general or special education environments that were inappropriate.

Participants also mentioned advocating for more than just academic goals to be listed on the IEP. One participant who has a child with Usher syndrome stated, "Goals have to be non-academic too. Like, is he going to after-school activities? Is he able to participate? Is he happy? That's not an academic goal, but it's an important goal. If these non-academic goals are not addressed, it can lead to mental health issues." Many participants also mentioned the desire of having self-advocacy goals for their children. More about self-advocacy will be discussed later in this paper when talking about student involvement in IEP meetings and student self-advocacy.

Some participants shared the belief that teams' expectations of students are too low. For example, one mother indicated that although her son with Usher syndrome was getting high grades and capable of honors classes, the school was willing to look only at team-taught special education classes for her son, even though they were not appropriate. She said that she had to advocate for her team to see her son as "cognitively able." Ultimately, after a long meeting and advocacy skills practiced on behalf of the mother, the team agreed that her son should receive the same opportunities as any other student

and should be allowed to try honors courses. Meanwhile, another mother who has a son with Usher syndrome talked about how her son received less attention from teachers because his teachers did not understand how he was impacted by the dual sensory loss. Although her son had a high amount of services on his IEP because he was so successful emotionally and intellectually, his needs were often overlooked by teachers.

Lack of professional expertise. A majority of participants mentioned the lack of educational team member expertise as being a challenge, mostly related to the lack of knowledge in deafblindness. The professionals' lack of understanding of deafblindness and the unique student needs was a primary reason that participants felt they needed to advocate and develop strategies to ensure their child's needs were met. Because of a lack of knowledge on the team, participants indicated that students and the family felt responsible for sharing knowledge about deafblindness and the individualized student needs with the team. When necessary, participants reported that they bring in outside resources, such as the state Deaf-Blind Project representatives, to help supplement knowledge and offer support.

When participants mentioned a lack of knowledge of deafblindness on their child's professional team members, they emphasized the importance of professionals understanding the individual needs of their child. The discussions about lack of knowledge always led to comments of the professionals not comprehending their child's individual and unique needs. Participants focused on the importance of understanding deafblindness *and* the individual student needs. A majority of the participants indicated that their teams were unfamiliar with the impact of dual sensory loss to the level that they should be. One participant discussed that "the deaf and hard of hearing teacher and the visual impairment specialist, neither of them understood the combination of the two

[vision and hearing loss]. It is sometimes hard to get someone on the team to accept

responsibility for 'deafblindness'". Another participant shared her frustration:

> The hearing itinerant saying "I'm just a hearing itinerant. I can just worry about taking that part," and then the vision itinerant, "Well, I'm just the vision itinerant. I can only worry about the eyes," . . . I would hope and wish that they would maybe take some classes or go to a seminar or something to understand how the two work together. If they are going to be so adamant about keeping those two services separate, then at least those two could get some kind of knowledge in how they kind of interact with each other. That would be my number one.

The most common response had been:

> "Oh yeah. We worked with a kid with Usher [syndrome] once." So, I don't really have an expert in it [on the team]. They were somewhat familiar because maybe they had worked with a kid with Usher a long time ago or there were one or two kids who have gone through the program with Usher in the past, but we do not have an intervener or anybody who's an expert on our team.

Another mother stated that "having people that know deafblindness makes a huge

difference in the room because it's not like you have to start at the very beginning. They

have some, I guess, knowledge in it." If the family is the only one knowledgeable, there

is pressure related to the family sharing that knowledge with the team.

> Families sometimes turn to outside service providers who are experts in

deafblindness to provide a different perspective to the team.

> That's one of the main reasons we went to Perkins [for assessments]. I could just tell, we needed a fresh look at my son. A lot of kids like him, most educators have never worked with someone like him. So, I have to remind myself that they are not trying to be ignorant. They just are, not in a mean way, but just like I am half of the time. None of us expected to have children that had all these challenges, so the more resources that I can advocate for the team.

Participants realized that this lack of knowledge and expertise is not intentional. One

mother added, "Educators may not know what they do not know." Another mother stated,

"I've never come across a team member that I think intentionally didn't want to help my

child. I think it's an [lack of] education piece." She continued to provide an example, "I

have a new special education teacher straight out of school, basically, and she really,

honestly I think, felt like she was including my son, and she just couldn't wrap her head

around the incidental learning that wasn't taking place." A mom of a child with

CHARGE syndrome has had similar experiences, "These people are doing the best they

can within the school district, but they don't have a child that is as complex as mine." She

mentioned that she wishes the team would spend time in the classroom observing her son

so they can gain a better understanding of what goes on:

> They have really good intentions, but they want all of these children to fit in a certain box, and with my son having CHARGE and not being autistic or Downs, I don't think they know how to help me, but at the same time, they don't ask how to help me. My Deaf-Blind specialist has said numerous times that she would be glad to talk to these people to give them some guidance.

Parent need to push for vision and other services due to professional lack of

understanding. Team members do not always understand the needs of students who are

deafblind, so participants said they often needed to push for services related to

deafblindness such as: (a) vision services, (b) braille instruction, (c) orientation and

mobility training, and (d) interveners. Mothers push for different reasons. For families

who have children who are born deaf, but lose their vision over time, participants

mentioned needing to push for vision services, braille instruction, and orientation and

mobility because their teams did not see value in starting so early. Mothers find it

challenging to advocate for services that will help their children later in life when they

start to lose more vision. There is a perception that IEP teams are sometimes too focused

on the present and not focused enough on what is needed to prepare the student for the

future dual sensory loss. One mom of a young child with Usher syndrome stated,

We got pushback from the [Teacher of the Visually Impaired] TVI about interest in braille. We want to introduce braille now, whilst he is still interested in it, and they didn't want to do that, so that led to kind of our biggest problem when we first moved here. . . . So that kind of led to the conflict initially.

Participants discussed the benefits of having interveners to support their children. For those who have interveners, they had to fight hard for them. In addition to the lack of knowledge, participants noted a lack of regulatory and statutory requirements for interveners. One mom of a child with very complex needs who has a terminal disease got so frustrated by the lack of understanding that she enrolled herself in school to become an intervener herself. Once she took that step, it helped the team understand the benefits, and her son now has an intervener. She has insisted that the intervener be at all IEP meetings, because their input is so valuable, and she documented this in writing in the IEP. A mother of a teenager talked about the misunderstanding that can occur because of the lack of knowledge of interveners:

For my daughter, her hearing loss is not such that she needs sign language interpreting. In fact, that would in some ways be harder for her because she did not know that. So, at one point what they gave her for an intervener was a sign language interpreter, who was a lovely woman, but had zero background in deafblindness. . . .I requested that she go through intervener training and become certified. . . .She wasn't obligated to, but she agreed to do it.

The same mother discussed how being an intervener is a calling:

It's sort of a calling, rather than a checkbox on training. . . .They're intuitive. They can sense what is working for a child who communicates and receives information differently than maybe other students that would have other needs. You have to be highly attuned to figure these things out.

Professionals not valuing different communication methods. Participants mentioned challenges they faced while advocating and ensuring the team understood and valued the student's preferred communication mode. Some participants mentioned the conflict, especially during preschool years, about communication choice. Although time

has passed and their children are now in elementary or middle school, participants still vividly remember the conflict and equate it back to a lack of understand of the unique student needs. For students who are non-verbal, participants mentioned challenges in getting the team to use an augmentative communication device in a way that helped increase a child's language skills. This is tied into the discussion of how participants want the team to have high expectations for their child. One mom who has a teenager with CHARGE syndrome, talked about how the team has had low expectations of her son related to using his communication device. His team was trying to get her son to sign when her son did not like to use sign language. Her son wanted to use the communication device and was starting to form sentences. She had to advocate for her son and get her son's team to have higher communication expectations. The need for and right time to introduce tactile sign language was also mentioned. Another mom of a teenage child with complex needs insisted that her son learn tactile sign language because she knew that he was capable and that he would need it in the future. Her son's team did not think her son was capable of learning tactile sign language because of his complex needs, but, because of her insistence, he now knows more than 50 tactile signs. Another mom of a child with CHARGE syndrome gave insight into the changing demands that are hard for the team to understand at times. She said it is about balance and meeting her son where he is on any given day. For her son, he grew up learning American Sign Language (ASL), but now he wants to use spoken language. He is thriving using a spoken language approach, but she also does not want him to miss opportunities to continue learning ASL, and she wants him to be part of the Deaf culture. Another participant had similar experiences with her son. American Sign Language was his first language, but he transitioned to spoken

language. Now, he has an interest in ASL again, so she is advocating to add ASL to his IEP.

Students unable to communicate their needs directly. For students who are not able to communicate their needs directly to their team, mothers shared that they felt even more pressure to advocate for their children. One participant who has a son who is non-verbal indicated that, although he uses multiple different methods to communicate, "he doesn't have the ability to step in and obviously advocate for himself, so I'm very much his voice in that matter. I come in and play a huge role in educating . . . advocating for him and educating the other team members about him." A participant who has helped many families, mentioned the importance of advocating for appropriate communication for a child: "If a student isn't a good communicator or can't communicate with everyone on the team, how [do] we monitor their communication and make sure that everybody's on the same page using the same tools." Participants mentioned the importance of having appropriate communication goals on the IEP and ensuring the entire team is on the same page with those goals.

Collaborating with a large team of service providers. For families of children who are deafblind, their child's IEP teams are generally quite large, especially if the child has additional needs other than deafblindness. Participants stated that when a team is large, it can be difficult to ensure that everyone is on the same page and is collaborating. Because each team member needs to share progress related to their section of the IEP and because of the increased collaboration necessary because of the dual sensory loss, IEP meetings can take a long time. Participants mentioned that long meetings can be tiring and that they prefer having multiple meetings throughout the year to go over progress. Some participants suggested the benefits of including family in preparatory meetings. For

children who have complex needs, participants indicated they felt that a once-a-year IEP

meeting was not enough, primarily because of the continually changing needs of their

children. Participants reported that they appreciated being involved in preparatory

meetings, and that such meetings help the team be on the same page before formal IEP

meetings. "The teachers or the service providers have, they seem to operate very

independently, and that's good and bad. I feel like the services aren't as integrated as I'd

like them to be, because of the particulars of deafblindness".

Lack of access to families with similar experiences. Participants described

lacking a sense of community because their child is the only one who is deafblind in their

school district or community. For families who have older children, connecting with

other families was harder when their children were younger because there were not as

many ways for families to connect online. Still, however, one mother talked about the

isolation that can occur:

> I don't know anyone here in my city. I'm still connected with families around the country, but there's no one local, and so I think it's worth some networking online like through the [National Center on Deaf-Blindness Family to Family] networking calls, you know, where you are connecting people around the country, rather than just locally, but I think that's very important to be able to talk to other parents who understand.

Further, because of the heterogeneous nature of deafblindness, finding other families who

can relate to the specific challenges that parents are going through can be hard to find.

Participants talked about the benefits of connecting with other families, but participants

mentioned that it has been difficult to find the time to network with others. So, as another

mother mentioned, that often leaves them to "try to forge a path [alone] and figure out

what to do along the way."

Emotional impact on families. There are emotional impacts on families as they advocate for their child's needs. Some participants described their experiences as mostly positive, meanwhile others talked about how stressful it has been, and some mentioned how there were both ups and downs. Unintended family outcomes resulting from advocacy activities fell into three areas: (a) choosing to move to another school district, (b) one parent choosing to stay home, and (c) the financial impact of these decisions.

Half the participants discussed the time commitment and stress associated with advocating for their child's needs. One mother said that she responded to a question on the study questionnaire (required of all participants) that asked if participants had attended at least five IEP meetings in the past; she indicated that when she schedules the annual meeting, she always plans a follow-up at the same time and that, then, has several meetings throughout the years. Several other participants indicated that they also have multiple meetings and talked about the impact of the time commitment on their families. When helping other families one participant talks about the approach,

> I think it actually has taken time from our family with the frustration and the disappointment and trying to fight more, and I'm gonna sit down, and I'm going to figure this out, and I'm going to get more help. If I would have taken a step back 10 years ago and say "Oh, I could put all this energy I'm using to fight the system and just sit down with my kids and play and help them grow." . . . I'm like "I can't tell you what to do, you just gotta weigh what's important to you at that moment." And at the back of my mind, I'm like, just go play with your kid, it's not a game changer. But, I can't make that decision for them. So, I think when you get towards the end [transition to post-secondary] you start to get smart and then you're done. So that's where we are at.

She said that the constant strategizing and tug of war is so unnecessary and takes up so much time. Another mother added that "it's tiring, it's exhausting. You're already dealing with so much, so for any parent, do what you can and know that the more you do, and learn, the better it's going to be." Yet another participant said that their family stresses

about everything all the time. There is also an immense pressure to be a conduit of information for the team and that can cause frustration.

In the midst of all this stress, some participants shared that, for the most part, their IEP experiences have been positive. One mother who helps other families said that she considers her experiences in IEP meetings to be a "growth experience." Another mother who has two children with Usher syndrome elaborated and said,

> G said he didn't think our family would be as close, so he wouldn't change it because we have such a close relationship because we're always collaborating and talking and doing presentations together, so it's just brought together our family because he doesn't think some of his friends talk to their parents the way he and his brother talk to us.

Challenges with Individual Education Program Teams

Participants indicated that past challenges associated with getting their child's needs met led to the development of advocacy strategies used for working with their child's education team. These challenges included: (a) IEP compliance and implementation, (b) district-level issues, and (c) difficult transitions. Notably, most participants did not necessarily see these challenges as experiencing conflict with the education team. Instead, these participants viewed the procedural problems as sources of frustration that they needed to deal with as they advocated.

Individual education program issues. Conflict related to the IEP fell into three subcategories: (a) IEP implementation, (b) IEP meeting issues, and (c) IEP compliance. For IEP implementation, participants reported challenges making sure goals are attainable and appropriate. One mother who has a teenager with CHARGE syndrome, mentioned that she brought in a Deaf-Blind consultant who looked at her son's IEPs. Upon counsel, she was told that her son's last five IEPs were the same, except for the

date. When she asked the district personnel about it, she was told that her son had not advanced enough to change in any percentages. She had seen her son progress at home, but the team was not seeing the same progress and, therefore, would not update the goals. When another mother, who has a teenager with Usher syndrome, had the same thing happen to her son, she told the team that she would not tolerate carry-over goals. She told the team that "either the goal was unrealistic, or the intervention was not appropriate." Another participant mentioned concern that she did not see the progression she felt her daughter needed to succeed and, as a result, her daughter was falling further and further behind, being pulled out of her general education classes, and suffering without the peer-to-peer educational opportunities.

Lack of coordination of service providers when working on deafblindness leads to IEP implementation issues. One mother of a teenager with Usher syndrome gave a story about her high school son's pullouts and how he would get pulled out to work on vision first, and then work on speech. Her son told her, "I can never be deafblind. I can be deaf, and I can be blind, but I can never be deafblind during this period." He said that the time is not productive, and he has a hard time finishing anything. His team has tried different ways to provide the itinerant vision and hearing services, but to date, it is still a challenge. It is also hard to find time for service minutes during the school day, especially for services such as orientation and mobility and braille, that are difficult to do with push-in. Participants stated that this situation got harder as their kids got older and did not want to be pulled out of class.

Unproductive IEP meetings were another source of conflict mentioned. Often, the team is large, making it hard to manage the meetings and make sure that everyone is on the same page. One mother talked about how IEP meetings are a waste of time and that

she has given up trying to make them more productive. She said that she "lets IEPs be what IEPs are, legal documentation." As a result, she focuses on making sure her son's needs are written down and then, she said, she works with the team later on the details in other non-IEP meetings. She added that the team has typically wanted to open a document and read through it in the meetings, but she has not let them waste time on that. A few participants have moved districts and others have received new case managers or transitioned to new schools. Participants mentioned how the experience was different with each team and that it depends on the special education environment in each district.

A few participants brought up IEP compliance issues. Initially, the mothers did not recognize compliance issues, but as they educated themselves on parent rights and special education law, these compliance issues became apparent. Compliance issues mentioned were no prior written notice, not giving parents copies of IEPs, not setting up the IEP meeting in time for team to provide proper input on updates, holding meetings without an administrator present, and the IEP not reflecting what was discussed in the meeting.

District-level issues. Participants discussed district-related issues. One mother stated that she quickly learned "the difference between the boots on the ground, the teachers in the school that are working daily with the child versus the district." She said she wishes the district would have a team approach for multiple sensory problems so that maybe there would be the support the teams needed. Another mother joked, although she said it is not funny, that she calls it "musical chairs" because the district staff has changed so much. She said the district moves people around so much and she wonders if it has been intentional. Other district issues mentioned were difficulty finding qualified staff, especially for aids and interveners. A few participants indicated that they thought that a

lack of district funding played into some of the decisions made in IEP meetings. Sometimes, state policies played a part in these challenges.

Difficult transitions. Participants reported having to spend more time advocating during times of transition, not just the post-secondary transition. These included: birth to three to preschool, preschool to kindergarten, elementary to middle school, middle to high school, and post-secondary. One mother said that transitions were tough and that she would be more involved during those times and then back off after her son "got on a roll." During these transitions, IEP teams usually change, meaning a "whole new set of people who do not know it." During member checking, one participant elaborated on the topic of transitions. She feels that staff turnover transitions are also a challenge. For her children, she has seen frequent changes in programming due to staff illness, change of educational placement due to behavior or health, and transition issues related to unqualified staff. She says that all of these types of transitions have been difficult for her children.

Valued Family-Professional Collaboration

To answer research question 2, *How do parents define collaboration with their IEP teams?*, it is necessary to understand participant views of collaboration because these views impacted the strategies that they developed to advocate for their children. It is important to understand participant views of collaboration to better understand why they developed the types of strategies they did. Collaboration was not the easiest topic to discuss during interviews. In fact, participants had a difficult time defining collaboration when asked. Interestingly, when discussing advocacy and knowledge, mothers mentioned several characteristics of collaboration that they valued. Additionally, participants reported having various levels of success with team collaboration, with all participants

providing examples of collaboration and lack of collaboration. Mothers reported varying levels of frustration in IEP meetings. Most participants mentioned that they have found that having a conflict approach to meetings has not been productive, so they strive for a collaborative approach to meetings, which seems to be more effective in getting their child's needs met. Many of the strategies that participants use when advocating for their children are collaborative, with a focus on team-building. Those strategies will be discussed in more detail under the theme of advocacy.

Participants mentioned the need for better collaboration, not just between families and educational team members, but also between professionals. To best serve students who are deafblind, participants emphasized the importance that the entire team be on the same page with services and goals. Often times service providers that specialize in sensory disabilities are itinerant, making collaboration even more challenging. Because parents are often the most knowledgeable on the team about deafblindness and certainly about their child, participants encouraged collaboration between team members, by acting as case manager.

Participants provided detailed examples of the valued collaboration that fell under the following partnership principles: (a) trust, (b) respect, (c) equality, (d) communication, (e) advocacy, and (f) commitment. Detailed examples of each of these partnership principles are described below. These examples are related to the unique needs of students who are deafblind.

Trust

One participant who is both a special educator and mother, talked about how important it is to feel like you can speak to the team and know that they have your child's best interest at heart. Since she is both a special educator and a mother, she has been on

both sides of the table. She has seen that the minute trust is broken, even just a little bit it can be tough to reestablish that connection. When she works with parents, she tells them to find one or two team members they can trust to talk with. She said that, as an educator, she has seen families come in with past negative experiences and a lack of trust. When that happens, she said she tries to bridge the gap and help them to understand that they are a valuable member of the team.

Respect

Respect was mentioned several times by participants, specifically the need for mutual respect. One mother discussed how much they appreciate when teachers respect what they are doing at home,

> You know some team members do it better than others, is for them to be really mindful of the parent's role. If they think it's hard at school, you know I've had some IEP meetings where I've heard ... It usually doesn't happen in the meeting, but before or after, they're complaining about how stressful their job is as a teacher, and you're like, yeah, I'm at home with this child and I don't have a para helping me. For them to be really respectful of everything the parent is trying to do and to really honor that. If they're involved to really thank them for that because they're doing it because they love their kid, not because they're trying to be jerks for the most part. I'm sure there's a few parents out there.

When there is a lack of respect, it can lead to emotional meetings and frustrations, as one mother discussed,

> I personally get ruffled feathers when any educator thinks they know better and wishes to completely disregard anything that the parent would have to say. Some mutual respect needs to be shown.

When one mother moved to a new school district, she said her first IEP meeting in the new district hit her the wrong way because no one made any attempt to know her family. Participants stated that knowing where the other side is coming from is equally as important. One mother who helps other families said she feels that it is essential for families to understand where the school district is coming from and for educators to

realize that all families want is to have the best and most services for their children.

Sometimes emotions get in the way of building strong relationships, so she said that

when she coaches families, she tells them to listen to the professional's point of view so

they can see that the rest of the team wants the best for the child, too.

Equality

Participants mentioned wanting to be equal members of the team. One participant

said that she approaches IEP meetings with the confidence of knowing that she is equal

member of the team,

> We've been at great schools, so we were at [specialized school], we're now at
> [neighborhood school], so I will say that those schools really helped, because they
> do listen to me so much.

She said that she makes sure the team understands her role. Another mother has tried to

frame it in terms of thanking the team, making sure they know she is there to help, and

that it is a two-way street. She appreciated when she was given the time to look things

over and was asked for feedback on what she would like to see. Another participant said

she felt like an equal member when the team asked for her input and used that input to

help inform decisions, of which she was an integral part. When she helps other families

said she tries to avoid the "us versus them" attitude and she tries to help families see that

compromise is necessary.

Problem-solving. Because of the knowledge that parents bring to the team,

participants said they valued being included in problem-solving. For one mother whose

young adult son has CHARGE syndrome, she said she was upfront with his team and told

them that she has been problem-solving for her son longer than they have and she urged

them to use her as a resource and advocate. She said that many times, it has to do with

how the team approaches the parents and whether they respect the knowledge that

families bring to the team. Another mom with a younger son with CHARGE syndrome said she has felt that teams have come to her with recommendations that have felt like they are the "end-all-be-all" when, in reality, the recommendations were meant to start a problem-solving discussion with her. Another participant gave a heartfelt example of collaborative brainstorming and how having a team approach to problem-solving helped relieve some pressure off her,

> I spoke first, and I spoke clearly, and I said, "These are my expectations." They said, "Okay, those are great. We also think we need to do this, too, and that, too." They had watched her individually, said, "I think she has these needs. What do you think about this, and what do you think about that?" I sat there, and I wanted to cry.

One mother of a teenager with Usher syndrome provided a specific example of collaboration between her son's speech and language pathologist and an occupational therapist. The two service providers were trying to find a way to minimize the amount of pull-out time, so they collaborated to find ways to do speech drills at the same time as practicing his motor skills. She said this was a win-win for both service providers and her son and she wished there were more examples of service integration. Another mom with a teenager with Usher syndrome gave another example of how team members work together to problem solve. She said that her son was having a hard time accessing video content in the classroom. The teacher of the visually impaired (TVI) gave a potential solution, which contradicted the suggestion that the teacher of the deaf had. The two teachers collaborated to determine a good compromise, given the dual sensory loss.

Communication

A majority of participants talked about the importance of communication. Because there are so many emotions around IEP meetings, when one mom advises other families, she tells parents to "talk about the elephant in the room" and if something is on

their mind, to get it out in the open so that the team can have a full picture. Participants talked about shared knowledge and how good communication is vital to ensure everyone is on the same page.

All participants talked about the benefits of frequent communications. For some, that meant just daily notes home. For others, especially those with children with complex needs or with large IEP teams, they had frequent meetings. Regardless of the method of communication, participants talked about the importance of timely communication, "not waiting." Often, participants were in contact with someone on the team each day. One mother who has a son with CHARGE syndrome has used OneNote to manage daily communications for her son, who is non-verbal,

> We have ongoing communications. We do not leave it up just to those meetings. I think that's been a huge part of our relationship building process with all of his teams is that we don't wait.

The participants who have children who are non-verbal expressed that having daily communication was critical because, without it, they have no idea if their child had a good or bad day. Participants shared that having frequent communication throughout the year has helped because, you do not have the pressure of going into an IEP meeting and feeling like you need to solve everything there. As a mother, you know that this team is supporting your family year-round and that this is a year-long process, not just a once-a-year discussion. Another mother has seen similar benefits to having frequent communication. She said that, as a result of frequent year-round communication, the IEP meetings have just been updates where the team "rubber-stamps" decisions that have already been discussed. A mother who often helps other families shared that she feels that families need to let the school know how they want to be communicated with and how much they want to be involved in communication, because it differs for each family.

Another mother who helps families said she has learned how to use the right

words when trying to get your point across. Communication will be discussed in more

detail as an advocacy approach, but participants shared that they choose their words and

approach based upon a goal of getting their child's needs met. They have found that if

they communication is positive, they are more successful in advocacy efforts. One

mother's view of good communication is to ensure everyone is heard, by listening and

hearing everyone out. Team communication sometimes becomes strained, which can lead

to conflict. Mothers shared stories of team members who were told by district staff to not

communicate with them. There were also extreme examples in which participants said

the teams consciously shut down communication with them and that led to obvious

conflict. One mom mentioned her frustrations,

> I would talk with the teacher. I would talk with the aide. I would talk with the
> principal. I would talk with the individuals. I'd reach out to them, ask their advice.
> That was challenging because I didn't know this until after, but they were given a
> strict ... They were forbidden to communicate with me and they were given red
> marks in their files if they did communicate with me. They were penalized as a
> bad employee and their future employment was jeopardized if they did give me
> any advice in this particular district. But I did have a couple of them talk to me off
> the record to give me more information on what was going on so that I could then
> at least navigate.

Because deafblindness is a low-incidence disability and because children who are

deafblind have individualized needs, participants expressed the importance of

communication between team members. Communication is essential when sharing

knowledge within the team and when problem-solving situations related to the dual

sensory loss.

Advocacy

Participants said they appreciate when team members have their child's best

interests at heart and when the team have advocated for their children. Small things can

make a big difference. One mom of a teenage son with CHARGE syndrome described

how much it meant to her when the special education director, after hearing about some

IEP challenges they were having, picked up the phone and told her, "I want to get this

right." She said she felt like she was not alone. Ultimately, the special education director

advocated for her son's needs and made it better for him. I heard success stories from

participants who said the team worked together to advocate for district-wide

improvement. Another mom said that she feels that advocacy goes both ways. She has a

good relationship with her team and just went to Perkins School for the Blind with her

son to get some more ideas for the team. She discusses her advocacy role,

> Honestly, it's to keep pushing everyone. To push ... Sorry, I'm just emotional
> about it right now because of going to Perkins and stuff. Just to keep pushing
> everyone to think bigger and more creatively of what can we do here and not just
> checking boxes.

She has always started the year off by telling the team that she will advocate for anything

they need. She said that she feels like a reciprocal advocacy approach has helped her to

build a trusting relationship with her son's team.

Commitment

Although participants have had some negative experiences, all participants

acknowledged that, for the most part, the teams were committed to ensuring their

children were successful. One participant who has two children with Usher syndrome

said that from the get-go, she felt the team was willing to do whatever they could to help

her boys. Sometimes, she said, the team did not know precisely how to help her boys, but

that they were committed to figuring it out. Another mother shared similar experiences.

She said that her daughter's team has always acted professional with her and that she felt

that they have tried hard. They have met with her throughout the year. They have listened

to her concerns and needs and tried to make everything possible. Although there were some disagreements over time, she said she could not think of anything the team could have done differently to show commitment. Another participant said that she felt that team members were more committed if they felt respected. So, she has worked hard to foster mutual respect in meetings.

Findings indicated that participants value relationship building when working with their child's teams. One mother said that she knew, because of her background in public relations, that relationships are everything. She said she never threatened her son's team and she just "found a way to make it happen." Another mother, when working with other families, tries to get them away from "the teacher doesn't want to help my child, and they just want to get done by the end of the day" to figuring out how to work together. She explained that this entails doing something for the team, showing that you are willing to work with them in partnership, whether it is taking notes or providing ideas for accommodations.

Participants gave many stories about how they felt that the educators and service providers had their child's best interests at heart. Although there may be disagreements along the way, participants seemed genuinely grateful for teachers and service providers who care for their children. One mother shared that she sees all that her son's team does for her son and she wants to help make their job easier.

Advocacy Strategies Used by Families

To answer research question 3, *What knowledge and strategies do parents use in IEP meetings to promote collaboration?*, it is necessary to understand participant advocacy strategies. Participant advocacy strategies fell into the following three themes: (a) advocacy through action, (b) advocacy through knowledge, and (c) advocacy through

student involvement. Mothers play multiple roles on IEP teams: sharing knowledge, advocacy, case management. One mom of a teenager with Usher syndrome talked about those roles,

> I'd like to say I was the parent. Unfortunately, I was more of the educator, the advocate, everything mostly beside the parent until this year. This is the probably the first year I finally felt that I was actually going in as a parent, but prior to this year, I was always having to educate, having to advocate the entire time.

Advocacy Through Action

All participants talked about the importance of a family's role as an advocate. One mom gave some advice to other parents. She said that, as a parent, you are the best advocate for your child and sometimes you have to push hard for what is essential for your child. All participants said that they had gained strategies for advocacy over time. Participants stated that they felt like they needed to advocate the entire time because if they did not, their child's needs would not get met. Sometimes, those skills were learned from networking with other families, connecting with outside organizations such as Hands and Voices, or by trusting your gut. Participants outlined advocacy strategies that fell into two categories: direct strategies (e.g., requesting IEP in advance) and leadership skills (e.g., consensus building, positive approach).

Direct approaches. Participants stated that they felt like, although their child's team had a district-assigned case manager, they played the role of case manager. One mother stated that "her job was basically to be the general contractor, to oversee it and look at it and go, 'This seems reasonable.'" As case manager, participants are responsible for (a) pre-planning for IEP meetings, (b) IEP meeting management, (c) goal setting, and (d) ensuring their child's needs are met. They also indicated that they have conflict prevention strategies in their toolkit that they use as needed.

Pre-planning. Participants said they need to keep organized, especially during pre-planning. Preparation for IEPs is essential because to go through each item in detail at a meeting could take all day, said one mom of a child with very complex needs. That same mom added that especially for a child who is deafblind, there needs to be collaboration within the team on goals. For instance, if a speech therapist comes in with a pre-determined goal that no one has seen before, there will always be something that is forgotten.

Participants stated how unproductive it is to sit in a meeting and read the paper; it should be a discussion. To prepare for meetings, one mom, who is also a teacher, asks for copies of evaluation reports and draft IEP goals in advance. That allows her to feel more prepared and know what questions she wants to ask. She said that she doesn't always think well on her feet and having this information in advance helps her be more productive in meetings. Another mother who has a son with CHARGE syndrome indicated that her team is still hesitant to send draft goals in advance because they like to start fresh. She said that she pushes to have a draft because, if they don't, those meetings can go on for hours. So, at the very least, she requires information about present levels in advance so they can hit the ground running in meetings. She said that, although she prefers having a draft IEP before meetings, communication is crucial because you don't want parents to think that things have been pre-determined:

> If I'm in a meeting and they're turning on the overhead or the computer, I'll say, "Can we blank this out for a second? Please explain why you have this written up." . . . But for expediency, we can change it. We can edit it. This is not a decision that has already been made.

Another mom with a child with complex needs said that she requests that team members highlight anything that has changed on the IEP to help her with the review. Her son's IEP

is 30 pages, and she said it's hard to have to compare the entire document to the previous version.

Participants check in with all the team members in advance of the meeting so that any issues are addressed before the meeting. One participant said that this usually results in better IEP outcomes and said that it has helped because there are no longer surprises in meetings. Another strategy to keep focused in meetings is to write things down, both your concerns before the meeting so that you can ensure you remember to address all the issues, and by taking notes during meetings. When one mother works with other families, she suggests to families that they write their goals down in advance. She outlines a specific strategy:

> When you are going into an IEP, just before you do that, to prepare, write down. Take your paper and split it into three columns. Write down on the left what you want. Shoot for the moon. And then write down on the right what you won't compromise. If the child's deaf, you won't compromise them in having a teacher of the hearing impaired. Then in the middle, write down what you can live with, [and then you can compare] what the school is offering and what you can live with.

She offers to walk through the IEP with families before meetings, helping them write out their goals and vision statement. She helps them to think about any upcoming transition. She has a form she uses to help them write down their child's strengths, successes, and areas of concern. She said that this helps because it can be very nerve-wracking to have everyone sitting around a computer. For the participants who involve their children in IEPs, they sit down with their kids in advance to be sure the entire family is on the same page.

Participants are very thoughtful about what they bring to meetings. One mother said she brings books, documents, and as much paperwork as she can. Usually, it's not needed, but having it there shows people that "I'm prepared, I'm serious, and that I know

what I'm talking about. It gives me validity." Another mom comes prepared with bulleted

lists of examples to support each concern, including videos and pictures. She said she

has, in the past, brought a color-coded poster board to show the pyramid of incidental

learning. When this mom coaches parents, she tells them not to be afraid to bring

everything. "I literally pull a cart in with me to an IEP. I am prepared for anything and

everything, and I think that's the best thing you can do." Another mother has learned to

bring copies of previous IEPs because she has found that no one on the team comes

prepared. In the past when she wouldn't bring past IEPs, the team would roll the same

goals over to the next IEP and that was impacting her son's progress. One of the families

that one counseled brought in a great visual to the meeting,

> I had a family that brought in a visual about all the different providers that the
> mom had been in contact with because her child is medically complex, and she
> mapped it out like a visual mapping tool. My gosh, if that didn't make a massive
> difference to the district. And I think sometimes the districts don't get involved in
> our lives. They don't see all that we do, and that's fine. I've always said, "I'm not
> looking for your pity." But, I also think it was an a-ha moment. Oh, she has 40
> some people that she's gotta keep straight and that's where it kind of tipped the
> balance [when she was advocating for not changing the intervenor].

Individualized Education Program meeting management. Participants thought

about all aspects of the meeting, including logistics about where the meeting is held and

the atmosphere they want to have in those meetings. One example that participants

provided was to bring treats and coffee to the meetings, especially when it is a new team,

a way to honor the contributions of the team and to ensure the team "is seen and heard

and know that we're not just beating them up all the time." Another mother thinks about

the room itself. She said it's helpful to have a room "where there is enough space, enough

chairs, where the temperature is pleasant, and there's water or something available, and a

bathroom nearby." She said this makes a big difference in comfort because if everyone is irritable, the meeting is not going to go as well.

Many of the participants employ meeting management strategies that they have used in their careers. One mother said her husband, as an attorney, brings a lot of experience to meetings and that he helps keep things on track. Participants take charge of the meetings, including drafting the agenda or ensuring the case manager puts together an agenda with their feedback. In meetings, participants ensure that the agenda is followed. One mother said time management is critical, otherwise, you'll end up in a meeting all day or essential issues will not be addressed or will be addressed but will be rushed. She uses a parking lot to keep track of all the issues that aren't able to be discussed at the meeting. Another mother said that she makes sure that someone in the meeting is assigned to keep things moving because, since there is such a large team and because her son's needs are complex, the meeting can go on forever. One mom who has a young son with CHARGE, said that she tries to limit the time because after about an hour and a half, people's eyes tend to glaze over and the outcomes are not as good. Participants know when to stop the meeting and when it would be best to schedule a second meeting. For more complex IEP meetings with large teams, mothers have learned that they need to have multiple meetings per year to adequately address all issues, but to make sure that the parents are always involved in every meeting. One participant indicated that that her team used to hold meetings without her and, although she would provide examples of why she needed to be there, the team kept going ahead. She said it was hard, but she would let them fail because they were missing her piece of the picture. It was a lot of wasted time, especially when her son has a terminal disease. Now, her team does it her way. Participants also stated that they felt that it was beneficial not to call those additional

meetings *IEP meetings*. If they are not considered IEP meetings, she said, you do not "have the district babysitting so you can speak more freely."

On participant said she always makes sure the right people are at the meeting. Similarly, another mom reported that her daughter's team is so large that she also makes sure she learns in advance about everyone who is at the meeting, what their roles are, what they do, where they are from, what their background is. That way she knows what she's walking into.

Goal setting. Because parents bring a lot of knowledge of their child to the table, participants want to lead the goal discussion. Participants indicated that teams do not always have high enough expectations for their children, so they bring ideas to the team. One mother of a teenage with Usher syndrome calls herself "the champion of high expectations." Another mom said that she's always trying to push the team to think bigger, more creatively. The goals need to be realistic. Participants also ensure goals are individualized, and not generic. There is a balance, and parents need to share data on how their children are performing at home. Two mothers who have been through transition to adulthood process, talked a lot about how they try to get the team to think beyond the current year, to look 3, 5, or 10 years out. One of these moms said she spent a lot of time teaching her son's team "what an IEP for a child with deafblindness and CHARGE syndrome needed to look like in order to prepare him for a post-secondary life." Mothers also play a role in prioritizing goals, making sure that how they are prioritized fits into the long-term plans for their child.

Ensuring needs are met. Participants advocate and push to get their child's needs met using specific strategies. For the two moms who have special education backgrounds, they both said they come to meetings with data to support what they think their children

need to grow. Both of their background, they are also able to help the team analyze the data. Other participants also mentioned use of data. Another mom said that bringing data and work samples has allowed her to have tangible evidence, instead of having to say, "You aren't doing your job." If there are no existing data, participants said that they push for additional assessments. Another participant has figured out that if she presents data supported arguments, it has helped the team understand why certain proposed strategies won't work.

For one participant who often works with families, she said she always tells families that, although you always want to ensure your child's needs are met, "the most doesn't always mean better." So, part of a mother's role is prioritizing. Sometimes a child's needs are not met because of a lack of knowledgeable personnel on the team. When one mother found herself in that situation, she fought for additional training for different team members. Another mom said that she always has to fight for the IEP to be individualized. She said that in the past, her team would say things like "This is what we do with our hearing-impaired children." When that happened she said she responded, "That's not appropriate," or "The I in IEP stands for individualized, not inclusion, so I don't care what you've done in the past. I don't care what you say you do with these kids. This is an individualized IEP.,' And I keep bringing the focus back."

Conflict prevention. Some participants have had experience with mediation or state complaints. Because of these past experiences, they have learned conflict prevention strategies. One participant has had a few facilitated IEP meetings that were successful. Participants learned to understand that you need to have support and meetings and that different families find that support in different ways. It seems to matter less about who attends, and it is more about balance. One mom who has a large team said that she doesn't

like going alone when "there is an entire team of people on one side of the table and you on the other." She said that it got so bad a few years ago that she decided, "If they are going to pull up a team and try to divide us, I'm going to bring my own team with me." One mother had a parent advocate attend meetings with her. Another participant had her attorney attend some meetings when it became contentious, and she now makes her husband go because he takes notes and keeps her calm. As her son got older, she also brought an advocate for transition and employment to meetings. Another mother also brought her husband so they could "play good cop, bad cop." At times, participants included their Deaf-Blind Project representatives or the Commission for the Blind.

Leadership skills. Mothers see their role as a leader, needing to know what is going on and being responsible for outcomes. Participants identified the leadership skills that they use to get their child's needs met in IEP meetings. Those leadership skills include: (a) a team mindset, (b) positive approach, (c) consensus building, (d) being firm, (e) flexibility and creativity, (f) thinking ahead, and (g) problem-solving.

Team mindset. A majority of the participants mentioned the benefit of having a collaborative, team mindset. One mother said that she feels like her role is to be supportive of the team and to honor what they do. She tries to be vulnerable and respectful to her son's team. She tells them, "If there is something you want me to do differently, just let me know." She said she was talking to another parent who was frustrated that her son's teacher wasn't using his communication device at school. She asked that parent if they were using it at home, and they said "no." So, she said that it's important to have realistic expectations. If, as a mother, you aren't able to make something work at home, you can't expect perfection at school. She also is a big advocate for her team. If they are struggling with getting something approved through the district,

she tells them that she is willing to "battle it with them," as part of the team. Other participant said she has tried to help the team to relax, and she also makes sure she is honest about her feelings and desires. Other mother said she chooses her words wisely, using words like "team," "it's great to work with you," and "together," words to show support. She thanks the team in meetings and individually, and often. She said, however, that it's harder to do during difficult times. Participants said it's all about mutual respect and making sure there is trust. Trust and respect were talked about by most participants as well as trying to connect with the team on a personal level, to build a relationship.

One participant mentioned that several years ago she used to think, "They are educators so they should do this." She stopped taking that approach because she realized that she needed to have realistic expectations. She realized that the educators were just one piece of the overall team, so she stopped trying to pressure them to do everything that she didn't know how to do or feel comfortable doing. It took her a long time to understand that "the system was not set up for the IEP team in the school to do everything."

Positive approach. Participants pretty much all had realized long ago that a conflict approach to advocacy was not effective. One mother who often helps other families mentioned that she had seen parents go into meetings saying, "If we don't get this resolved, we are going to due process." She said that everyone got tense, and everyone was on the defensive. Instead, she coaches parents to talk honestly about the elephant in the room. If they are going into a meeting upset, they should try to be honest about their feelings so that the approach can be more positive. Participants prefer to employ a positive approach to working with their child's teams. One mother said her role is "almost to be like a cheerleader, a motivator." She uses humor and tries to keep a

positive mood. Keeping emotion out of it also helps to maintain a positive approach. The meetings, because they are about your child, can turn emotional easily, making it easier for the meetings to turn into conflict.

Consensus building. Participants shared strategies for getting everyone on the same page. One of the participants that often helps families described the importance of reciprocity; both professionals and parents have a responsibility and want what is best for the child. She said it's about the give and take and respecting other viewpoints. To build consensus, she asks clarifying questions and takes the time to explain the reasoning behind what she is asking for. It's about getting people on the same side. Often, that is easier done outside of the meeting, using the team mindset approach. One mother said that things are so much easier if everyone is satisfied and being okay with everyone agreeing that no service is going to be perfect, with doing the best you can at this time. Another mother said that she knows she should put all her cards on the table, but because of past experience, part of her strategy is to know which cards to keep in her back pocket and when to play them. Asking questions of the team also helps build consensus, probing questions like "help me to understand" and putting it back on them. A few participants mentioned "pretending to know less than you do" and "making them think it's their idea." One participant gave an example. In the past, she has said, "You have so much wisdom and experience. What do you think I should do?" when she knew what she wanted for her child. It was a strategy for gaining consensus.

Being firm. Sometimes the best leadership strategy is to hold your ground and to be firm in approach and in keeping the team accountable. One participant said it is about finding a balance between coming across as a pushover versus "It's my way or the highway." You need to come across as someone with authority to be respected. One

mother who was trained as an attorney said that her professional background has taught her to be demanding, but professional. She knew how to demand using the right words and approach. She would start by listening and hearing them out to understand where they were coming from. Participants stated that they were more overinvolved than uninvolved and that sometimes that equated to "being a thorn in their side," being firm to ensure things get done.

Flexibility and creativity. Participants want their teams to be thinking bigger when determining goals and strategies. One collaborative mother told her son's team, "I'm not an expert. I'm an expert on my son, but I don't even know sometimes if I know that kid's brain very well. I'm just guessing sometimes." So, she urges them to think big, think outside the box, to help the team to generate better, different ideas. One mother said that her son was struggling with a writing goal and she asked the team to brainstorm creative ideas to keep writing as a goal. The team was able to find a different way to get to the same result by being creative. Another mother said that every meeting with her son's team has been an active brainstorming because of his complex needs. For one participant who has a son with CHARGE, she said that she has found that things are not "black and white" for her son, so she works hard to help her team think of different ways that might work for her son. Participants all agreed that because of the unique needs related to deafblindness, sometimes it's all about experimenting to see what works. One participant said she and her team would always try new things, sometimes limping along. Participants said they felt it was their role to help the team to be creative and come up with new ideas.

Thinking ahead. Participants try to be proactive as much as they can. They are always looking at where their child is currently to try to think about how it relates to the

future. Problems are still going to come up, but one mother said that she tries to avoid the "wait to fail model" because then it's often too late. She frequently meets with the team and urges them to see any warning signs that something needs to be adjusted.

Problem-solving. Team members do not always agree. Participants help narrow down the issue so that they can effectively problem solve and outline potential solutions. They appreciate it when team members involve them in problem-solving and make sure that the team knows that they are glad to be involved in the problem-solving process. Participants, although they do not like to go down this road, realize when they have come to a point when they need to go up the chain of command to get a problem solved.

Advocacy Through Knowledge

All participants shared how families bring a wealth of knowledge to share with IEP teams about their child and deafblindness. Families also gain knowledge of the law and parent rights. Participants brought up issues related to how they gained knowledge, how they shared knowledge with team members, and the knowledge they brought to the table because of their educational backgrounds.

Gaining knowledge. Participants shared stories of how, when their children were first diagnosed, they did everything possible to gain knowledge that would help them understand how to help their child. Participants said they have done extensive research on deafblindness and any specific needs but noted that knowledge gathering was time-consuming and often overwhelming. Often, it was hard to find resources or to connect with other families who could relate. Participants also talked about the knowledge that families build by just being with their child, "figuring it out along the way" and "doing the best they can." They all agreed that they see themselves as "the expert on their child." Because deafblindness is so heterogeneous, participants found that they learn the most

about their child by observing them at home and school, and they recommend that the rest of the team gets to know the child through observations as well. One mother said that when you have that foot on the ground perspective you gain a different perspective and sometimes you are like "Oh, what I'm asking for does not even meet the needs," and it can help you to understand where the teachers are coming from.

Knowledge is sometimes gained by connecting with outside agencies. One mother of a son with CHARGE syndrome, for instance, travelled to Perkins School for the Blind to collaborate with the team there to get a different perspective on how to address her son's needs. Participants were also well connected with organizations such as the Usher Syndrome Coalition, the Charge Syndrome Foundation, National Family Association for Deaf-Blindness, and Hands and Voices. Through these organizations, they joined with other families who had been through similar experiences and learned advocacy skills. The state Deaf-Blind projects were also a resource that participants used to supplement the lack of deafblind-specific knowledge not available on their child's IEP teams. The staff at the Deaf-Blind projects have shared resources, gave suggestions for interventions, and provided support for parents in IEP meetings. Knowledge of parent rights and special education law was gained in the same way, a combination of outside research and learning as you go. Parent training and information centers (PTIs) were mentioned as a good source of information for parents who want to understand their rights better.

> I think parents don't know their rights, and I think the teams show up to these meetings, and they hand you this booklet with your parental rights, and it doesn't really give you anything that is telling you what your rights are, especially when you are dealing with a unique disability like deafblindness.

When it came to placement, mothers spent time researching options. One mother who has a young son with CHARGE syndrome talked about how she took the time to visit all

potential placement options so that she was able to go into the IEP meeting with enough knowledge to inform the placement decision for her son. No one told her to do that, but she felt it was necessary.

All of the participants indicated that they, at least occasionally, help other families in advocating. Participants mentioned that, although they are the ones helping other families, they stated that networking with other families and helping other families is what helps them support their kids the most. One participant mentioned that helping other families and networking has helped her not to feel alone. When talking with other families, she often thinks of things that could translate to helping her boys.

Sharing knowledge. Another role mothers play is in sharing knowledge with team members. Often, for families of children who are deafblind, because of the low-incidence nature of deafblindness, parents hold the most knowledge about deafblindness, especially about their child. Participants shared that knowledge by: (a) connecting the team with outside resources; (b) helping the team to understand the unique needs of their child; and (c) sharing ideas, interventions, and knowledge related to deafblindness. Participants did mention, however, that, although they expect a high level of competency from service providers, they do not expect everyone to know everything about deafblindness and their child. But, the team needs to be willing to learn.

Participants all acknowledged that they are the expert on their child. One mother who has a young adult son with CHARGE syndrome said that the more she understood her son, the more she realized what he could do, the potential of what he could do, and the skills that he had that other people weren't seeing, which helped her to be a better advocate. I heard many stories of how participants helped the teams to really "know their child" and making sure that the team was considering the big picture, long term past the

current year. In the early years, one participant said she used to bring a standup picture of her son to IEP meetings. She then made sure the team went around the table and talked about her son as a person first. Another mother has done the same thing, and then she makes sure the team knows what impact they are having on his life, seeing him as a human being that they affect.

A majority of the participants talked about a version of "All About Me" that they use to help people understand their children. Sometimes the "All about Me" was as simple as a one-page document outlining both strengths and challenges of the child. Other times, it was in the form of a PowerPoint presentation that was presented during each transition, an in-service with any new members. Some participants make these in-services more elaborate to include hearing and vision loss simulations.

> After it was over, I would ask them, "Tell me about what you experienced. Tell me about what you saw and heard." And, you know, some of them would get really choked up and say, "I had no idea. Like I always knew she worked really hard, but I had no idea."

For one mother who has a teenage son with very complex needs that are often misunderstood, she shows pictures and plays videos of her son at each meeting, showing him in different environments: at school, at home, and out in the community. Oftentimes, she saw behaviors arise because of some change at school. She indicated that she wants the team to better understand her son so that they are better able to look at reasons behind behaviors. Another mom who has a young child with Usher syndrome stated that sharing this knowledge has helped team members understand the unique needs of child and not to make assumptions.

Because of the low-incidence nature of deafblindness, participants have networked and researched interventions that may be appropriate for their children and

then brought that knowledge and those ideas back to the team. One mother of a son with CHARGE syndrome said that she has done this to help the team to "think, to dig in themselves, dig into research . . . to think bigger" and that she believes that sharing of knowledge helps the team think bigger. Because parents have been living with their child and living with the disability for so long, they are often experts on the disability. Participants have shared research articles with teams, recognizing that the team may not always read them. Another mother said that she has an entire electronic folder of documents about deafblindness that she shares with new team members, with the contact information for the staff at their state Deaf-Blind project. When necessary, participants stated that they would connect the team with people and organizations that could help them, like bringing in a deafblind expert to observe the classroom and give suggestions to the teacher. Participants have helped teams understand necessary accommodations. One participant gave a specific example. Her son was having difficulty advocating for his needs with a teacher who was allowing students to use a 4x6 notecard of notes on the test. This teacher would not let her son use a larger piece of paper because they thought it would be unfair to the others. She had a lot of calls with the teacher to help him to understand the impact of her son's vision loss, and, ultimately, he was able to receive accommodations for the test.

Knowledge sharing can be tricky. One participant said that sometimes professionals "get intimidated because they are 'quote on quote' professionals" and she tells them that they may be a professional in the field, but that she is a professional of her child.

What do you do when a parent knows more than the professional, whether it's medical or educational? And, most parents do. So, really teaching, training the parents on how to deliver that information, but also saying to the professional, that they may know more than you so let's both be humble and figure that out together.

Educational background. Participants in this study have a high level of education: seven have graduate degrees, six have undergraduate degrees, and one has some college experience. Two participants are attorneys, three participants are educators, and the remaining have business background that they found helpful in meetings. One participant who is a special educator talked about the benefits of background knowledge:

I don't know if they do it because they know I'm in special education and they don't quite realize that they're somewhat isolating my husband then because he's not familiar, but I definitely think that there's an advantage. I knew right away what I needed to ask for because I'm not sure if we hadn't asked for those resources that they would have put them out there. (participant name)

One of the participants who has a special educator also has a background in assessment, which she has found helpful when reviewing her son's academic progress reports. She said that, although the team knows of her experience of assessment and in special education, she tries to keep it out of the conversation. Other participants also try to keep their educational background out of the discussion, but like she said, because of the experience, she felt confident in what she was doing and felt like she had some advantage. Another participant who is an attorney also talked about her background,

I will say, though, that if I wasn't an attorney, I think about some of the families who don't have all the resources that I have, and all the education that I have, and I think that it would have been really beneficial for them to have somebody from the Deaf-Blind Project with them regularly. But, I didn't always want or need it there.

Another participant went to school to be trained as an intervenor to help her son's team understand the benefit. She described that process and the knowledge she gained to help her son.

And through that process, I was able to just start doing all the things that I told the school I wanted to do. I started doing at home myself because my son was my assignment, literally. So, we were both learning, my son and I both, and I realized how much we needed it. And two things happened with that. One, I was able to show [the team] the progress he could make when the right tools were in place for him, and the training was in place, and then number two was I was able to be more educated about the process of deafblind intervention to advocate for him.

Participants are well informed and immerse themselves in training that they feel necessary to help their children.

Advocacy Through Student Involvement

Eight participants mentioned the benefits of student involvement and advocacy. However, several also said how hard it has been to find ways to involve their children. Some participants involve their children in their IEP's. Others haven't, either because their child wasn't ready for that or sometimes the family was not interested yet.

One participant who has involved her teenage daughter shared how hard it has been to involve her daughter meaningfully. Even in high school, the IEP meetings began by talking directly to her daughter, asking her opinions directly, and that by the end of the meeting, the team was back to talking about her. She added,

I don't think we are there yet. We don't have IEPs written with "I" statements. It's about A. It's "A this," "A that," instead of writing it for A. So, I don't think we are there yet, though I've tried and I've talked about it. They've [the team] tried. I can't say they haven't. I just don't think it's something that they're used to, unfortunately.

Her daughter told her that "It [the IEP meeting] is not meant for her. It was meant for the educators." In the past, her daughter's team has had her daughter read her IEP goals, but just because she verbalized them, doesn't mean she has a connection to the goal. Her team has tried to find ways for her daughter to self-monitor IEP goal progress with minimal success.

Another mom of two has involved both her sons in their meetings and all educational decisions related to them. She said that her sons were hesitant at first, but that once they realized how it helped them, they were onboard. As a family, they have prepared for the meetings in advance by making sure everyone is on the same page before going into the meeting. She said there have been times when one of her sons had said, "I don't need that," when they hadn't thought it through completely yet. Her sons have done annual presentations to their teachers about Usher syndrome and their strengths and challenges. Her son has told her, "I wish the teachers would ask me what I need and not do what they think I need." One mother's son was hesitant to be involved in middle school, but gradually became more involved. She said that having her son involved helped the team better understand his needs. She said that she has found that it is harder for the team to argue with the kid directly, which helped him get his needs met. However, she said that the meetings were hard for him to stay engaged in. Although her son did not mind being involved in his education, he did not like attending his IEP meetings. He liked coming to listen to his teachers talk about his strengths, but most of the time, he felt the meetings were focused on his deficits. Another mom said her son had the same experience. Most of her son's involvement was throughout the year, giving feedback to the team on accommodations, and not during the IEP meetings. One participant who did not regularly involve their child said she thought the meetings were "too technical" for her daughter and that her daughter had not been previously engaged when at meetings.

Student self-advocacy. Some participants have goals to put their child in the role of self-advocate. One participant who has an elementary age son with Usher syndrome said that her son's team suggested adding a self-advocacy goal on her son's IEP, at the

age of 9. Although her son has not yet attended his IEP meetings, she said that his service providers have had to address what her son says he needs. She said that often she is not involved in these discussions, they happen between her son and the team. She said that she feels like her son's level of self-advocacy has been "partly a success of himself and partly a success of the team." She said she is looking forward to having him involved in IEP meetings so he can better understand the outcomes of his self-advocacy. Another mother said that because of her daughter's self-advocacy skills, she has found that she has been able to step back more, hoping that it will help her daughter to give input herself and start making her own decisions. A participant who has two boys with Usher syndrome said that has received multiple compliments of both her family and her son's advocacy skills and that made her feel good because she has worked hard to ensure her boys are knowledgeable and part of every step of the process.

One mother of a teenage son with Usher syndrome said that she has been trying to get her son to self-advocate for his needs for a while now, but that he still struggles with standing up for what he needs. She said he's a people pleaser and doesn't want anyone to get upset with him. He has heard them talk about how hard it is to get services, and he knows he is the only one who is deafblind and he doesn't want to cause problems. She said that, in hindsight, she wishes that they would have started to work on self-advocacy earlier. She feels that when kids start getting a voice, it takes the stress off the parents because they can say precisely what they need, instead of the parents guessing what they need. She said she sees the benefit of stressing self-advocacy at a young age, and she wishes she involved her son in IEP meetings before seventh grade because it would have helped with the transition to middle and high school.

Conclusion

The results from this study revealed valuable insights into the various and vital roles that mothers play on their child's IEP teams, including case management, advocacy, and knowledge sharing. Three categories emerged from the data: (a) problems parents experience that lead them to develop advocacy strategies, (b) valued family-school collaboration, and (c) advocacy strategies used by families. As previously described, although the goal of the study was to understand the advocacy strategies used by parents, participant past experiences and views of collaboration serve as building blocks to thoroughly understanding the advocacy strategies that mothers developed. Mothers of children who are deafblind shared insight on how they use collaborative strategies to build strong relationships with other IEP team members, and reasons behind why they developed those strategies.

CHAPTER V

DISCUSSION

Past research repeatedly describes parent dissatisfaction with the Individualized

Education Program (IEP) process (Feinberg et al., 2002; Stoner et al., 2005; Valle, 2011;

Zeitlin & Curcic, 2014). Previous studies also identify a lack of qualified personnel in the

area of deafblindness that impacts their ability to serve and address the unique needs of

that population (Parker & Nelson, 2016). The combination of these two obstacles,

dissatisfaction with the IEP and a lack of professional knowledge about the

deafblindness, have resulted in parents of children who are deafblind experiencing unique

challenges in IEP meetings where they are often the most knowledgeable about

deafblindness on the IEP team (Correa-Torres et al., 2018). Indeed, a focus of past

literature has been on the conflict parents experience during the IEP meeting process

(Mueller et al., 2008), however, not all parents have experienced conflict. In both prior

research and this study, some parents have had mostly positive meetings, and others have

had both challenges and positive meetings (Childre & Chambers, 2005; Esquivel et al.,

2008). Thus, inspired through reading literature and my own experiences at my children's

IEP meetings, this study sought to explore the challenges families of children who are

deafblind experience when attempting to collaborate with an IEP team, and the related

advocacy strategies they use to address the challenges.

The results from this study revealed valuable insights into the important roles mothers play on their child's IEP teams, including case management, advocacy, and knowledge sharing. It was not surprising to find that mothers play an essential role in advocating for their children. What was surprising was the depth of strategies mothers use and the leadership skills needed to implement these strategies. Findings from this study also indicated that a positive approach to relationship building is at the core of these strategies. It is my hope that the strategies identified by participants in this study could be further investigated so they could be provided as a parent training, to help other families of children who are deafblind work collaboratively with IEP teams. Notably, half of the participants in this study help other families work with their IEP teams so, although the sample size was 14, the depth of their experience working with IEP teams extends beyond their personal experiences.

Restatement of the Research Problem

As detailed in the review of the literature, there has been little progress made in the area of family-professional partnerships over the last four decades. There are 40 years of research on IEP dissatisfaction and conflict, but recent studies show parents continue to be dissatisfied. Past research has focused on the negative aspects of IEP meetings and the resulting parent dissatisfaction and conflict (Fish, 2008; Mueller et al., 2008). Parent experiences in IEP meetings vary. Levels of conflict experienced in IEP meetings differs as well. Some parents have been able to resolve disagreements without the use of due process. Other parents have had to use due process to address their child's needs. It is important to consider what parent-initiated strategies are effective to build collaboration with IEP teams.

Parents are an essential part of their child's education. Parents of children who are deafblind are, reportedly, the most knowledgeable ones on the team about deafblindness and indeed, about their child's individual needs (Correa-Torres et al., 2018). Parent knowledge and advocacy are essential roles, and there is a need to understand better how parents advocate and share knowledge. Families and educators can benefit from understanding of the strategies that parents employ to increase collaboration and address their child's needs. This study focused on parent-initiated strategies used to increase IEP team collaboration and address their child's needs. There is a lack of research on strategies initiated by parents. There is also sparse research on families of children who are deafblind overall.

The purpose of this phenomenological qualitative study was to explore the strategies that mothers of children who are deafblind use in fostering a collaborative relationship with their children's IEP teams. Mothers of children who are deafblind were interviewed about the unique and essential perspectives they have concerning IEP team meetings and collaboration. Open-ended interview questions were used to collect in-depth information as mothers shared their experiences of attending IEP meetings, with the goal of identifying themes regarding their experiences working with IEP teams. The following questions were posed:

Q1   What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Q2   How do parents define collaboration with their IEP teams?

Q3   What knowledge and strategies do parents use in IEP meetings to promote collaboration?

Three categories emerged from the data: (a) problems parents experience that lead them to develop advocacy strategies, (b) valued family-school collaboration, and (c)

advocacy strategies used by families. The three categories were mapped directly back to the three research questions. In this chapter, the three categories are discussed in detail, including their interdependencies, and how these categories and associated themes relate to the research questions.

Problems that Parents Experience
that Lead them to Develop
Advocacy Strategies

Q1 What experiences lead parents to develop and use collaborative skills with their child's IEP team?

Two themes gave insight into this question. The themes were: (a) challenges associated with the deafblind population in schools and, (b) challenges with the IEP process.

Challenges associated with the deafblind population in schools. During data analysis, I chose to create a separate theme for deafblindness to gain more in-depth knowledge about the challenges specific to families who have children who are deafblind. Consequently, each deafblind-related challenge overlaps with other themes and categories. Professionals lack of understanding about deafblindness and the accompanying unique student needs is one reason that mothers in this study advocated and developed strategies to ensure their child's needs were met. Challenges identified by participants included: (a) professionals misunderstanding student needs, (b) lack of professional expertise, (c) parent need to push for vision and other services due to professional lack of understanding, (d) professionals not valuing different communication modes, (e) students unable to communicate their needs directly, (f) collaborating within a large team of service providers, (g) lack of access to families with similar experiences, and (h) emotional impact of advocacy on families.

Participants indicated they found that it was up to them to advocate for appropriate goals for their child, because they were the ones that were the most knowledgeable about their child. Almost all participants expressed that IEP goals need to be both challenging and appropriate. Participants felt that, for the most part, IEP teams underestimate a child's abilities, saying things like "honors classes are not appropriate for children like yours," or "your child is unable to communicate, so [something that all the other students are doing] is not an option for them." For mothers who have children with progressive vision or hearing loss, as is the case with Usher syndrome, participants in this study reported that teams may be too focused on a child's current levels and not focused enough on what will be needed in the future, once vision declines. It was up to the mothers in this study to keep the team focused on what is necessary for the child to prepare them for future vision and hearing loss, which is a reason to teach braille and start white cane training at a young age. For mothers of children who are non-verbal or are more significantly impacted, a role parents in this study played was to push the team to understand how their child communicates and accesses information. For these parents, partnership was important because the communication system developed for the student needs to meet the needs both in and out of the classroom (Riggio & McLetchie, 2008).

Participants reported that often team members had never served a student who was deafblind, and their child is likely the only one in the district, which leads to a lack of professional knowledge of deafblindness on the IEP team. Depending on the geographic location and hiring policies, there may be situations, as stated by one participant in this study, when a district is unable to find qualified personnel, even though a student's IEP includes that service. In the review of the literature, it was mentioned that having someone who specializes in deafblindness on the team is critical (Parker & Nelson,

2016). Interveners were mentioned as being an essential support for students who are deafblind (Riggio & McLetchie, 2008). Participants reported that districts often do not have knowledge of interveners, so mothers have to educate the teams. Sometimes a district will ask a paraeducator to fill the role of the intervener, without providing intervener training, or confuse the role of interpreter and intervener (Riggio & McLetchie, 2008). This study showed that not only is the lack of qualified personnel frustrating for parents, but it is also reportedly stressful for parents to be the primary source of deafblind knowledge on the team.

Even though the makeup of the IEP teams varied greatly, all participants referred to their IEP teams as "large". To exacerbate the problem, none of the participants reported that they had anyone on their child's core team that was an expert in deafblindness. As reported in this study, the role of the case manager is critical for mothers of children who are deafblind, because of the large team and lack of professional knowledge. Mothers in this study are, reportedly, concerned that if they do not step into that role, things may get missed and their child's needs may not be met. In addition to parent knowledge, participants brought in outside resources such as representatives from the state Deaf-Blind Projects to support them. Professional team members may acknowledge their lack of knowledge and recognize the need for collaboration in serving a student, but, as one participant mentioned, that does not change the fact that "the professional may not know what they do not know."

Being a parent of a child who is deafblind can feel isolating (Riggio & McLetchie, 2008). Early on, participants sought out ways to connect with other families by getting involved in family-centered organizations such as the Charge Syndrome Foundation, the Usher Syndrome Coalition, Hands and Voices, and the National Family Association for

Deaf-Blindness. Mothers in this study stated that it can still be isolating, even with those connections because there may not be another family that they can connect with nearby. Participants mentioned that they may now know other families of children who are deafblind, but often those families live in different states, which makes it difficult to connect to the extent they would like.

As reported by participants in this study, advocacy activities can have impacts on families, such as financial impacts, choosing to move to other school districts, deciding that one parent needs to stay home, and feeling pressure to be the conduit of information for the team. The most common description participants used to reference IEP meetings was "stressful." In fact, some participants in this study uprooted their families so that their children could attend a different school or be in a district that offered better support. For others, there were financial impacts, mainly from a decision for a previously working parent to stay home to take care of the caregiving needs of their children. In a recent study, Valle (2018) recounted the intense and ongoing engagement required to advocate for the education needs of children and how it is often the mothers who take primary responsibility. Mueller and Buckley (2014) previously reported about fathers' roles in special education and how fathers can have a sense of being "left out" of meetings. Participants in this study eluded to gender roles that are existent in IEP meetings and educational decisions overall. For the most part, participants used this to their benefit, playing off of each other's strengths.

Challenges with the Individual Education Program process. Past challenges in getting their child's needs met have led to mothers in this study to developing advocacy strategies to ensuring their child's needs are met. These challenges include: (a) IEP compliance and implementation, (b) district-level issues, (c) difficult transitions. As

reported by participants, most of these past negative experiences were because the team misunderstood student needs, thus overlapping with the other themes. Even when everyone on the IEP team has the same goal of doing what is best for the child, this does not always happen because of a lack of knowledge and misunderstanding of the needs (Feinberg et al., 2002). A commonly reported challenge in this study was in regard to goal setting. As previously stated, participants mentioned how frustrating it is for goals to not be appropriate. For some this meant that the student was not being pushed to make significant progress. For others it meant that the goals did not challenge the student. Sometimes, the lack of appropriate goals led to IEP compliance issues. One mother told a story about how her son's IEP goal had not changed in five years, which she told the team was unacceptable.

Sometimes there are challenges in implementing an IEP because of a lack of qualified personnel (Feinberg et al., 2002). Participants in this study reported that another implementation challenge is finding ways for services to be coordinated. Mothers in this study noticed that often, a teacher of the deaf or teacher of the visually impaired would be providing independent services to the student, with little or no coordination. This was, reportedly, frustrating for the family and the student. Like one mom said, her son told her that "I can never be deafblind. I can be deaf. I can be blind, but I can never be deafblind". If neither professional is an expert in deafblindness, the student will not gain the skills necessary to address the impact of the dual sensory loss on learning (Riggio & McLetchie, 2008). If professionals are able to collaborate with each other on goals and service provision, mothers in this study indicated the outcomes were better for their children and it, typically, meant less time outside of the classroom.

Participants indicated that transitions can be difficult. Mothers in this study stated concern that when teams think of transition, they often think of the transition to post-secondary, but because deafblindness is a low-incidence disability, any transition that necessitates a change in team or placement may lead to challenges. Therefore, as stated by mothers in this study, for many students, each year is a transition, which requires an extensive review of services and supports. For some families in this study, the staff turnover on their child's team was so high that transitions happen much more frequently than once a year. Many participants have spent a significant amount of time educating the teams any time there is a transition of staffing or placement, even if the staffing or placement is short-term. One common strategy shared by most participants was to provide "in-services" for team members, or by creating an "All About Me" document. Some participants even have their child provide this information themselves. Frequent transitions are also a reason that many of the participants meets with the team frequently throughout the year.

Valued Family-School Collaboration

Q2   How do parents define collaboration with their IEP teams?

Participants in this study reported having varying levels of success with IEP team collaboration, which is supported in the literature (Wang et al., 2004). Several participants mentioned that using a conflict approach to meetings was not productive and that using a positive, collaborative approach to meetings was often a more effective way to get their child's needs met. Participants were not asked to define collaboration specifically, but they did mention several team-building and collaborative approaches to advocacy. Relationship building with team members was referred to as a key focus for study participants.

During discussions about relationship building, participants shared examples of how they use the collaboration principles of trust, respect, communication, advocacy, equality, commitment, and competence (Blue-Banning et al., 2004). Not only did the mothers in this study indicate that these principles were important, participants also encouraged professional team members to follow these principles. Because of the unique needs associated with deafblindness, collaboration between team members who are serving the child is vital to student success (Riggio & McLetchie, 2008). Partnership, as reported by participants, comes in the form of problem-solving and knowledge sharing and in understanding the impacts of dual sensory loss. Knowledge sharing is sometimes challenging because, often, families are the ones most knowledgeable about deafblindness and certainly of their child, yet families sometimes are frustrated because they wish that someone on the team would bring knowledge and ideas back to them (Correa-Torres et al., 2018). A strong collaborative relationship built on communication was suggested by participants as a way to bridge knowledge differences. Because of the experience that parents hold, participants mentioned how beneficial it is to be actively involved in problem-solving, which takes strong collaboration and communication.

Advocacy Strategies Used by Families

Q3   What knowledge and strategies do parents use in IEP meetings to promote collaboration?

To give insight into this question, I look in depth at the category of advocacy strategies used by families. Advocacy strategies mentioned by participants fell into the following three themes: (a) advocacy through action, (b) advocacy through knowledge, and (c) advocacy through student involvement. Mothers in this study reported that they play multiple roles on IEP teams including: (a) sharing knowledge, (b) advocacy, and (c)

case management. Participants outlines advocacy through action strategies that fell into two categories: (a) direct strategies (e.g. meeting management strategies) and (b) leadership skills (e.g. consensus building, positive approach), which will be discussed in more detail below.

When a child's needs are complex and when IEP teams are large, parents often play the role of "case manager" (Kervick, 2017), which was also something that participants reported. To advocate and have the knowledge necessary to get their child's needs met, participants did extensive research on deafblindness, the specific challenges that their child has, and their parental rights in special education law. Becoming "disability experts", in this case deafblind experts, may help families who feel that professionals do not have the necessary knowledge needed to make decisions for their children (Trainor, 2010).

Families bring a wealth of knowledge to share with IEP teams about their child and deafblindness (Correa-Torres et al., 2018). Participants shared stories of how they gain and share that knowledge with IEP teams. However, past research indicates that parents do not always know how to best assimilate that information to their teams (Mueller, 2017). The mothers in this study were successful in sharing information with their child's teams, however, it was reportedly not easy. Participant knowledge of special education law was reportedly helpful when they were determining how to share knowledge and advocate. Mothers in this study indicated that if they understood IEP law, they find they were better equipped to present information in a way that was necessary to obtain the services and supports their child needed, which is consistent with the literature (Mueller, 2017). Mothers in this study, for instance, make use of data to support their requests because they know that data-driven decisions are necessary. Participants in this

study all had knowledge of the law, parent rights, and conflict prevention strategies, which served them well when working with IEP teams.

As case manager, participating mothers reported being responsible for direct strategies such as: (a) pre-planning for IEP meetings, (b) IEP meeting management, (c) goal setting, and (d) ensuring their child's needs are met. Although each IEP team has an assigned case manager from the school district, each participant mentioned the leadership role they have played on the team regarding meeting management. Leadership skills came over time; as part of the advocacy efforts, participants have found that having a leadership role has helped them be more effective in their advocacy role. Having pre-planning meetings is a strategy that was investigated by Goldstein and Turnbull (1982) as a means to increase parent involvement. Holding pre-planning meetings was a strategy used by a majority of participants in this study, and participants mentioned that pre-planning meetings were much more productive and pleasant than formal IEP meetings. Goal setting was specified as a specific focus of participants in this study because they felt that if they were not involved, teams would choose goals that were not appropriate or not high enough. Goal setting was discussed further in the discussion of the findings related to deafblindness.

Leadership skills included specific actions mothers use in meetings to advocate such as (a) a team mindset, (b) positive approach, (c) consensus building, (d) being firm, (e) flexibility and creativity, (f) thinking ahead, and (g) problem-solving. This study fills that void in educational literature on the leadership skills that parents use when working with IEP teams. It was evident in talking with mothers in this study that they had, over time, learned what approaches to advocacy were most effective. The mothers in this study were confident in their knowledge about deafblindness and special education law,

which suggests that it may be easier for them to be firm in their approach to advocacy. Participants seemed to be able to remain firm, while still fostering a collaborative, positive environment. All participants put a strong emphasis on the important of remaining positive and trying hard to not have a "conflict approach" to advocacy. They, reportedly, have found that once they became frustrated or upset in meetings, the meetings typically turned to conflict. Participants had strategies to monitor their emotions, such as bringing appropriate family support to meetings to keep them focused and calm.

Several participants in this study mentioned the benefit of student involvement and student self-advocacy, especially the mothers of children with Usher syndrome. In talking with participants, it was evident that student involvement may look different depending on a student's ability to communicate their needs. Mothers of children who had more significant needs reported that teams often did not know how to communicate with their children and, therefore, underestimate their communication abilities. Participants stated that if teams cannot effectively communicate with their child, their child may not be able to effectively express their needs. If IEP teams can determine how to communicate effectively with the student using their mode of communication, mothers in this study indicated that there are considerable benefits to having their children learn self-advocacy skills. The families who have children who are strong self-advocates reported less pressure to advocate and to "be the most knowledgeable." Of the families whose children were working on self-advocacy, it was promising that it was the professionals on the IEP teams who had suggested that they add goals related to self-advocacy. The participants who had children who were strong self-advocates mentioned

what a welcome shift this was in advocacy. Participants indicated that it relieved the pressure to have their children advocate for themselves.

Because of past experiences and knowledge, mothers in this study knew when to bring support to meetings and knew how to best determine who to bring. Mothers in this study built connections with outside organizations and networked with other parents to gain knowledge. Through this knowledge-building process, mothers in this study met other parents and professionals at organizations who support them in various ways. Participants in this study were all mothers who had the primary responsibility for educational decisions. As previously mentioned, participants knew when to bring their spouse or family members for support. Before meetings, the family would discuss the roles each would play in the IEP meeting.

Relation of Findings to Previous Research

Myriad research highlights the benefits of collaborative family-professional partnerships (Haines et al., 2017; Turnbull et al., 2015). Further, Blue-Banning and colleagues (2004) identified seven principle indicators of partnership to better understand the concept of a collaborative partnership: (a) trust, (b) commitment, (c) communication, (d) advocacy, (e) equality, (f) competence, and (g) respect. In addition, participants in past studies have provided suggestions to educators about how to build collaboration within IEP teams (Fish, 2008; Zeitlin & Curcic, 2014). Nevertheless, findings from this study are different. Findings from this study identified parent-initiated strategies to advocacy. Mothers in this study also described talking with other parents who, because of past negative experiences, feel that the only way to get what they need from IEP teams was to utilize a conflict approach. Participants described using what we termed leadership skills in meetings. The leadership skills and strategies mentioned in this study, however,

provide researchers with ideas on how families can advocate and share knowledge using a firm, yet positive approach. Meanwhile, professionals can benefit from reading this study to help them acknowledge the leadership role that families can play in the IEP meeting and to understand collaborative strategies parents use to get their child's needs met. Results of this study could also be used to inform university personnel preparation programs on the challenges professionals who work with students who are deafblind experience and how those challenges could impact, sometimes negatively, the parent-professional relation during the IEP process.

Parents as Advocates

Three advocacy strategies used by the participants in this study were identified and described: (a) advocacy through action, (b) advocacy through knowledge, and (c) advocacy through student involvement. Specifically, participants identified direct strategies (e.g. meeting management) and leadership skills they employ when advocating for their children. Previous research has shown that advocacy plays a significant role in the education of students with disabilities (Burke & Hodapp, 2016). Families advocate for various reasons, one of those reasons being to improve services and supports for their children (Wang et al., 2004). Further, parents are often the most knowledgeable about the disability and about their child (Shepherd et al., 2017) and use that knowledge to advocate for their child's needs. Nevertheless, parent advocacy does not come without stress on the parent and family (Blue-Banning et al., 2004). In a study by Kervick (2017), parents mentioned how they felt they needed to act as a case manager, especially on large IEP teams. Because students who are deafblind have large teams of professionals who serve them, the findings from this study are particularly relevant to this population.

Children who are deafblind have unique challenges in the classroom because of the impact of the dual sensory loss on development, academics, incidental learning, communication, and social relationships among other areas (Ferrell et al., 2014; Riggio & McLetchie, 2008). There is scant research on families of children who are deafblind, and the research that does exist suggest that parents of children who are deafblind struggle to get appropriate services for their children because of the lack of IEP team knowledge of deafblindness (Correa-Torres & Bowen, 2016; Kyzar & Summers, 2014; McInnes, 1999). There is a need for additional research on families of children who are deafblind and the challenges they face when advocating and sharing knowledge with teams. Although the results of this study provide some insight on the experiences of parents of children with deafblindness during the IEP process, there is still a need for deeper understanding of strategies that these parents use to build collaboration with IEP teams.

Meaning and Significance of the Study

The findings of this study fill a gap in family research in the field of deafblindness. Because of the dual sensory loss, children who are deafblind are impacted in the classroom and experience challenges with communication, learning, and access to the environment among others. Because of the low-incidence nature of deafblindness, oftentimes parents are the most knowledgeable about deafblindness on the IEP team, which leads to some unique challenges with IEP team collaboration because of the necessity of knowledge sharing.

As a mother of two children who are deafblind, I am often asked by other families who have children who are deafblind to provide advice on how to obtain the appropriate services and supports for their child. Often, parents are frustrated because of a team's lack of knowledge of deafblindness. My viewpoint is similar to those I talk to. As a

mother, I am conflicted. I want to look to professionals to be experts in education.

However, I know that I am the expert in *my child*. For our family, this was especially true

immediately after the diagnosis when we knew very little about deafblindness and the

effects of dual sensory loss in the classroom. Gradually, we located resources and

connected with organizations and families who could help us. The knowledge-building

process was stressful and time-consuming, and it impacted our family in many ways. I

now have many advocacy strategies in my toolkit, and I can effectively get my children's

needs met in meetings, positively. I came up with the idea for this study because I

wondered if other families had similar strategies that they would be willing to share.

There has been very little change in practice over the last 40 years, and parents

continue to report dissatisfaction with IEP meetings (Correa-Torres et al., 2018; Zeitlin &

Curcic, 2014). This study contributes to the almost non-existent body of research on

families of children who are deafblind, looking at the unique challenges that these

families face because deafblindness is often misunderstood. Participants in this study

have extensive experience advocating and sharing knowledge with IEP teams and were

willing to share those experiences.

The findings from this study have implications for both future research and

practice. Participants offered many advocacy and collaboration strategies that, if shared

with other families, could help families ensure their child's needs are met. Findings

contribute to educators' understanding of the unique perspective of families of children

who are deafblind. It is important to acknowledge the time commitment that participants

in this study have made to knowledge and advocacy. Participants in this study admitted

that not all parents have the same time and resources to devote to advocacy activities and

they wish to share advocacy strategies with other families, in hopes that it will save other families' time.

Implications for Practice

Findings from this study have implications for practice for families and professionals, providing insight into: (a) the problems that parents experience that lead them to develop advocacy strategies, (b) valued family-professional collaborations, and (c) advocacy strategies used by families. Participants in this study provided valuable strategies that may be used by other families as they advocate for the needs of their children.

For participants in this study, the most commonly reported challenge was lack of professional knowledge about deafblindness. We know from previous literature in the field of deafblindness that there is a lack of qualified personnel in deafblindness (Correa-Torres & Bowen, 2016; Parker & Nelson, 2016) and that lack of professional knowledge of deafblindness results in conflict (Correa-Torres et al., 2018). In a recent survey of professionals who serve students who are deafblind, less than 34% of participants stated that they received training on deafblindness as part of their teacher training programming (Correa-Torres & Bowen, 2018). Participants in Correa-Torres and Bowen's (2018) study on deafblindness stated that they needed more training on the unique needs, teaching techniques, and accessibility to resources. Interveners are a critical support for students who are deafblind and having an intervener on the team can help bring a depth of knowledge. However, there is still a lack of family and professional understanding of the role of an intervener. The Council for Exceptional Children has published nationally recognized intervener knowledge and skills competencies; yet, there is still a need for more intervener training programs and additional standards (National Center on Deaf-

Blindness, 2012). Regarding teacher preparation programming, findings from this study suggest a need for additional deafblind teacher preparation programming to prepare teachers to serve the needs of students who are deafblind. Although much progress has been made in teacher preparation and in the introduction of an intervener model to support students who are deafblind, we still need to better prepare our teacher to serve the diverse needs of this population. Specifically, we need more teacher preparation programs that train teachers to be experts in deafblindness.

Mothers in this study had all experienced past struggles in working with their child's IEP teams. These challenges included: (a) IEP compliance and implementation, (b) district-level issues, (c) difficult transitions. We need additional teacher preparation in how to support families in the IEP process, and the importance of building a collaborative partnership with families. Some of the challenges that participants mentioned are district-level challenges. It is important that district-level representatives be familiar with deafblindness, so that they can support the staff in their district.

In addition to teacher implications for practice, findings from this study also demonstrated implications for family support and practice. Families are capable of playing a leadership role in IEP teams, thereby leading to the improvement of collaboration. Not all families have the time to devote to advocacy activities and we owe it to families to make advocacy easier for them. Families may benefit from learning advocacy and collaboration strategies from other families. We know from previous research (Mueller, 2017) that families also benefit from learning from other families. The advocacy strategies identified in this study could be utilized along with an intensive training program for families of children who are deafblind. Shephard and colleagues (2017) found that advocacy trainings could be empowering for parents. Many parent

trainings focus on knowledge of special education law and the direct advocacy strategies. The leadership skills and collaborative strategies that participants shared could be valuable to add to parent training. In addition, this study and research indicates that family support is valuable (Mueller, 2017). One way to increase family support is for families to help other families. Families may benefit from learning from other families. The leadership strategies can be shared with other families to help more families build collaborative relationships with IEP teams.

Finally, we know from past research that IEP meetings are stressful (Zeitlin & Curcic, 2014). Participants in this study shared how pre-planning meetings are often more productive than formal IEP meetings and, yet, this practice is still emerging, perhaps because of the time commitment involved (Mueller & Vick, 2017). Having pre-planning meetings is a practice that was investigated by Goldstein and Turnbull (1982) as a means to increase parent involvement, however it seems to still not be common practice today. Educators can benefit from hearing from parents about the benefits of such meetings. Formal IEP meetings have a less collaborative feel than other types of planning meetings, perhaps because there is so much pressure placed on school districts to follow all of the guidelines of IDEA.

Limitations and Implications for Future Research

Because research related to families of children who are deafblind remains scant, this study is a significant contribution to this body of inquiry. While the findings from this study suggest meaningful insights into parent knowledge and advocacy, some limitations must be addressed. Although participants in this study were from diverse geographical areas and seemed to be a representative sample, all 14 mothers had high education levels. Because of the high education levels, participants had past education

that helped them in IEP meetings. Not all parents have the time, educational background, or financial resources to advocate and gain knowledge in the same way as the participants in this study. However, examination of the demographic variables is essential in future research.

All participants were mothers therefore the experiences may not be representative of those of fathers. Past research shows that dads are often "the odd man out" (p. 41) in IEP meetings (Mueller & Buckley, 2014). Although the mothers in this study would often involve the fathers in IEP meetings, all of the mothers in this study were the lead parent in education planning for their child. A future line of research could be to replicate this study by interviewing fathers who are actively involved in educational planning.

More research focused on parent knowledge and advocacy is needed, in particular, looking at how cultural and socioeconomic diversity may impact future findings. A next step might be to survey parents of different socioeconomic and cultural backgrounds, with the goal to better understand their knowledge of the advocacy strategies suggested by participants in this study. Future research could also evaluate the effectiveness of parent training that were suggested as part of the implications for practice.

Previous research has identified the following seven principles of partnership: (a) communication, (b) commitment, (c) equality, (d) competence, (e) respect, and (f) trust (Blue-Banning et al., 2004). Findings from this study provided examples of how these seven principles of partnership and associated indicators relate to families of children who are deafblind and their IEP teams. We know from past research (Blue-Banning et al., 2004) that these seven principles of partnership are indicators of collaborative partnership. Findings from this study suggest mothers play an important role in fostering this collaboration. Additional research is needed in the area family-initiated strategies that

may improve collaboration, more specifically to expand the research to consider how cultural and socioeconomic diversity may have an impact on findings.

Findings from this study also suggest that student involvement in the IEP may improve a family's ability to ensure their child's needs are addressed. However, this is just a speculation based upon a small sample size. All of the mothers in this study who had children who were involved in self-advocacy activities indicated how beneficial the child's input was to the team. In fact, a few mothers mentioned how much they appreciated having their children involved, saying that it resulted in less pressure on the them to advocate. We know from past research that there are benefits to student involvement in the IEP (Martin et al., 2006), however this practice is still evolving. Although student involvement in the IEP is required as part of the IEP as part of the transition process, additional research is needed to show the benefits to student self-advocacy and involvement in their educational planning. Although it seems like an effective practice, it remains an emerging practice to involve students in their IEPs at a younger age than what is required per IDEA. Future research could include interviewing parents of children who are deafblind about their child's involvement in the IEP process and in self-advocacy activities.

The mothers in this study who had children with Usher syndrome had very different deafblind related challenges than those mothers with CHARGE syndrome or other disabilities. This study is limited by the small sample size. The sample may not be representative of the population of students who are deafblind because of the high percentage of participants with children who are deafblind due to Usher syndrome. Future research could delve deeper into the etiology specific deafblind challenges that their children face.

I am a mother of two children who are deafblind. Although care was taken to mitigate bias, my past experiences have shaped my views about advocacy, knowledge, and collaboration in IEP teams. Although some may see this background knowledge as a limitation, I believe that the culturally responsive relational reflexive ethics framework (Lahman, 2017) allowed me to connect with participants in a personal way. I was able to relate to participants because I have experienced the phenomenon of study and I built a relationship with each participant.

Conclusion

Although active parent involvement is mandated as part of the IDEA, parents continue to report dissatisfaction with IEP meetings (Zeitlin & Curcic, 2014). Past research has focused on parent dissatisfaction and the resulting conflict (Fish, 2008). In 2004, Blue-Banning et al. identified seven indicators of family-professional partnership. Follow up studies have been focused on collaboration within IEP teams. Even though parent participation has increased since then, the partnership that was envisioned by the adoption of IDEA is arguably not consistent with practice (Wang et al., 2004). Participants in past studies have given suggestions to educators on how to build collaboration within IEP teams (Fish, 2008; Zeitlin & Curcic, 2014); however, findings from this study are different. This study was focused on the proactive strategies that *mothers* initiate to ensure their child's needs are met.

Three categories emerged from the data: (a) problems parents experience that lead them to develop advocacy strategies, (b) valued family-school collaboration, and (c) advocacy strategies used by families. Although the purpose of this study was to identify parent-initiated advocacy strategies, it was necessary to first understand what led the mothers to develop these strategies. Participants shared insight on how they use

collaborative strategies to build strong relationships with IEP team members. Participants advocated and shared knowledge by employing positive, collaborative strategies. There are many roles that parents play in educational planning including: (a) knowledge sharing, (b) advocacy, and (c) case management. Participants shared strategies they use when playing these roles.

Mothers of children who are deafblind have unique challenges in IEP meetings because there is often a lack of IEP team member knowledge of deafblindness. This study adds to the scant literature on families of children who are deafblind. The results provide meaningful insight into parent IEP experiences, and the importance of knowledge of deafblindness and advocacy. Educators can benefit from reading this study to understand the leadership role that families play in the IEP meeting and to learn about strategies mothers use to address their child's needs. As a mother, it is my hope that this study helps families like my own to better advocate for their child's needs. I know first-hand how much time and energy parents put into advocating for their children. Over the years I relied on my network of fellow parents of children who are deafblind to help me develop strategies. It is my hope that this research does the same for others and makes someone's life easier.

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APPENDIX A

INTERVIEW PROTOCOL

Interview Protocol

Demographic information (Collected by Google Form prior to Interview)

1. Tell me about your child:
    a. Type of disability
    b. Age of diagnosis
    c. Current age
    d. Years receiving special education services?
    e. Educational setting (gen ed/resource, self-contained classroom or specialized school)/(private/public school). Has this changed over time?
    f. IEP or 504 plan?
    g. Who is on the IEP team and what are their roles? Has this changed over time?

2. Tell me about your family
    a. What state do you live in?
    b. Any other children? (any on IEPs?)
    c. Have you ever been involved in:
        i. Due process?
        ii. Mediation?
        iii. State complaint?
        iv. Resolution session?
    d. Who from your family typically attends IEP meetings? Have you ever brought anyone else to meetings?
    e. How often do you mentor/help other families who have similar experiences to yours?

IEP Experiences
1. What have been your overall experiences with your child's IEP teams?

2. What do you see as your role in IEP meetings? (probe: was any of it to foster collaboration?)

3. Do you feel your voice has been heard with your child's IEP teams?
    a. Has this changed over time? Please describe.

4. What knowledge and skills did you bring to the IEP meetings?
    a. How did you gain the knowledge and skills?

5. Have you engaged in any proactive strategies to ensure your child's needs were met in IEP meetings?
    a. If so, please describe these strategies.

6. (If applicable) Has your child participated in their IEP meetings?
    a. If so, what did that look like (what was their role, when did they start).
    b. Were there benefits? Please describe.
    c. Were there any downsides/barriers to including them? Please describe?

Resolving Conflict/Improving Collaboration
1. (If not answered previously) You are being interviewed because you have reported experiencing disagreements that you have resolved without due process. Can you tell me more about one specific situation of conflict/disagreement?
    a. How was the situation addressed?
    b. What strategies or actions did your family use to try resolve the issue?

2. Do you have any advice for other parents that might be having disagreement with their child's IEP teams (strategies to try to get needs met/improve collaboration with teams)

3. What do you see as a professional's role in fostering collaboration or ensuring the family's voice is heard? How about a family's role?

4. Do you have any suggestions of things that IEP team members can do to improve your IEP meeting experiences?

APPENDIX B

REFLECTION PROMPTS

Reflection Prompts

Thank you for participating in the interview and sharing your IEP team experiences and collaboration strategies.

- Reflecting back on the interview, did anything that came up in the interview surprise you in any way? (i.e. Did it make you remember anything differently? Did it make you think about any issues in a different way?) If so, please describe.

- Is there anything that you thought of after we talked that you feel is important for me to understand or know?

- If another family asked you for one piece of advice as they prepared for their first IEP meeting, what advice would you give them?

- Similarly, what one piece of advice would you give an educator that is preparing for their first IEP meeting?

Thank you again for your time.

APPENDIX C

QUESTIONNAIRE

Questionnaire

Thank you for your interest in my study on IEP meeting experiences. Please take a moment to answer the following questions about your IEP experiences to determine your eligibility to participate.

1. Tell me about your child:
    a. Type of disability
    b. Age of diagnosis
    c. Current age
    d. IEP or 504 plan? Which?

2. Tell me about your family
    a. What state do you live in?
    b. Any other children on IEPs?
    c. Have you ever been involved in:
        i. Due process?
        ii. Mediation?
        iii. State complaint?
        iv. Resolution session?
3. Have you experienced both negative and positive IEP meetings?
4. How often do you mentor/help other families who have similar experiences to yours?

5. Do you have at least one child who is deafblind between the ages of 10 and 18 who either is in special education services or has exited special education services and is achieving positive student outcomes as determined by the family?
6. Have you attended at least 5 IEP meetings?

7. Have you experienced some conflict with their IEP teams and overcome some or all of those disagreements without the use of due process? Please briefly describe the source of conflict.

_____
_____
_____
_____

8. Have you attended a meeting that required specific parent-initiated strategies to resolve the conflict?
9. Have you had IEP experiences that have resulted in you either having multiple IEP meetings to address the issue or requiring longer than normal IEP meetings?

10. Do you have any unresolved conflict with your child's IEP teams?

APPENDIX D

RECRUITMENT POST

UNIVERSITY OF
NORTHERN
COLORADO

Hello parents,
I am a parent of two children who are deafblind and I am a doctoral student in special
education. Are you a parent of a child who is deafblind who has ever struggled with
previous or current educational teams about your child's IEP planning and programming?
If so, I would like the opportunity to talk to you about your experiences and learn how we
can improve parent-educator interactions.

If you are interested and available, please go to _____ and send me your email
address so I can contact you. This interview should take no longer than an hour and it will
be completely confidential.

Thank you! I look forward to hearing from you.

Ms. Lanya McKittrick mcki9421@bears.unco.edu

Doctoral Student
School of Special Education
University of Northern Colorado

APPENDIX E

INSTITUTIONAL REVIEW BOARD
APPROVAL LETTER

UNIVERSITY OF
NORTHERN COLORADO

Institutional Review Board

DATE: November 16, 2018

TO: Lanya McKittrick
FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [1341306-2] Strategies that Parents of Children who are Deafblind Employ
                           to Foster Collaboration within IEP Teams
SUBMISSION TYPE: Revision

ACTION: APPROVAL/VERIFICATION OF EXEMPT
STATUS DECISION DATE:November 16, 2018
EXPIRATION DATE: November 16, 2022

Thank you for your submission of Revision materials for this project. The University of Northern
Colorado (UNCO) IRB approves this project and verifies its status as EXEMPT according to federal
IRB regulations.

Dear Lanya,

*Thank you for making the requested changes to your documentation. I am approving your project. I wish
you well in your research.*

Sincerely,

Wendy

Highby

We will retain a copy of this correspondence within our records for a duration of 4 years.

If you have any questions, please contact Nicole Morse at 970-351-1910 or nicole.morse@unco.edu.
Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of
Northern Colorado (UNCO) IRB's records.

APPENDIX F

PARTICIPANT CONSENT FORM

UNIVERSITY OF NORTHERN COLORADO

Consent Form for Human Participants in Research- University of Northern Colorado

Project Title:	Strategies that Parents of Children who are Deafblind Employ to Foster Collaboration within IEP Teams
Researcher:	Lanya McKittrick, Doctoral Student
Research Advisor:	Dr. Silvia Correa-Torres
Email:	mcki9421@bears.unco.edu / silvia.correa-torres@unco.edu

I am a doctoral student at the University of Northern Colorado and I am researching the perceptions and experiences of parents of children who are deafblind about strategies used to resolve conflict with Individualized Education Program (IEP) teams. I am also a fellow parent of two children who are deafblind. With your permission, I would like to interview you about your experiences with your child's IEP team and how you were able to resolve the issues.

There are minimal risks for this study. Participants may experience some psychological discomfort because the subject of conflict will be discussed; therefore, counseling services resources will be provided as needed. While participants do not directly benefit from participation in the study, an indirect benefit will be the knowledge that you have participated in a study that will benefit the field of special education and deafblindness by investigating and learning about parent experiences with special education conflict and strategies for resolving the conflict. This research will be used to inform educators and parents with strategies they can use to increase collaboration within Individualized Education Program (IEP) teams.

The interview should take between 30 minutes to 1 hour by phone and a follow up interview may be scheduled. Participants will be asked to submit a reflection within 48 hours of the initial interview. The reflection may be written and emailed or I can collect your reflection with you on the phone if more convenient for you. The interview(s) will be audio recorded for the purpose of allowing us to correctly report the information; however, transcripts of the interview will be confidential. All audio recordings and transcripts will be kept in a locked cabinet in a locked room. All identifiable data, including recordings and consent forms, will be destroyed three years after the study is completed. Your name will not be used when sharing information learned through the interview; instead we will assign each participant a pseudonym. Only the researchers and the research advisors will have access to the data.

Please feel free to contact Lanya McKittrick or Dr. Silvia Correa-Torres via phone or e-mail if you have any questions or concerns about the study. Participation is voluntary. You may decide not to participate in this study and if you begin participation you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having heard the previous information and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact Sherry May, IRB Administrator at Attn: Nicole Morse, Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado, Greeley, CO 80639, 970-351-1910.

_____   _____
Participant's Signature   Date

_____   _____
Researcher's Signature   Date