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Caregivers' and Professionals' Perceptions on Collaboration in Early Intervention

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CAREGIVERS' AND PROFESSIONALS' PERCEPTIONS ON
COLLABORATION IN EARLY INTERVENTION

Sara J. Edwards

73 Pages

The current study explored the perceptions of collaborative practices and possible methods to overcome the challenges identified by caregivers and professionals in Early Intervention by documenting the perspectives of four multidisciplinary team members. This qualitative study included in-depth interviews with a caregiver, service coordinator, occupational therapist, and developmental therapist/hearing specialist whom all shared an Individual Family Service Plan within the past year. Data analysis revealed five major themes that included: 1) communication, 2) best practices, 3) co-treating, 4) knowledge, and 5) respect. Future research ideas and implications for caregivers, early intervention professionals, early intervention program managers, and agencies employing early intervention professionals were discussed.

KEYWORDS: Collaboration, Collaborative Practices, Disabilities, Early Intervention, Family Centered, Individual Family Service Plans, Infants, Multidisciplinary Teams, Toddlers

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COLLABORATION IN EARLY INTERVENTION

SARA J. EDWARDS

A Thesis Submitted in Partial
Fulfillment of the Requirements
for the Degree of

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COLLABORATION IN EARLY INTERVENTION

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CHAPTER I: INTRODUCTION TO EARLY INTERVENTION

Although some disabilities, such as specific learning or emotional/behavior disabilities, may not be diagnosed until an individual is older and in a school setting, many medical conditions and developmental disabilities may be evident at birth or shortly thereafter. The Centers for Disease Control and Prevention (CDC) defined developmental disabilities as “a group of conditions due to an impairment in physical, learning, language, or behavior areas” that often impacts daily functioning (CDC, 2016). The exact cause of many developmental disabilities is unknown however, many developmental disabilities begin prior to a child’s birth due to genetic or environmental factors, such as prenatal health, complications or infections during pregnancy or birth, and exposure to toxins (CDC, 2016). Families with infants and toddlers who have been diagnosed with a medical or developmental condition and are at risk for developmental delays are eligible to receive support and resources from Early Intervention (EI) programs in order to promote their children’s development and growth.

EI programs deliver direct therapeutic or consultation services based on a family’s identified needs, priorities, and concerns through center-based playgroups or home visits (Dinnebeil, Hale, & Rule, 1999). The benefits of EI to families and children with disabilities are numerous. Research has shown EI programs “yield benefits in academic achievement, behavior, educational progress and attainment, delinquency and crime, and labor market success, among other domains” (Karoly, Kilburn, & Cannon, 2005). In fact, a recent nationwide survey conducted by the U.S. Department of Education from 2013 to 2014 indicated approximately 23,000 infants and toddlers exited EI programs with referrals for services and programs to continue at the age of three while approximately 10,500 young children, slightly more than 30% of both groups combined, exited EI programs without the need for a referral (U.S. Department of

Education, 2015). One major component that often prevents the provision of effective EI services is lack of collaboration among stakeholders (Dinnebeil et al., 1999).

Part C Program and Prevalence

The Individuals with Disabilities Act (IDEA), originally enacted in 1975, is a United States federal law that regulates how states and agencies provide services to individuals with disabilities from birth to 21 years of age. Congress established the Program for Infants and Toddlers with Disabilities, also known as Part C of the IDEA, in 1986. Part C of IDEA is a federal grant program that assists states in providing Early Intervention (EI) services for children with disabilities from birth until three years of age.

The U.S. Department of Education conducts an annual census on the number of children who have been identified as having a disability and receive EI services. According to the most recently published IDEA Part C Child Count and Settings Survey, there are approximately 350,000 infants and toddlers, nearly 3% of all children under three, served by the Part C program nationwide (U.S. Department of Education, 2015). Although federal law mandates appropriate assistance to be available through EI programs for every identified child in all states and territories of the United States, each state may structure and coordinate their EI programs differently. However, the ultimate goal of Part C of IDEA, or EI, is the same across the nation.

Goals of Early Intervention

The goal of the Part C program is to ensure that families who have children with disabilities receive the necessary support and resources to assist with their children's growth and development. In addition, the Part C program provides families assistance with transition into educational and related services available by Part B of IDEA for children ages 3 to 21. Arne Duncan, former U.S. Secretary of Education, stated:

As everyone who works in education understands, one of the most important things we can offer children is a high-quality early learning experience that prepares them for kindergarten. This is true for all children – but it’s especially important for infants and toddlers with disabilities to have access to high-quality early intervention services that prepare them to successfully transition to preschool and kindergarten. The Part C regulations will support the Education Department’s commitment to the goal of preparing more children with high needs with a strong foundation for success in school and beyond. (U.S. Department of Education, 2016)

Structure of Early Intervention

As mentioned previously, all states may structure their EI programs differently but the ultimate goal is to maximize the child’s growth and development and to prepare them for future education. For the purpose of this study, the structure of the Illinois EI program will be identified. According to the Illinois Early Intervention Clearinghouse (2016), a child is initially referred to the Illinois Early Intervention program for concerns regarding their development or a medical diagnosis by a medical professional, family member, or child care provider. A service coordinator is assigned to the family and performs an intake, or initial home visit, to obtain more information regarding the child’s medical history, development, and family concerns. Following the initial visit, the service coordinator then arranges evaluations to be conducted by service providers within their respective disciplines in at least two areas of family identified concerns or priorities.

Once the child is evaluated and deemed eligible for services, an Individual Family Service Plan (IFSP) must be written within 45 days of the initial referral. Service providers and families partner to develop an IFSP that identifies the families’ needs, strengths, resources,

priorities, and concerns. The IFSP encompasses the outcomes, or goals, identified by the families and which services will be provided, by whom, and how often. Review of the IFSP is required every six months while re-evaluations are required annually by the IFSP team. However, a family may request an IFSP meeting to discuss any concerns or desired changes at any time.

As indicated on the IFSP, direct services, consultations, resources, and assistance with assistive technology are provided to the children and their caregivers by professionals of various disciplines in order to meet the needs, priorities, and concerns identified by the families. The providers then implement strategies within their respective disciplines to facilitate the child's growth, development, and participation in family and community activities. The IFSP encourages interventions to take place within the natural environments in which the family and child live and interact and focuses on daily routines in the home and community (Raver, 2009). Including the families in this collaborative process empowers them and encourages them to make decisions concerning their children's progress and growth and to participate in the delivery of services that are most appropriate for their children (Brown, Pearl, & Thurman, 1993). Therefore, successful collaboration and a family centered approach when working with families and children with disabilities allows for professionals to better meet the unique and diverse needs of each family.

Collaboration Barriers

According to Dunst, Trivette, Davis, and Cornwell (1988), a family centered approach promotes caregivers' self-determination, self-efficacy, and a collaborative decision making process between families and professionals. Furthermore, a professionals' role within a family centered practice is to facilitate and collaborate with the family rather than be the expert with more knowledge (Block & Block, 2002). Collaboration among service providers, program

managers, service coordinators, and families is essential to meeting the needs of children with disabilities and their families. A number of factors however, may hinder collaboration between all stakeholders on an IFSP team, specifically between the caregivers and the service providers.

Diverse cultural backgrounds may hinder collaboration due to a difference in needs, concerns, and priorities. Professionals working with families enrolled in EI need to consider a family's values, customs, and beliefs in order to promote family engagement (Tomasello, Manning, & Dulmus, 2010). A family centered approach to providing services within EI includes implementing strategies within established routines. Collaboration among families and service providers may be hindered if professionals suggest changes in daily routines that families may be hesitant to make due to their concerns or beliefs. Therefore, collaboration is promoted when families are not expected to alter their daily routines in order to follow a schedule that interferes with the families' priorities, needs, or cultural beliefs (Segal & Beyer, 2006).

Lack of knowledge regarding possible services may also hinder collaboration between professionals and families. Within the health care setting, barriers to collaboration exist when medical providers fail to appropriately diagnose a child with a developmental disability or have not made the necessary referrals for further evaluations (Hendrickson, Baldwin, & Allred, 2000). In addition, within the EI program, families may not be provided with information regarding possible services. Shannon (2004) indicated funding and reimbursement of services may guide which services are offered to families instead of what services the family needs. Furthermore, in a study conducted by Sabatino (2001), less than one half of the IFSP records reviewed contained outcomes, resources, and assessments based on the families' needs, priorities, and concerns. Therefore, it is imperative all stakeholders are provided with the necessary information in order

for collaboration among families and professionals to occur and appropriate family centered services be provided.

Purpose of Study

The purpose of this study was to explore the perceptions of family members and professionals on collaborative practices within the EI system. Past research has focused on factors that either promote or hinder collaboration as perceived by individuals in specific roles. Currently there is a lack of research available that explores collaboration concerns among all stakeholders whom share an IFSP for the same child. The identification and elimination of challenges to collaboration is significant because past research has found that collaboration between agencies and individuals working toward a common goal is an effective and efficient method of providing “high quality” services and in meeting the needs of children with special needs and their families (Yang et al., 2013, p. 57).

Therefore, the purpose of this study was to provide a better understanding of how families and professionals of various disciplines can improve their collaborative practice while holding equally important but distinct roles on a multidisciplinary team. By doing so, it is hoped that caregivers would be more willing to be active participants on the IFSP team.

Research Questions

1. What are the perceptions of collaboration as perceived by the families receiving services from multiple professionals with various disciplines in Early Intervention?
2. What are the perceptions of collaboration as perceived by the professionals on multidisciplinary teams providing services to families in Early Intervention?

CHAPTER II: REVIEW OF LITERATURE

This study explored the perceptions of collaboration challenges as perceived by professionals of various disciplines and the families they serve within the EI program. In addition, the study sought to identify how the identified collaboration barriers could be eliminated in order for all IFSP team members to collaborate successfully and achieve the outcomes in EI. This chapter presents an overview of the literature from 1993 to 2015 and was designed to examine research related to collaboration barriers in EI. This literature review focuses specifically on the following topics: (1) collaboration with physicians, (2) collaboration with families, (3) collaboration with agencies, and (4) gaps in literature.

Search Procedures

My research topic focused on collaboration among professionals and the families they serve in the EI program. For the purpose of this thesis, search procedures were used to find literature that identified factors which hinder successful collaboration between professionals and caregivers enrolled in EI. For the purpose of this research, caregivers are defined as individuals who take care of a child with a disability and include biological, foster, or adoptive parents. Keywords used in the literature search included the following: collaboration, early intervention, family centered, family centered based services, and multidisciplinary teams. The literature search included peer-reviewed journal articles, books, literature reviews, and government websites. An electronic search procedure was used on Illinois State University's Milner Library's website using ERIC and OVID search engines. An electronic search was also conducted using Google Scholar. Articles which explored factors that promoted or discouraged collaboration among stakeholders while either receiving or providing EI services were reviewed.

Articles which focused on collaboration experiences between caregivers and professionals for school aged children, but did not include infants or toddlers, were not included.

Collaboration with Physicians

Physicians play an important role in the identification of young children with disabilities and in the referral process in EI. With their expertise and ongoing observations of infant and toddler development, pediatricians and family physicians are often the first individuals to identify children with disabilities. Furthermore, families “are most likely to express initial concerns about their child’s behavior or development” with their pediatricians (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004, p. 887).

A variety of reasons may delay the identification of a disability which in turn delays the referral of a child for EI services. According to a study conducted by Bailey et al. (2004), pediatricians were more likely to refer children at a younger age for EI services who displayed severe delays or had been diagnosed with medical conditions. The authors further indicated that children with less obvious delays were typically monitored, rather than screened for behavioral or developmental concerns, and not identified or referred for special services until approximately 3 years of age or older.

Once a child has been identified and referred for services, health care providers are responsible for providing accurate medical assessment information and coordinating medical care with the families, service providers, and service coordinators. Buck, Cox, Hash, and Shannon (2001) found that identification and referral rates from physicians to EI providers were inconsistent, medical information from the physicians was wrong or confusing, and families were not being informed about available resources or services offered through the EI program.

Buck et al. (2001) conducted a study to investigate the physicians' role in EI as perceived by pediatricians, family physicians, and service coordinators. The authors indicated that the majority of the family physicians reported having received information about EI programs and feeling knowledgeable about the providers in their communities. A higher percentage of pediatricians however, reported feeling knowledgeable about the local EI program and providers in their communities. In addition, pediatricians reported a higher number of referrals. Furthermore, Buck et al. (2001) discovered that the majority of the health care providers surveyed indicated they had no interest in formal training and preferred "receiving early intervention information in reports or formal letters" from service providers (p. 14).

The responses collected from the service coordinators were not consistent with the responses from the medical providers. The study conducted by Buck et al. (2001) further indicated the majority of service coordinators who were surveyed reported having provided medical professionals with information regarding the EI program. However, at least half of the service coordinators reported low referral rates from all medical providers. Service coordinators felt formal training for medical providers would be beneficial and would possibly increase communication and referral rates. Almost all of the service coordinators indicated they wanted more referral rates and involvement from physicians and pediatricians and felt telephone contact or office visits would be more effective to discuss a child's diagnosis (Buck et al., 2001).

In summary, the physicians' role in EI is significant. Medical care providers "assist families in the promotion of the optimal health, growth, and development of their infants and young children" (Brown et al., 1993, p. 254). However, Buck et al. (2001) discovered inconsistencies in the perceived roles of the medical professionals in EI programs. Clarification of roles, improving communication, agreeing on efficient methods of sharing information, and

defining expectations of who is eligible for a referral may help strengthen the working relationship between physicians, families, and providers in the EI programs (Buck et al., 2001). Therefore, training medical office personnel on the local EI programs, providers in their communities, and the referral process may also enhance collaboration between service coordinators, families, and medical providers. Collaboration between physicians and EI providers is imperative for families and young children with disabilities to receive appropriate services as early as possible in order to ensure the greatest opportunity for progress in all developmental areas.

Collaboration with Families

Collaboration among the families and professionals is vital for successful interventions. Dinnebeil et al. (1999) indicated effective EI services occur when there is a “collaborative relationship between the family members and the professionals with whom they interact” (p. 225). Many families require the services of professionals with a wide variety of knowledge and skills due to the complex health, developmental, and physical needs of their child. Collaboration within a multidisciplinary team is essential because “no one individual or discipline has the expertise or resources to adequately meet the needs of young children and their families” (Johnson, Gallagher, & LaMontagne, 1994, p. 11).

Embracing the ideal family-centered approach of service provision in EI is beneficial for professionals and families. It supports a team approach to work towards IFSP outcomes directed by the families’ needs, concerns, and priorities. In a study conducted by Bailey et al. (2004), almost one in four families were not aware of a written plan or an IFSP and wanted to be involved more in the planning of services for their child. According to Johnson et al. (1994), the family-centered approach “requires that parents not be treated as spectators who simply sign

necessary permissions, but that professionals create an atmosphere that encourages active participation and engagement” (p. 27). Most variables that affect the family-centered approach negatively can be categorized as either structural factors or interpersonal factors.

Structural Factors

Structural factors are those variables associated with the framework of the program and service delivery. A study conducted by Dinnebeil et al. (1999) investigated the perceptions of service coordinators and families on variables that interfere with collaborative relationships. An open ended survey was used to collect data. The majority of all participants (service coordinators and families) reported inflexibility in scheduling, such as not willing to schedule around the parents’ work hours or child’s needs, was the factor to hinder collaboration the greatest.

Another factor identified to detract from collaboration was the location of service delivery. Dinnebeil et al. (1999) indicated collaboration was affected negatively if home service delivery was unavailable or if center based delivery was not offered to families. Families had shared they preferred one-on-one services in their homes but also appreciated offers of play groups at centers so they could not only collaborate with professionals but with other parents who shared similar experiences. Furthermore, a study conducted by Pighini, Goelman, Buchanan, Schonert-Reichl, and Brynelsen (2013) indicated home visits or a combination of home and center visits provided caregivers with “a deeper understanding of their child’s condition(s) and developmental progress” (p. 267).

Program related issues, such as staffing and service areas, have also been determined to be barriers to successful collaboration. In a study conducted by Dinnebeil, Hale, and Rule (1996) lack of professional development and staff turnover were identified as factors that inhibit collaboration with families. In a similar study, Yang, Hossain, and Sitharthan (2013) added

shortage of staff and insufficient time as barriers to collaboration. Likewise, in a study conducted by Hiebert-Murphy, Trute, & Wright (2011), families indicated shortage of professionals to provide the support services for their child or family hindered collaboration as well.

Furthermore, large service areas, particularly rural areas, and poor weather may detract from collaborative relationships. These particular variables may lead to increased cancellations of services due to providers having to cover large geographical areas (Dinnebeil et al., 1996). Similarly, geographical locations may impact the amount of services a family receives which in turn affects collaboration. In a study conducted by Hiebert-Murphy et al. (2011), families expressed having “difficulty when they experienced inequities in services based on geographic location” (p. 152).

Interpersonal Factors

Research has indicated interpersonal factors are more relevant for effective collaboration than structural factors. Interpersonal factors are the personality characteristics and personal beliefs held by individuals that may affect collaboration. Dinnebeil et al. (1999) found that families reported knowledge, expertise, attitudes, and skills of providers in EI often promote a negative experience if the professionals’ behaviors and approaches do not communicate a desire to work with the families.

Communication. One significant variable that has been identified in studies to affect collaboration is communication (Bailey et al., 1994; Dinnebeil et al., 1996, 1999; Yang et al., 2013). In a study conducted by Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004), families reported EI professionals’ inability to be tactful when sharing sensitive information was a barrier to collaboration. EI professionals “should be honest and open, with no hidden information and no “candy-coating” of bad news” (Blue-Banning et al., 2004, p. 173). In

addition, Dinnebeil et al. (1996) identified infrequent communication and not listening as factors that affect collaboration negatively between families and service professionals. Furthermore, Blue-Banning et al. (2004) indicated the act of professionals discounting or ignoring a families' point of view can also discourage collaboration.

Beliefs and values. Valued beliefs and concepts have been shown to have a direct effect on collaboration between families and service professionals. According to Dinnebeil et al. (1996), families were less likely to collaborate successfully with EI professionals when they felt EI professionals had a lack of concern for their family unit and more specifically their child's well-being. In a similar study conducted by Pighini et al. (2014), families indicated collaboration was often dependent upon the relationship or bond they had developed with EI providers. Successful collaboration occurred when families felt providers cared for the entire family and attended to their needs by "checking on all of us" (Pighini et al., 2014, p. 266). In addition, professionals with behaviors and actions which reflect a family centered approach to working with families is significant for promoting collaboration (Blue-Banning et al., 2004; Dinnebeil et al., 1999; Yang et al., 2013). Encouraging the family and the child and regarding them "more than a case" has been shown to lead to higher satisfaction for all participants and effective collaboration (Blue-Banning et al., 2004, p. 175). Barriers to collaboration occur when families feel professionals do not value their time and only get the minimum amount done (Blue-Banning et al., 2004). Furthermore, EI professionals have shared that working together with families is challenging when parents have negative beliefs about disabilities (Dinnebeil et al., 1996).

Trust and respect. Families have expressed the need to be able to trust the professionals they are working with and to feel respected. Blue-Banning et al. (2004) indicated families felt collaboration was affected negatively if the EI professionals did not follow through with appointments or actions. Lack of follow through was perceived by families as a lack of respect. Similarly, discussing a child's condition and not inviting families to "participate in the decision making process related to their children" hinders collaboration between families and EI professionals (Pighini et al., 2014, p. 267). Families also shared collaboration is difficult when EI professionals have "violated their confidence" by not being discreet with sensitive and personal information (Blue-Banning et al., 2004, p. 179).

Furthermore, being respectful of families' opinions and concerns during the decision making process of setting goals and IFSP development also impacts successful collaboration. Parents indicated collaboration was comprised when EI professionals did not trust or respect their decisions (Dinnebeil et al., 1996; Hiebert-Murphy et al., 2011). In a study conducted by Hiebert-Murphy et al. (2011), caregivers shared they felt "appreciated knowing that the worker respected that the final decision-making power about services rested with the parents" (p. 149).

Experience and knowledge. Inexperience in a professional role either as a service provider or a service coordinator may also interfere significantly with collaboration (Dinnebeil et al., 1996). Yang et al. (2013) indicated professionals with fewer years of experience had more difficulty with collaboration which led to ineffective teamwork with professionals of varying disciplines and family members. Furthermore, families identified "inadequately trained professionals to provide the support services they needed for their child or family" as a barrier to collaboration (Hiebert-Murphy et al., 2011), p. 151). The skills of the professionals and the knowledge they already possess also plays a role in effective collaboration. Families have shown

a preference to work with confident and skilled professionals who can adapt instructional approaches to meet their children's needs and who have "high expectations for their children and provide appropriate challenges to ensure their children's progress" (Blue-Banning et al., 2004, p. 178). In addition, Hiebert-Murphy et al. (2011) indicated service coordinators in EI need "to be knowledgeable about the service system, be aware of the family's needs and desire for service, and monitor the services being provided" in order to provide effective services to families (p. 150).

In summary, structural and interpersonal factors play a crucial role in effective collaboration between families and service providers. Successful collaboration begins when the time and place of service delivery align with the families' availability so that families may gain a "deeper understanding of their child's condition(s) and developmental progress" (Pighini et al., 2014, p. 267). Being respectful, knowledgeable, and valuing beliefs are additional factors that promote successful collaboration between families and EI professionals. Furthermore, communication with the family "sheds light on family needs, not just child needs in early intervention" (Votava & Chiasson, 2015, p. 19). Therefore, listening to the families' needs and concerns would assist in matching families with the most appropriate providers rather than assigning the "next one available". By giving the caregivers a choice of available providers in their area with a description of their background, the families would be able to choose the providers they feel would be the best fit for their family and child.

Collaboration with Agencies

Providing services to families in EI requires a number of professionals with various disciplines. In many cases, the providers are employed from different agencies. According to Swan and Morgan (1993), collaboration within a multidisciplinary team involves uniting

“organizations and people for the purpose of achieving common goals that could not be accomplished by any single organization or individual acting alone” (p. 19). Johnson, Zorn, Yung Tam, LaMontagne, and Johnson (2003) indicated the variables that most hindered interagency collaboration included lack of common goals, lack of leadership, and lack of commitment of participating agencies. Furthermore, Johnson et al. (2003) indicated lack of communication between agencies and “turf issues” contributed to problems with collaboration (p. 201). Lack of commitment and lack of time devoted to team meetings and working with professionals from different agencies also plays a crucial role in the effectiveness of collaboration (Yang et al., 2013)

Families and professionals, particularly EI providers from various agencies, have minimal opportunities to work together as a team. Although they are considered a “team” on the IFSP, service providers essentially work towards the goals aligned to their expertise separately. Program managers need to “develop and implement ways for team members to share information” (Dinnebeil et al., 1999, p. 230). Providing more opportunities for staff and families to work together is critical for including parents as “full team members” (Dinnebeil et al., 1999, p. 233). Allowing for more flexibility in work hours and scheduling meetings when parents can attend will support parents’ participation. Scheduling meetings at times that allow for all team members to participate will also promote collaboration and a better understanding of the child’s development in each area of discipline.

In summary, a child enrolled in EI may require the expertise from a number of professionals with varying disciplines. In addition, the providers may often be employed by different agencies. Although this may pose a challenge to successful collaboration, literature has

supported the need for all providers and caregivers who share an IFSP to find ways that allow them to work together in order to help the child and family obtain their desired outcomes.

Discussion

A collaborative approach to the delivery of EI services is desirable so that the needs, priorities, and concerns of families may be met. The family centered approach to providing EI services is highly valued; however, it is not always put into practice. In order to be an “effective family centered practitioner”, providers need to be taught the skills to collaborate with families and be knowledgeable of the available resources and services that can be provided to the families within their communities (Yang et al., 2013, p. 72). Training on the family centered approach at pre-service schools and mentoring upon entering the EI system as a professional could also promote more understanding and implementation of the family centered approach when working with families (Votava & Chiasson, 2015).

Gaps in Literature

Past studies have focused on factors impacting collaboration between particular roles in EI such as service coordinators and families, service providers and families, or service coordinators and physicians. There is minimal research however, that focuses on the collaborative process between multidisciplinary team members and the families in order to promote parental involvement. There is a need to identify the existing barriers to collaboration among professionals of various disciplines and the families they serve. Furthermore, there needs to be further research on how the collaboration barriers can be eliminated so that the needs, priorities, and concerns of the families may be met. Therefore, this study explored the perceptions of collaborative practices and possible methods to overcome the challenges

identified by families and professionals in EI by documenting the perspectives of multidisciplinary team members. The following research questions were addressed:

1. What are the perceptions of collaboration as perceived by the families receiving services from multiple professionals with various disciplines in Early Intervention?
2. What are the perceptions of collaboration as perceived by the professionals on multidisciplinary teams providing services to families in Early Intervention?

CHAPTER III: METHODS

The data for this study were collected by interviewing four team members who shared an IFSP in order to explore collaborative practices among stakeholders. For the purpose of this study, a caregiver is an individual who is responsible for the care of a child and may include a biological, adoptive, or foster parent. A service coordinator is the case manager and is responsible for organizing meetings and connecting the family with service providers. Service providers are therapists who work with the families and their children toward the outcomes indicated in the IFSP. Service providers may include physical therapists, occupational therapists, developmental therapists, speech therapists, feeding therapists, and nutritionists.

The team members for this study included a caregiver, service coordinator, and two service providers with various disciplines. The service providers were also employed by different agencies. This section provides a detailed description as to how the study was conducted within the following areas: (1) participant criteria and recruitment, (2) interview selection process, (3) setting, (4) instruments, (5) procedures, (6) data interpretation/analysis, and (7) reflexivity.

Participant Criteria and Recruitment

Participants in this study included team members on a shared IFSP who received or provided EI services in central Illinois. Families with children with disabilities and who are currently enrolled or were enrolled in EI within the past year were targeted. In addition, the families with children with disabilities must be receiving or have received EI services from a minimum of three service providers with various disciplines and employed by different agencies.

In order to recruit the participants, the researcher invited, via email, all the service coordinators who served families in central Illinois to participate in the study. Service coordinators' names and contact information are public knowledge and were accessed through

the Child and Family Connections of Central Illinois website. The purpose of the email was to explain the study, what their role would be, and asking if they would like to participate (see Appendix A). They were asked to reply within five days from when the email was sent. After the provided date, one service coordinator was randomly selected from the pool of possible participants. The selected service coordinator was then notified and asked to sign the Service Coordinator Consent Form (Appendix B) which explained their role in reviewing their caseload for inclusion and exclusion, randomly selecting five Individual Family Service Plan (IFSP) teams, and disseminating recruitment packets to the selected IFSP teams.

The recruitment information packets were dispersed to the selected service coordinator, caregivers, and service providers on a shared IFSP. A shared IFSP means all individuals are listed on the same IFSP for a specific child while serving a distinct role. The recruitment information packets included a Description of the Study (Appendix C), a Participant Consent Form (Appendix D), a Participant Information Form (Appendix E), and an envelope with paid postage addressed to the researcher. Each recruitment information package and documents enclosed were identified as IFSP A, IFSP B, IFSP C, IFSP D, or IFSP E. All team members who shared an IFSP received a packet with the same identifying information in order to group willing participants accordingly and to ensure the appropriate number of participants on each team were willing to participate in the study.

Potential participants mailed back the participant information and signed consent forms in the provided paid postage envelope addressed to the researcher. The researcher contacted each potential participant via telephone to review the purpose of the study as well as their rights and responsibilities. During the telephone conversation, the potential participants were provided with the opportunity to ask questions and reach an understanding of the research study.

Interview Participant Selection Process

As the research participant information and consent forms were received, the researcher reviewed the forms and grouped them according to IFSP A, IFSP B, IFSP C, IFSP D, or IFSP E. The researcher then determined if the appropriate team members on a shared IFSP had agreed to participate in the study. In order to be selected for the study, the researcher initially sought to have received signed consent forms from the following team members: (1) caregiver, (2) service coordinator, and (3) three service providers from various disciplines employed by different agencies. Due to time constraints and inability to obtain the necessary signed forms, the number of necessary service providers was reduced from three to two. An IFSP team was excluded from the study if the appropriate team members did not agree to participate.

Only one IFSP team which met the criteria was selected to be interviewed. Selection of the IFSP team to participate in the study was based on the order of when all necessary signed participant information and consent forms had been received by the researcher. Once the researcher had received signed consent forms from all required participants who shared the same IFSP, then each participant was contacted by telephone to set up a face-to-face interview. The researcher also contacted the participants who were not selected for the study via telephone. They were thanked for their time and provided with an explanation that a sufficient number of participants had been selected for this study. The researcher also informed the non-selected participants their contact information would be kept in a secured location in the event the selected team was not able to complete the research.

As a result of the interview selection process described above, four individuals of two separate IFSP teams responded to the recruitment of participants. One IFSP team, made up of four team members, was selected to represent the potential participants for this interview study.

The four participants had a shared IFSP for the same child within the past year. They were selected to be participants in the study because they were the first IFSP team to have returned all necessary signed participant information and consent forms to the researcher. The participants for this study included one caregiver, one service coordinator, and two service providers (see Appendix F). Pseudonyms were provided for participants and agencies to protect and maintain confidentiality. To gain a better understanding of each participant's role on the IFSP, short descriptions and background information have been provided.

Ann, a 34-year-old Caucasian female, was the caregiver (CG) participant for this study. She was employed, married, and had two biological children. Her youngest child, Kevin, was diagnosed with CHARGE syndrome. At six months of age, Kevin suffered from a respiratory illness that led to heart failure and was resuscitated. Due to lack of oxygen during his arrest, Kevin suffered from brain injury and had a tracheostomy. He was later diagnosed with significant bilateral hearing loss, cortical visual impairment (visual impairment that occurs due to brain injury), and seizure activity. Due to Kevin's high medical needs, he had full time in-home nursing. He received EI services in his home from when he was two and a half months of age until he aged out of the program at three years old. A physical therapist and developmental therapist/vision specialist provided services to Kevin once per week each. He also received services from a speech and feeding therapist, developmental therapist/hearing specialist, occupational therapist, and a developmental therapist two times per month each.

Samantha, a 31-year-old Caucasian female, was the service coordinator (SC) who was interviewed for this study. At the time of this study, Samantha, was employed as an EI service coordinator in central Illinois for six years. She was the service coordinator on Kevin's IFSP from the time he was one year old until he exited out of the program at three years of age.

A developmental therapist/hearing (DTH) specialist, Jenn, shared her experiences as a service provider on Kevin's IFSP. Jenn, a 46-year-old Caucasian female was employed as a deaf educator in a local public school prior to providing services in EI. She had served children in EI as a DTH for a non-profit agency for 10 years. She started providing services for Kevin and his family when he was 18 months old and continued until he aged out of the program at three years of age.

The occupational therapist (OT), Jackie, provided services for Kevin from the time he was two years old until he was three years old. Jackie, a 41-year-old Caucasian female, had been an OT in EI for 12 years at the time of this study. Although an OT for a local public school, she was self-employed in EI and had never worked for an agency.

Setting

The interviews took place in a location mutually agreed upon by the participant and researcher. Locations included a participant's home and private areas in local coffee shops. According to Gillham (2000), participants are more likely to provide meaningful feedback when they are comfortable in the setting and with the interviewer. Since the interviews were audio recorded, they took place in comfortable and private areas to ensure the protection of confidentiality. There were no children present during the interviews.

Instruments

Participant Information Form and Consent Form

Each potential participant completed an information and consent form which was returned to the researcher. The items on the Participant Information Form (Appendix E) included the participant's name, contact information, and primary role on the IFSP team. The Participant

Consent Form (Appendix D) described the purpose of the study, the participants' role in the study, any risks involved, and voluntary participation.

Interview Protocol

Caregivers' and EI professionals' perspectives on collaborative practices that impact the level of success and effectiveness of EI experiences were collected through a semi-structured interview and a follow up discussion. A semi-structured interview is guided by the pre-determined topics and main questions to be asked but allows for flexibility with interviewees' responses (Drever, 2003). An interviewee is able to respond to questions with openness. In other words, in a semi-structured interview an interviewee is able to decide how much they want to say and how they want to express their thoughts (Drever, 2003).

The initial interviews with all participants took place in person. The researcher also conducted follow up discussions with each participant after the initial interviews had been transcribed. Follow-up discussions provided the researcher with an opportunity to ask the participants' any additional questions, clarify any prior responses, and ask the participants' if they had any additional thoughts or comments.

The interview protocol (Appendix G) included two sections. The initial interview began by the researcher asking the participant to share information about their role on the IFSP team. The interview then focused on the collaboration practices experienced while working with other team members. Follow up interview questions were determined following the review of the initial interview transcripts. Follow up interview questions focused on obtaining more information regarding the child's health and development. Participants were also asked to clarify responses regarding co-treating and the structure of the EI program.

Procedures

The initial interviews with the participants of the study were scheduled and conducted by the researcher. Each participant was interviewed individually in a location and at a time agreeable to both the participant and researcher. The initial interviews took approximately 30 to 45 minutes in length. The questions for the follow up discussions were developed after the initial interview data had been collected and analyzed by the researcher and her advisor (Votava & Chiasson, 2015). The follow up discussions were approximately 30 minutes in length.

Each interview was audio recorded. The participants were informed when the recording was being turned on and off. The data collected from each participants' interview were assigned a pseudonym in order to protect the participants' privacy and confidentiality. The audio tapes were transcribed by the researcher shortly following the interviews. The researcher then reviewed each transcript while listening to the audio recordings and edited the transcripts for any errors to establish accuracy in transcription (Hiebert-Murphy et al., 2011).

Data Interpretation and Analysis

Once the interview data was transcribed and reviewed for accuracy, the researcher identified recurring themes. The transcripts were reviewed repeatedly in order to develop common themes among the participants' responses (Dinnebeil et al., 1996). To confirm validity, the developed themes were checked by an additional researcher. This is referred to as "peer debriefing" and is an important step in producing reliable qualitative research (Brantlinger, Jimenez, Klinger, Pugah, & Richardson, 2005, p. 201).

Reflexivity

Reflexivity refers to a person's values being represented in their work. My role as a researcher has been informed by my personal and professional experiences within EI. I am a

parent of two children who received EI services when they were younger. I currently work as an EI service provider in Illinois. In these personal and professional roles, I have had the opportunity to talk with many families and service providers about their EI experiences. I have also had the opportunity to share my own experiences on a personal and professional level.

I provide EI services to many families with children with disabilities and medically complex histories. Due to the families' needs, priorities, and concerns, many of the families I currently serve, and have served in recent years, have large IFSP teams and are faced with collaboration challenges. I have become a responsive listener who seeks to find strategies to improve collaboration among families and professionals in order to promote the success and effectiveness of EI.

CHAPTER IV: RESULTS

This study was designed to explore collaborative practices as perceived by caregivers and professionals from a multidisciplinary team in EI. Interviews were conducted with four team members who either received EI services or provided EI services to the same child within the past year. The interviewees included the following: 1) Ann, the caregiver (CG) of the child (Kevin), 2) Samantha, the service coordinator (SC), 3) Jenn, the developmental therapist/hearing (DTH), and 4) Jackie, the occupational therapist (OT). See Appendix F for participant information. Data analysis identified five major themes that team members shared regarding collaboration among stakeholders on a multidisciplinary team in EI. The results section is organized by the five themes as follows: 1) communication, 2) best practices, 3) co-treating, 4) knowledge, and 5) respect.

Communication

As a result of data analysis, the first theme identified was communication. Communication among all team members is essential for successful collaboration. The three following subthemes regarding communication were identified and will be discussed: 1) communication between EI professionals, 2) communication between the caregiver and EI professionals, and 3) suggestions to improve communication for multidisciplinary teams.

Early Intervention Personnel

The first subtheme in communication concerns the communication between EI professionals, which includes the service providers and service coordinator on a shared IFSP. In regards to communication between the service coordinator and service providers, interviews with the participants revealed some discrepancy as to how often communication occurred. Samantha (SC) shared she communicated “pretty often” with the service providers. However, both Jenn

(DTH) and Jackie (OT) indicated there was “minimal contact” with Samantha (SC). Jenn (DTH) and Jackie (OT) shared that they typically only heard from Samantha (SC) when she was needing to gather dates and times of service provider’s availability to meet for Kevin’s IFSP meetings rather than to receive updates regarding the child’s developmental progress or health concerns.

Both service providers did agree that they primarily initiated communication with the service coordinator. Jenn (DTH) and Jackie (OT) indicated they were the ones to reach out to Samantha (SC) if they had concerns or pertinent information to share regarding Kevin and his IFSP. Samantha (SC) also stated the service providers on Kevin’s IFSP team “would contact me if there was something that needed changed or if we needed to meet because of frequency change.”

Team members shared the most communication between EI professionals on a shared IFSP occurred between the service providers. The ability to have face to face interactions with other service providers appeared to promote communication. Jackie (OT) stated the following:

With this particular team, there were probably one or two therapists that I talked with regarding this child just because I would see them often. I think it’s definitely easier when you see another therapist while working with other children.

Similarly, Samantha (SC) indicated service providers whom worked in the same agency had “more opportunities” to consult face to face because they “may see each other across the hallway at their place of work and can discuss a child’s case.” Her concern however, was that she was “not sure how much consulting with other providers occurs” outside of their agency if they do not see other service providers regularly.

Both service providers and the service coordinator identified email as the most frequently utilized method of communication among team members from different agencies. Jackie (OT)

shared “the majority of the communication happened pretty much on a weekly basis via email.” She referred to the weekly email as an “email chain”. Jackie described an “email chain” as follows:

An email was sent out saying how sessions went or, you know, how things may have changed, or a new concern at this time but the emails were, um, pretty regular and would go out to the team. There was some good input or some good information that we needed to know as far as a health change or something like that.

All participants expressed an “email chain” was the best method of communication for service providers to “provide updates” and to “obtain good input and information” between sessions regarding the child’s development.

Samantha (SC) and Ann (CG) also felt the “email chains” were beneficial. Samantha described the team as “more cohesive” because “everybody was in the know.” She felt the “email chain” enabled the service providers to attend Kevin’s IFSP meetings with the same information and not on “different pages.” Ann (CG) felt the email chain among Kevin’s service providers “was very instrumental in communicating information” because she “didn’t have to remember who I told what or have to tell them the same story over and over again.”

The majority of communication between EI professionals on a shared IFSP occurred between the service providers. Although the service providers had minimal opportunities to meet face to face, communication was maintained via email. All participants found the “email chain” to be beneficial in order to keep everyone updated on the child’s progress.

Caregiver and Early Intervention Personnel

The next subtheme identified involved communication between the caregiver and EI professionals. Discrepancies regarding the frequency of contact between the service coordinator and caregiver were identified. Samantha (SC) indicated she made “monthly contacts” with Ann (CG) via text, email, or phone calls to “check in with the family unless something may have

come up and the parent contacted me.” However, Ann (CG) shared she was uncertain as to what the service coordinator’s role was and only heard from her “every six months.”

It was evident that the service providers and caregiver communicated more frequently and utilized text messaging for this purpose. All EI professionals indicated text messaging “worked out the best” and was the “easiest” way to maintain communication with Kevin’s family. Ann (CG) stated “text messaging was the best way for me to communicate to the therapists.” She explained:

I think we used text messaging a lot when he was in Early Intervention. That was just the easiest for me. I put all of the therapists in a group message so that in one text message I could say “hey Kevin had a seizure for the first time today, we may need to back off therapy this week.” Or sharing what Kevin was doing like “Kevin batted at a toy today.” Sharing those ups and down and how he was progressing or “his physical therapist had the suggestion that we could carry over to his vision therapy” or “his vision therapist had a suggestion that we need to isolate what he was doing.”

Communication with caregivers may be hindered if the caregivers are not present during EI sessions. Jenn (DTH) and Jackie (OT) shared how they accomplished maintaining communication with Kevin’s parents if they were unable to attend sessions. Jackie (OT) described how she communicated with Kevin’s parents:

I would call while I was there or send a picture via text or email...so they could see some new activity that we were doing or new position or placement we had. They always enjoyed having that feedback.

Jenn (DTH) also shared how she communicated with the family in their absence:

A session note was always written and left for the parents to review and then from time to time if there was, um, a certain issue or a certain question I usually, just because texting was easier, sometimes an email, I would email or text the parents to ask them for more information on a particular situation.

Kevin received full time in home nursing due to his medical needs. Since his nurses were consistently present during EI sessions, they also played an important role in maintaining

communication between the service providers and Kevin's family. Jackie (OT) explained how she worked with the nurses to get information to his parents.

They would also sometimes give feedback to the family during my sessions whether it was text or picture just to share that with mom or dad. A lot of the information could get relayed from them. They were able to relay that information and show the family what was done earlier to help the carry over.

Jenn (DTH) indicated she often referred to Kevin's nurses as well to "find out what the latest update was" when his parents were unable to attend her sessions.

Communication occurred more consistently and frequently between the service providers and caregiver. Text messaging and emails were utilized to maintain communication if the caregivers were not present. Nursing staff also assisted in relaying important information between both parties.

Suggestions for Improvement

The third topic revealed under communication were suggestions for improvement. All participants recommended that large IFSP teams, particularly those with service providers from different agencies, utilize an email chain to promote communication among the service coordinator and all service providers. Although Jenn (DTH) and Jackie (OT) felt email chains were "fairly redundant", "just summaries of therapists' sessions", and "keeping up with them" was difficult, it was suggested "new information" and "relevant information" regarding any medical or developmental changes should be shared to keep all team members up to date. In addition, Samantha (SC) felt service coordinators should be added to the email chains "since they are only in the home a few times and may not know new information."

Regular meetings for service providers who share an IFSP was also suggested to improve communication. Jackie (OT) shared her concerns about collaboration with EI professionals on Kevin's IFSP team prior to and during his annual service plan meetings.

I think for this child we tended to have a pretty good turn out. I think everyone communicated pretty well but I don't know that beforehand everybody knew where everybody was at. There wasn't that collaboration necessarily prior to any changes or recommendations.

Jackie (OT) expressed holding regular meetings would be “a better way to communicate with the entire team.” She expressed “monthly or bi-monthly face to face meetings or teleconference” would be beneficial for service providers, from all agencies, to discuss a child's development, any concerns, or medical updates.

Lastly, Jackie (OT) also indicated service providers need to leave some type of documentation for the caregivers who are not present during sessions. She stated:

I think it's hard when you have that many therapies and appointments and when parents are working. It's hard for them to always be a part of it. So, you know, I think everyone should try to leave documentation of what they did.

Documenting sessions through email, text messaging, phone calls, sending pictures, or leaving session notes were all recommended strategies to maintain communication with the family. In addition, regular emails and face to face meetings were suggestions to sustain communication among EI professionals.

Best Practices

The second theme identified by data analysis was best practices. EI professionals and caregivers working closely together is critical for optimal success and collaboration in EI. Best practices in EI revolve around the family centered approach. The following four subthemes were revealed and will be discussed: 1) the caregivers' role in the development of IFSP outcomes, 2) the caregivers' participation in EI sessions, 3) the service providers' willingness to model appropriate play and recommend follow through activities throughout the child's daily routine, and 4) the use of materials found within the child's natural environment to promote learning and progress towards the identified IFSP outcomes.

Development of IFSP Outcomes

The caregivers' role in the development of IFSP outcomes was identified as one subtheme within best practices. All team members interviewed reported the development of Kevin's IFSP outcomes were based on the needs, concerns, and priorities identified by the family. Jackie (OT) shared the "family's concerns" were discussed "as a group" at the IFSP meetings and were "very family oriented." Jenn (DTH) stated her thoughts on how Kevin's family played an active role in the development of outcomes:

I think with this particular family the parents were more of the driving force of what they wanted. The family was very knowledgeable and involved in what they wanted and many of the goals were based on what the family wanted for the child.

Ann (CG) explained how the service providers being "very attentive to what his next steps would be" helped with the development of Kevin's outcomes. She shared the following:

I feel that we always shared what was most important for Kevin's goals. All of our therapists were very receptive of what our goals were for Kevin and how Kevin developed. Over the time of his therapies, he became more alert and so I think his goals or what we were able to focus on changed a lot and the therapists were very open to listening to that.

Similarly, Samantha (SC) described the process of developing outcomes at Kevin's IFSP goals as follows:

At our meetings, we would always ask Mom what her priorities were for him and she would kind of give us what she wanted worked with but sometimes she would also look to the therapists like "they're the ones that know best" as far as his next steps and development.

Jenn (DTH) and Jackie (OT) both indicated that the service providers assisted more with the appropriate wording of outcomes rather than the development. Jenn (DTH) shared that the family "may not have known how to word what they wanted" therefore, service providers would assist in wording the "parents' goals." Jackie (OT) also stated, "We would take the family's concerns

and goals and as a team word them in a way that met intervention criteria as well as in a way that the family could understand.”

All participants reported that the caregiver played a significant role in the development of her child’s IFSP outcomes. The IFSP outcomes were “family oriented” and based on the family’s identified needs, concerns, and priorities. Service providers assisted with identifying the next stages of development and the appropriate wording of the IFSP outcomes.

Caregiver Participation

The second subtheme identified within best practices was related to the caregivers’ participation in EI sessions. All participants indicated Kevin’s caregivers were involved, but some discrepancy regarding their participation or attendance level was noted. The service providers shared how Kevin’s full time, in home nursing staff also participated regularly; particularly when Kevin’s parents were not able to attend sessions. Ann (CG) described her participation in Kevin’s EI therapeutic sessions as follows:

I was working part-time from home at the time so I was almost always there for his therapy sessions. I felt like I could be included as much as I wanted to participate or as much as I was able to participate. I was working from home during his therapy sessions but when I was able to take a break and kind of be the extra hands and, you know, to be involved, I felt like I was always welcomed to be involved.

Ann (CG) also felt she participated in sessions by being “very involved” in learning how to use new equipment or by making suggestions to the service providers concerning her child’s tolerance level and different positioning.

Jenn (DTH) described Kevin’s caregivers’ participation as well. She stated:

I thought they were involved. Typically, I think Mom was more present than Dad when therapists were there but, you know, it wasn’t like Dad wasn’t paying attention and answering questions and being physically there. I just think Mom seemed to be more present and right there in the room and talking more and asking more questions and providing more information. Dad would answer questions but was not as forthcoming as

Mom was to relay information. But I don't ever remember them not being present or around when I was there for sessions.

Jackie (OT) shared a different experience.

Most of the time the parents were not present. That just had to do with days they worked or hours they worked. There were some times they were present or would go into work a little bit later or come home a little bit early. They were very involved and wanted to know what was going on and would ask for input.

Since Kevin had full time in-home nursing staff, Jenn (DTH) and Jackie (OT) discussed the nurses' participation level during their sessions. Both service providers reported the child's nursing staff participated in their sessions. Jackie (OT) described Kevin's nurses' participation in EI services as follows:

Most of the time the nurses would participate and would ask to, you know, to help do that position again or try it themselves. Or they would help keep him entertained while, you know, he was in a position that he was not super happy about. Or they were obviously needed to provide medical care as needed during his sessions.

Although Jenn (DTH) indicated participation level "depended on the nurse" she stated "most of the time most of the nurses participated pretty well."

Although the caregiver and service providers shared different views on the level of caregiver participation and attendance, they all agreed the family was involved and wanted to know what was happening during EI sessions. Also, the child's full time in home nursing staff participated in sessions if the child's caregivers were absent.

Modeling and Follow Through

Data analysis revealed the third theme under best practices as modeling appropriate play and recommending follow through activities. Effective collaboration involves service providers' willingness to work closely with caregivers and model appropriate play for their child. In addition, recommending follow through activities for daily routines is another strategy to promote collaboration between service providers and caregivers. Ann (CG) talked about how

beneficial she found the service providers' modeling appropriate play was to her and her family. She stated that "any time we are playing with Kevin has come from learning and watching the therapists when he was in Early Intervention." Both service providers reported they modeled appropriate play or positioning for Kevin's family to replicate. Jackie (OT) shared that she accomplished this by sharing videos or communicating with Kevin's nurses if his parents were absent during her sessions. However, if they were present, then they were involved by asking questions and helping with stretching and positioning. Jenn (DTH) talked about how "it's part modeling and working with the child and its part educating the family." She discussed how she accomplished modeling during her sessions:

Maybe not in so much as a direct approach by saying "Okay now you need to do this or you need to do that." It was more like, probably more modeling and showing and saying "oh look, did you see how he responded to that? Next time you play with him, try this or that." I guess that's some coaching but a lot of it is modeling when the parent was observing or even observing the parent with the child and pointing out, "oh, did you see him respond when you do that? Now keep doing that and see how he responds." Pointing that out to them.

In addition, both service providers indicated texting videos or pictures to Kevin's parents was a method used if they were not present at the sessions. This way the family was still provided with information as to how to "replicate play" with him.

In regards to follow through, or providing the family with recommendations of activities to implement throughout their daily routines, Samantha (SC) reported "home programming" was always listed on Kevin's IFSP as a strategy to make progress towards the identified outcomes.

Jenn (DTH) explained how she recommended follow through activities with Kevin's family.

There were particular toys that he liked so I would suggest different ways in playing with him or using that activity in a certain environment or in different positioning. This particular child needed to be in different positions so I would suggest "this would be a good toy, he likes this toy when he is in the stander or when is in this chair or in this position."

Jackie (OT) discussed how she collaborated with the family regarding follow through activities.

Probably most of that, for him, was stretching every day and different positions to put him in. Just letting them know of a particular toy that seemed to be of interest to him or, you know, safety in regards to stretching or positioning.

Ann (CG) also shared that they were “given examples” of different activities from the service providers to encourage appropriate follow through activities in between sessions.

Modeling appropriate play and recommending follow through activities were strategies used by the service providers to enhance collaboration with the child’s family. Again, the utilization of text messaging, sending videos, and communicating with the child’s nursing staff was beneficial if the child’s caregivers were absent during EI sessions.

Use of Materials

The final subtheme identified within best practices was the use of materials found within the home environment. Samantha (SC) reported that service providers should use materials found “within the child’s natural environment.” Jenn (DTH) and Jackie (OT) indicated they mostly used household materials in their sessions, such as toys found available within the home, because the child demonstrated “familiarity and preference” to those items. Ann (CG) discussed the use of household items during Kevin’s EI sessions.

We used loofahs and balloons or a lot of textures. Like a dish scrubbie or rice and beans. Anything that can be a texture or a visual. Anything that was red in our home or orange in our home we would bring into his room and use. I think that is definitely something we did learn was how so many everyday items can be turned into a therapy item.

All participants indicated some items were brought into the home to “work on certain skills” with Kevin. Those items, along with equipment, were often loaned to the family so they could continue with the same activities in between sessions as well.

Co-Treating

Data analysis identified co-treating as the third theme. For the purpose of this study, co-treating was defined as when two or more service providers work simultaneously while providing a therapeutic session for a specific child. Jackie (OT) shared her experience of co-treating with the vision developmental therapist while working with Kevin.

I would do a lot of the positioning and strengthening activities or facilitate reaching or grabbing for an object or hand eye coordination while the vision therapist worked on proper placement of visual input and finding activities and toys that would help the child be able to focus.

Jackie (OT) also shared that she occasionally co-treated with Kevin's hearing developmental therapist and physical therapist. With the physical therapist, she stated that they "conferred on equipment and proper positions."

Jenn (DTH) described her co-treating experiences during EI sessions with Kevin.

When I first started seeing the child I would go with the vision specialist to his home and we would provide services together. There were also times that I would co-treat with the occupational therapist while she was there. Usually it was kind of a joint activity where one therapist would be doing one thing and then maybe another therapist would jump in and do something else.

Participants' discussions concerning co-treatment focused on three areas of key interest including: 1) the process as to how the decision was made to co-treat or not co-treat, 2) the value of co-treating, and 3) the concerns of co-treating.

Decision Process

The first identified subtheme was related to how the decisions were made about whether service providers engaged in co-treating or not. The service coordinator reported co-treating was "always an option" of service delivery on Kevin's IFSP. It was written as a strategy to make progress towards all of the IFSP outcomes so the service providers could co-treat if decided. However, a discrepancy in the participants' responses regarding how the decision to co-treat was

made was identified. Samantha (SC) and Jenn (DTH) indicated the decision for therapists to co-treat was mainly made because it was “easier for scheduling.” However, Ann (CG) and Jackie (OT) shared the decision was made by the family and therapists together because of the benefits co-treating provided. Also, while Samantha (SC) indicated Kevin’s family shared “no opinion” as to whether they preferred co-treating or not, Ann (CG) reported she did provide input as to what therapies she thought would be best to co-treat and which disciplines she did not want co-treating.

Perspectives on how the decision to co-treat was made differed among participants. Ease of scheduling, benefits of co-treating, and caregiver choice were identified as deciding factors.

Value

The benefits of service providers co-treating was identified as the second subtheme within co-treating. Ann (CG) shared having certain therapists co-treat was a benefit because they “went well together.” She explained “vision and hearing I felt went very well together and it was a benefit to have them co-treating” since Kevin had a dual sensory loss. Both service providers discussed the benefits of co-treating with other disciplines. Jackie (OT) talked about the benefit of co-treating with other service providers while working with Kevin.

I think the family saw some value in the co-treats with certain disciplines to be able to get the most out of an activity. Also, to just get everyone on the same page once in a while with what they were doing and so people could follow through in their sessions with the same position or toy and things like that.

Jenn (DTH) and Jackie (OT) also found value in co-treating while working with Kevin because they were “able to get other service providers’ opinions on positioning, placement of materials” and by doing so they were “working as a team.” Jenn (DTH) shared her experience of working with the occupational therapist.

With the occupational therapist, sometimes I would be questioning her more on positioning...getting her professional opinion on what we could expect and could not expect when he was playing and looking at toys and what he could hold, what he could reach for, and things like that.

Jenn (DTH) also shared she felt co-treating was a benefit to Kevin's family because it was "easing it up on them because they had many therapists a day."

Service providers felt co-treating enhanced collaboration because they were able to work together and obtain and/or share professional opinions. Reducing the number of therapy appointments was also identified as a benefit to co-treating for the families.

Concerns

Although benefits to service providers co-treating were identified, concerns were shared as well which led to the identification of the third subtheme. All participants voiced concerns with service providers co-treating. Although Samantha (SC) did not have any specific concerns to share with Kevin's case, she discussed some general concerns shared by families in EI regarding co-treating. She stated families often indicate they are against service providers co-treating because they feel they "miss out on a session", they want "one-on-one time with therapists", and they are "paying for two sessions but ultimately only receiving one." Ann (CG) shared similar concerns with some of Kevin's service providers co-treating. She explained it was suggested for the developmental therapist to co-treat with another therapist that she could not recall at the time of the interview. She stated:

I didn't think that was to Kevin's benefit because he wouldn't have received as much therapy and I didn't think that they were able to focus on his needs to co-treat. So, I requested that those to not be together.

Jenn (DTH) and Jackie (OT) also talked about other concerns with co-treating. Jackie (OT) reported that certain disciplines "don't work well together due to activities", such as a physical therapist and a hearing specialist. Jenn (DTH) shared similar concerns. She stated Kevin

easily became “overwhelmed” as it was difficult for him to remain attentive in different positions. “Personality conflicts” among service providers was also identified as a concern for co-treating. Jenn (DTH) and Jackie (OT) indicated not all service providers have personalities conducive to successful co-treating.

Some concerns shared with co-treating included less therapy for the child and inability of the service providers to focus on the child’s needs. Overwhelming the child and personality conflicts were also identified as reasons co-treating may not be beneficial.

Knowledge

The fourth subtheme revealed via data analysis was knowledge. Collaboration may be hindered when the family may not feel as if they are being supported or given all the necessary information to make appropriate decisions for their child. Ann (CG) identified a strong need for advocacy for new families enrolled in EI to help them understand the services and resources available. As she reflected on her own personal experiences, she shared her perceptions on what a family needs as they begin receiving services for their child in EI.

You wish as a special needs parent that somebody would be advocating for you. Somebody that was telling you your rights. Telling you what the options are and really just somebody that wanted to help you. Not “this is how it is” or “this is what we can offer you because we are understaffed and underpaid and overworked.” It’s very overwhelming in the beginning of the special needs journey.

Having the knowledge of available resources and services promotes collaboration among caregivers and EI professionals. Data analysis uncovered two subthemes within knowledge. Participants discussed how the two following topics impacted collaboration in regards to knowledge: 1) the understanding of the availability or selection of services in EI and, 2) medical information or terminology.

Services

Helping caregivers understand their options and availability of service providers was identified as the first subtheme within knowledge. Families receiving services in EI are to be given options of available personnel who provide services in their area. Ultimately, caregivers make the final decision as to which providers they would like to come into their home and work with their child. Availability of services or the selection of service providers was discussed in depth. Jackie (OT) and Ann (CG) agreed families may be limited in their choices due to not being well informed by EI professionals. Ann (CG) shared her story of how service providers were chosen when they started receiving EI services for Kevin.

I don't think I even had a choice. We may have been given an option of two different organizations at the beginning. I just thought everyone came from Agency A. I didn't really understand there was private therapists that we could look at or there was other agencies even. I didn't realize until later that you could really pick and choose your therapists. I mean we just knew they were sending us those therapists and that is who we used.

Jackie (OT) also shared her perceptions on the choices families are provided with in regards to selecting service providers.

I think it's more the family is presented with a list but the family doesn't know anyone from that list. So, I think for the most part families don't have a choice. It's not because they are not completely offered a choice. It's just they don't understand their choice fully nor do they have the knowledge sometimes to ask around.

Furthermore, Jackie (OT) discussed concerns with service coordinators using the same IFSP teams for multiple children rather than giving the family a choice of different providers. She explained it is "not uncommon" for the same team members to share multiple IFSPs and frequently the service providers are from the same agency. Jackie (OT) stated that she knows "it makes life easy sometimes to have everyone from the same agency but sometimes it is not the best fit for the family either."

Participants also talked about how the availability of service providers may play a role in the selection process. Jackie (OT) discussed how “first available” is often how service providers are selected.

I think most families do first available because schedules are really tight for a lot of therapists and unless they come in with a recommendation for somewhere else or they worked with a therapist before, they don't really know who to choose.

Having the knowledge to request a change in service providers was also discussed. Jackie (OT) was not the initial occupational therapist to work with Kevin. Ann (CG) shared that in the beginning, she and her husband did not know they could ask for a change in therapists.

We didn't know there was an option to change. Just because you want a change doesn't mean the therapist is bad, they just may not connect with your child. You're just not really given that knowledge and sometimes you're just so overwhelmed that when they send you someone, you just take it. I think parents should know what options are out there rather than just what you're given.

Jenn (DTH) and Jackie (OT) discussed their role when a family expresses concern with certain service providers. Both participants reported they encourage the caregiver to talk with their service coordinator and inform the family of their rights.

The caregiver voiced concerns with not having the knowledge regarding the availability and options of service providers. A service provider expressed concerns with families not being provided with choices. Choosing service providers based on first availability or agency affiliation may not be the “best fit for the family.”

Medical

Assisting families with understanding medical reports and terminology was identified as the second subtheme under knowledge. Although Kevin's family was reported to have “had a good understanding” and were “pretty knowledgeable” of his medical diagnoses, all participants

indicated they assisted the family with any medical reports and terminology they had difficulty understanding. Jenn (OT) described her role with assisting the family.

I feel, especially with the specialists in hearing and vision, that's a big part of our job. Our job is to help the family deciphering those reports and the child's needs and helping the family understand the terminology.

Ann (CG) shared her experiences with service providers helping her and her husband understand Kevin's medical reports.

I think the therapists were very instrumental in helping us understand some of that stuff because the doctors are, you know, more of the medical but then when you bring it home you have to put in motion. The therapists kind of took over at that point.

Jackie (OT) talked about how she was able to help Kevin's family with understanding equipment needs. Jackie (OT) expressed her thoughts on this topic.

You have to go through the reports with them and help them understand what a diagnosis is or a procedure or a piece of equipment too. That may be something that therapists can be more equipped to help families understand. Their child may need certain equipment such as a stander, walker, or whatever.

Ann (CG) went on to further explain how Kevin's service providers helped them understand Kevin's diagnoses and what they meant in terms of his development and needs. She stated she developed a better understanding of "things he was or was not able to do" and what that meant "long term" for him.

Although all participants reported that the caregiver was knowledgeable and understood her child's medical reports, the service providers were able to assist with clarifying terminology related to their discipline, diagnoses, and development expectations. In addition, service providers were able to assist the child's family with understanding equipment needs.

Respect

Data analysis identified respect as the final theme impacting collaboration. Families in EI need to be able to trust the EI professionals and feel respected in order to have successful

collaboration and experiences. Ann (CG) shared she felt Kevin and her family were “given wonderful resources.” She stated they had a “good working relationship” with Kevin’s service providers because they were “very engaged” and “genuinely cared.”

Jenn (DTH) and Jackie (OT) shared similar stories about how to obtain the family’s trust. They both indicated finding out the “family’s expectations” and “listening to their needs” is vital in developing a positive relationship with the family. Jenn (DTH) also discussed the need for service providers to share their expectations with the families as well so that they have a better understanding of their role in EI.

Jackie (OT) discussed the need for service providers to work closely with the family and respect their choices. She talked how the entire team needs to be “cognizant” of when the child has other scheduled therapies or when it works best for the family. She described how being flexible when scheduling can be accomplished:

Just take into account that if someone has physical therapy at 9:00 then doing OT for feeding right after may not be a good choice. Just everyone looking more collaboratively, looking at schedules, and doing what is best for their child.

Ann (CG) also shared scheduling many therapies was “difficult” but most service providers were able to schedule when she was home or during Kevin’s “most attentive alert time.” Jackie (OT) also provided insight to improve collaboration among team members from different agencies while respecting the family’s choice. She stated the following:

Teams should work together rather than against each other as far as, you know, this agency versus that agency or whatever. Your team is the team that your family chose and that’s kind of what we all need to accept. Work with everyone’s strengths and weaknesses and schedules and everything else.

Participants discussed the importance of respecting the family’s choice regarding selection of service providers. Also, flexibility in scheduling, sharing expectations, and listening

to the family's concerns were reported to be factors that enhanced collaboration among IFSP team members.

Conclusion

Collaboration among EI professionals and caregivers influences the success of experiences in Early Intervention. The caregiver participant reflected on her EI experiences with her son and shared factors that either hindered or promoted collaboration. A service coordinator and two service providers discussed collaborative practices that impacted collaboration among all members on a multidisciplinary team. These factors fell into five categories: 1) communication, 2) best practices, 3) co-treating, 4) knowledge, and 5) respect.

Participants discussed the best methods of communication with team members from different agencies. The caregiver and EI professionals shared methods of communication they perceived as most effective and efficient to collaborate with other team members. EI professionals explained the importance of maintaining communication with the family and keeping them involved in their son's development especially if they were unable to attend EI sessions. In doing so, they shared strategies to promote caregiver participation through modeling appropriate play, recommending follow through activities, and utilizing materials found within the child's natural environment.

EI professionals and the caregiver also discussed various factors that promoted collaboration among all team members. Several experiences and strategies were shared. Service providers detailed the benefits of co-treating with professionals however, concerns were shared as well. Receiving less therapy time and overwhelming the child were the main concerns of service providers co-treating. The caregiver shared frustration with not being provided with pertinent information regarding services but discussed, along with the service providers, how EI

professionals were valuable in helping them understand their choices and medical information. Lastly, all participants discussed how respecting the family's concerns, schedules, and decisions impacted collaboration.

These four participants shared many stories about their experiences while working with the same child in EI. They also offered suggestions to improve collaboration among multidisciplinary team members as well as between EI professionals employed by different agencies. Their ability to openly discuss their personal experiences and concerns has helped to answer the research questions. It is hoped their willingness to share their unique experiences may help bring improvement to collaboration among multidisciplinary team members receiving or providing services in EI.

CHAPTER V: DISCUSSION

Effective collaborative practices among caregivers and EI professionals is essential to promote a child's development and have successful EI experiences. Consistent with previous research, the findings of this study expanded the current knowledge by exploring caregivers' and EI professionals' perceptions on collaboration with multidisciplinary teams in EI. Collaboration factors and concerns shared by the four participants are discussed in connection with the existing literature. The contents of this chapter focused on the five major themes that emerged from this study and include: 1) communication, 2) best practices, 3) co-treating, 4) knowledge, and 5) respect. In addition, limitations, implications for practice, and future research ideas are included within this section.

The four participants in the study shared an IFSP for a child who received EI services within the last year. The child's caregiver (mother), occupational therapist, and developmental therapist/hearing specialist, and service coordinator were interviewed. All participants shared their collaboration experiences while being a part of a multidisciplinary team that included EI professionals from different agencies. The findings within the five identified themes will be discussed.

Communication

The first theme identified was communication. During the interviews for this study, all four participants discussed how communication was maintained among EI professionals and the caregivers. Previous research has demonstrated that communication directly impacts collaboration among team members (Bailey et al., 1994; Dinnebeil et al., 1996, 1999; Yang et al., 2013). Such studies have shown infrequent communication negatively affects collaboration with families and EI professionals. All participants in the current study agreed that minimal

communication occurred with the service coordinator whereas the majority of consistent communication occurred between the caregiver and service providers. In addition, EI professionals expressed it was easier to maintain communication with other service providers if they saw them on a regular basis. Email chains were reported by all EI professionals as being the most used method of communication among service providers but shared concerns with the lack of relevant information when using email.

The caregiver and service providers talked about how they were able to maintain communication to schedule appointments or to share information. This was of particular importance when the caregiver was not able to be present for EI sessions. One service provider shared how sending pictures to the parent during EI sessions helped with keeping the parents involved if there were conflicts with scheduling and they could not be present. Both service providers also talked how the child's nursing staff helped communicate relevant information to the child's parents or other service providers.

Best Practices

Another theme identified was best practices. Previous research has indicated collaboration is enhanced when a family-centered approach is implemented and family engagement is promoted (Block & Block, 2002; Dunst et al., 1988; Tomasello et al., 2010). The participants in the current study discussed the caregiver's role in the development of IFSP outcomes, caregiver participation in EI sessions, service providers' willingness to model appropriate play and recommend follow through activities, and use of materials within the child's home.

All participants agreed that the family was involved in the development of the child's IFSP outcomes. They reported the child's IFSP outcomes were "family oriented" and based on

the concerns, needs, and priorities voiced by the family. As previous research has demonstrated, collaboration is enhanced when families feel EI professionals trust and respect their decisions (Dinnebeil et al, 1996; Hiebert-Murphy et al., 2011; Sabatino, 2001). Furthermore, results of the study indicated service providers assisted the caregiver with identification of the next steps of the child's development and appropriate wording of the IFSP outcomes.

Participants also discussed the participation level of caregivers during EI sessions. Johnson et al. (1994) specifically indicated collaboration is promoted between EI professionals and caregivers when "an atmosphere that encourages active participation and engagement" is created (p. 27). Although there was a discrepancy as to how often the child's caregiver was present, all participants agreed that the caregiver was involved in her child's development and kept in contact with service providers to learn what happened during EI sessions. In addition, service providers shared how the child's full time in home nursing staff often participated in the child's EI sessions, especially in the caregivers' absence.

Furthermore, all participants reported service providers modeled appropriate play and recommended follow through activities to implement within the child's daily routine. Encouraging families to participate in daily routines that are not altered from their typical schedule has also been found to promote collaboration among team members (Segal & Beyer, 2006). In addition, most of the materials used in EI sessions were items found within the child's home. Service providers did agree that items were loaned to the family to encourage progress in development of certain skills and use within the child's daily routine.

Co-Treating

Co-treating, the third theme identified, was also discussed by the participants during the interviews. Concerns shared with co-treating included loss of therapy time, inability to focus on

the child's needs, and possible conflicts between therapists. Although there were concerns shared, the caregiver did report that she thought certain disciplines worked well together and it was a benefit to have them provide services for her child at the same time. The service providers also discussed how co-treating enabled them to learn from other professionals and carry through recommendations into their sessions. This is significant for collaboration not only among professionals but with families as well. According to Dinnebeil et al. (1999) and Blue-Banning et al. (2004), working with other professionals and enhancing skills in areas of expertise communicates to families that professionals value their time, regard them more than a case, want to get more than the minimum amount done, and have a desire to work with the family and their child.

Knowledge

Knowledge was the fourth theme identified. A number of previous studies have indicated a lack of knowledge regarding program related issues as a barrier to collaboration (Dinnebeil et al., 1996; Hiebert-Murphy et al., 2011; Shannon, 2004; Yang et al., 2013). Such studies have indicated collaboration between families and EI professionals is impacted negatively when they are offered services based on availability rather than what the child needs. All participants interviewed in this study shared similar concerns. In fact, the caregiver shared her experience of not knowing what their choices were regarding service options until they had been involved in EI for one year. Service providers discussed how they believe families often are not aware of their options and agree to "first available" rather than seeking opinions on who may be a better fit for their child and family.

Helping families understand medical reports was also discussed in the interviews. EI professionals agreed that the family was very knowledgeable in this area and needed minimal

support. Participants did agree however, that EI professionals were able to assist the family in unknown medical terminology or equipment needs. Previous research has documented that families feel supported when EI professionals help decipher medical information (Dinnebeil et al., 1996; Hiebert-Murphy et al., 2011).

Respect

Respect emerged as the final theme when participants shared their experiences of working with individuals on a multidisciplinary team. The caregiver reported that she felt her child's IFSP team supported her family, provided wonderful resources, and listened to her needs and concerns. Similar findings were identified in a study conducted by Blue-Banning et al. (2004). In the current study, one service provider also indicated the importance of being respectful to all team members. Respecting each other's schedules and professional opinions is needed for teams to work together regardless of agency affiliation. Previous research has had similar findings. Collaboration has been found to be negatively impacted when EI professionals from different agencies lack flexibility in scheduling or commitment to communicate with team members outside of their agency (Dinnebeil et al., 1999; Johnson et al., 2003; Yang et al., 2013).

Limitations

While this study provided significant perceptions of collaboration practices among stakeholders on a multidisciplinary team in EI, some limitations were identified. One notable limitation was the geographical restriction. The recruitment of participants was restricted to central Illinois, which is not representative of all families receiving EI services in Illinois or throughout the country. In addition, the participants of the study provided and/or received EI services in a non-rural community. Therefore, the results of the study may not be generalized to represent the perceptions of stakeholders in EI nationwide.

Along with geographical limitations, it would have been helpful if a more diverse group of participants would have been included in this study. All of the participants in the study were female, the male perspective on collaborative practices in EI was absent. The perspectives of male family members or EI professionals would have added insight to this study. In addition, the three EI professional participants had worked in their current jobs for an average of 9 years. Although experience was important to the study, the perceptions of novice EI professionals were missing. Lastly, the average age of the EI professionals in this study was 39 years. Along with novice EI professionals, younger EI professionals may have shared different perceptions on collaboration with larger IFSP teams and family units.

Finally, this study would have had more depth if the number of participants were not so limited. While four team members on a multidisciplinary team were interviewed for this study, it would have been helpful to interview at least three multidisciplinary teams. In addition, interviewing more individuals with various roles on a multidisciplinary team would have been beneficial. The recruitment and participation of more IFSP teams and team members would have added beneficial insight to collaborative practices in EI.

Implications for Practice

The results of this study have identified a number of key messages for individuals involved in Early Intervention programs. Suggestions for improvements in identified areas of need would be beneficial to improve the collaborative practices among caregivers, EI service providers, EI service coordinators, EI program managers, and agencies employing EI professionals.

Consistent with previous research (Johnson et al., 1994), the parent in this study reported that collaboration is negatively affected when relevant information is not provided. Caregivers in

EI would benefit from information that clarifies the structure of the EI system, roles and responsibilities of EI professionals, and the expectations of parents and professionals of a family-centered practice. In addition, families would benefit from not only knowing what services exist but the options they have when making the decisions as far as who provides the service and the frequency of service. This finding supports the need for program managers in EI to develop and implement family education programs. Caregivers may be more engaged and collaboration with EI professionals may be enhanced if families were aware of the structure of the EI program in addition to their rights and responsibilities as recipients of EI services.

EI professionals interviewed for this study voiced concerns with communication among IFSP team members. Participants reported communication was difficult particularly for service providers who do not have the opportunity to see each other on a regular basis. In previous research, Dinnebeil et al. (1996) identified “infrequent communication” as a barrier to collaboration. EI professionals on multidisciplinary teams would benefit from monthly or bi-monthly meetings. Dinnebeil et al. (1999) suggested program managers need to create ways for communication to be shared among various team members. Regular meetings would enable EI professionals to share relevant information and support various disciplines by carrying over recommendations into their own sessions. It would also be beneficial for service coordinators to participate in the monthly or bi-monthly meetings in order to obtain new medical and development progress reports. Therefore, this finding supports the need for EI professionals to implement regularly scheduled face to face or teleconference meetings to enhance collaboration among the team and better support the families.

Another finding of the study demonstrated a concern with the scheduling of appointments which aligned with previous research conducted by Dinnebeil et al. (1999). Service providers in

the study reported that although the family was involved in their child's progress, they were often not present for EI sessions. EI professionals also reported concerns with scheduling appointments around other disciplines so that the child did not become overwhelmed. Flexibility in scheduling would benefit all stakeholders. In doing so, caregivers would have the opportunity to be present and participate in their child's sessions. In addition, the child would benefit if service providers coordinated their sessions to eliminate the possibility of the child becoming overwhelmed or fatigued so that optimal learning could occur. Therefore, scheduling appointments around the family and child's needs would promote collaboration between EI professionals and caregivers.

Future Research Ideas

There continues to be a need for future research to examine collaborative practices among multidisciplinary teams. First, future research needs to include participants in rural and urban areas to capture the perceptions of collaboration among stakeholders. There is also a need to interview multiple multidisciplinary IFSP teams in order to compare and contrast their perceptions on collaborative practices. In addition, it would be beneficial for future research to include male family members, family members with varied years of experience in EI, and novice EI professionals. By including a more diverse group of participants, future research could reveal a more comprehensive understanding on collaborative practices that either promote or hinder collaborative practices on multidisciplinary teams in EI.

Furthermore, to gain a better understanding of collaborative practices with caregivers, future research may need to focus on the relationship between families and service coordinators. Such research studies would include family education regarding roles and responsibilities, structure of the EI system, expectations, and service delivery options. More in depth experiences

concerning the provision of family education upon entering the EI system may provide EI professionals with valuable information that will assist them in promoting collaboration with families in the future.

Finally, further investigation into factors that either hinder or promote collaboration among multidisciplinary team members is necessary. Research studies that focus on co-treating strategies among service providers may provide valuable information to guide EI professionals in implementing similar strategies. In addition, strategies implemented to promote communication among service providers employed by different agencies would be beneficial as well. Similarly, research studies focusing on action plans to promote caregiver participation and follow through would add insight to the field on successful collaborative practices.

In conclusion, successful collaborative practices among caregivers and EI professionals are critical for optimal growth and development. It is important for stakeholders to understand the perspectives on collaboration of others on the multidisciplinary team. From the perspective of a small group of stakeholders, this study added to the existing literature by expanding current knowledge about collaborative practices among EI professionals and caregivers on multidisciplinary teams. The four participants shared their experiences of being on an IFSP for the same child who received services from multiple disciplines and from different agencies. They also openly shared suggestions to improve collaboration among stakeholders. The goal of successfully meeting the unique and diverse needs of each family in EI will be enhanced when caregivers and EI professionals consider each other's perspectives on collaboration.

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APPENDIX A: SERVICE COORDINATOR PARTICIPATION

To whom it may concern:

My name is Sara Edwards and I am a graduate student at Illinois State University. With your permission, I, along with my advisor, Dr. Sharon Doubet from the College of Education at Illinois State University, would like to invite you to participate in a research project.

In this project, I will interview five team members who share an Individualized Family Service Plan (IFSP). Specifically, I will interview the child's caregiver, the service coordinator, and three service providers of various disciplines and employed by different agencies. The IFSP team chosen to participate in the study will submit signed consent and information forms.

I would like the opportunity to ask IFSP team members questions so that I can learn more about the collaboration experiences in Early Intervention. In order to recruit participants whose confidentiality is protected, I am requesting your assistance in randomly selecting five IFSPs which fit the following criteria:

1. The IFSP is currently or was in effect within the last year.
2. There is one caregiver listed on the IFSP.
3. There is one service coordinator listed on the IFSP.
4. There are a minimum of three service providers listed on the IFSP.
5. A minimum of three service providers have different disciplines.
6. A minimum of three service providers are employed by different agencies or are independent providers.

Once five IFSP teams have been randomly selected, I will provide you with pre-paid postage recruitment packets and ask you to mail the packets to the caregiver and service providers listed on the IFSPs. I will also ask you to obtain a recruitment packet for yourself.

Your participation in this project is completely voluntary and you are free to withdraw your permission for participation at any time and for any reason. Your choice to participate or not will not affect your status within the Illinois Early Intervention system as a professional.

If you consent to voluntarily participate, please print and sign your name on the Service Coordinator Consent Form. You will receive a copy of this consent form. If you have any questions about this research project, please contact Sara Edwards or Sharon Doubet using the information below.

Sincerely,

Sara Edwards
sjedwar6@ilstu.edu

Sharon Doubet
sdoubet@ilstu.edu

APPENDIX B: SERVICE COORDINATOR CONSENT FORM

This is a research project focused on exploring collaboration experiences in Early Intervention (EI) in order to identify factors that promote or hinder collaboration between team members on an Individual Family Service Plan (IFSP). The duration of my participation is expected to be no greater than one hour. I will review my caseload and randomly select five Individualized Family Service Plans (IFSP) which fit the following criteria:

1. The IFSP is currently or was in effect within the last year.
2. There is one caregiver listed on the IFSP.
3. There is one service coordinator listed on the IFSP.
4. There are a minimum of three service providers listed on the IFSP.
5. A minimum of three service providers have different disciplines.
6. A minimum of three service providers are employed by different agencies or are independent providers.

Once five IFSP teams have been randomly selected, I will mail the provided recruitment packets to the caregiver and service providers listed on the IFSP. I will also obtain a recruitment packet for myself.

There are no physical risks but there are minimal psychological or social risks to this research study. My relationships with peers or colleagues, as well as my emotional well being, may be at risk from discussing my experiences in EI. Additionally, there is a slight risk of breach of confidentiality. However, the benefits outweigh the minimal risks because the opportunity to discuss and reflect upon one's collaboration experience in Early Intervention is believed to justify any potential risks.

The information that is obtained during this research project will be kept strictly confidential and locked in a storage cabinet in 526 DeGarmo office at Illinois State University.

Any sharing or publication of the research results related to this study will not identify any of the participants by name, geographical location, or agency.

My participation in this project is completely voluntary and I am free to withdraw my permission for participation at any time and for any reason without penalty or loss of benefits. My decision to participate or not will not affect my status within the Illinois Early Intervention system either as a provider or family.

I consent to voluntarily agree to participate in the research project described above. I will be provided with a copy of this Consent Form.

Signature

Date

Printed name: _____

If you have any questions or concerns about this study, please contact Dr. Sharon Doubet (dissertation chair) at (309) 438-8956 or via email at sdoubet@ilstu.edu. Or you can contact the Illinois State University Institutional Review Board at (309) 438-2529 or via email at ResearchOffice@IllinoisState.edu

Please mail the signed SERVICE COORDINATOR CONSENT FORM

in the stamped/addressed envelope provided.

If you have any questions, please contact Sara Edwards at sjedwar6@ilstu.edu

Or Sharon Doubet at sdoubet@ilstu.edu

Thank you very much!

APPENDIX C: DESCRIPTION OF STUDY

To whom it may concern:

My name is Sara Edwards and I am a graduate student at Illinois State University. With your permission, I, along with my advisor, Dr. Sharon Doubet from the College of Education at Illinois State University, would like to invite you to participate in a research project.

In this project, I will interview five team members who share an Individualized Family Service Plan. Specifically, I will interview the child's caregiver, the service coordinator, and three service providers of various disciplines and employed by different agencies. The IFSP team chosen to participate in the study will submit signed consent and information forms.

I would like the opportunity to ask you questions to learn more about your collaboration experiences in Early Intervention. A short face-to-face interview will be scheduled at your convenience and held at a convenient location. The interview will last approximately one hour and will be audio taped. To protect your privacy and confidentiality, pseudonyms will be assigned to replace your name at the time of the interview. The interviews will be transcribed shortly after the interview. After I have reviewed the transcripts to assure accuracy, I will analyze the data and look for patterns of information across all of the participants' responses. If needed, I will then schedule an approximate 15 minute follow-up interview with you to ask any additional information and to clarify any previous responses. The information we can gain from this study will help us provide support to families and professionals working together in the Early Intervention system.

Your participation in this project is completely voluntary and you are free to withdraw your permission for participation at any time and for any reason. Your choice to participate or not will not affect your status within the Illinois Early Intervention system either as a provider or family. The information that is obtained during this research project will be kept strictly confidential.

Any sharing or publication of the research results related to this study will not identify any of the participants by name, geographical location, or agency. We anticipate minimal risk to you due to your participation in this project. The possible loss of emotional well-being, confidentiality, and relationships with peers and colleagues is outweighed because the opportunity to discuss and reflect upon one's collaboration experience in Early Intervention is believed to justify any potential risks. The results of this interview study may be used for a journal article and conference presentations, again with no identifiable information shared.

If you consent to participate, please print and sign your name in the space provided below. You will receive a copy of this consent form. Also, please fill out the Information Form. If you have any questions about this research project, please contact Sara Edwards or Sharon Doubet using the information below.

Sincerely,
Sara Edwards
sjedwar6@ilstu.edu

Sharon Doubet
sdoubet@ilstu.edu

APPENDIX D: PARTICIPANT CONSENT FORM

This is a research project focused on exploring collaboration experiences in Early Intervention (EI) in order to identify factors that promote or hinder collaboration between team members on an Individual Family Service Plan (IFSP). The duration of my participation is expected to be no greater than 90 minutes. I will participate in a face-to-face interview for approximately 45 to 60 minutes. The interviews will be transcribed shortly after the interview. After the transcripts have been reviewed, I may be contacted to schedule an approximate 15 minute interview to clarify any responses from the initial interview or provide additional information.

There are no physical risks but there are minimal psychological or social risks to this research study. My relationships with peers or colleagues, as well as my emotional well being, may be at risk from discussing my experiences in EI. Additionally, there is a slight risk of breach of confidentiality. However, the benefits outweigh the minimal risks because the opportunity to discuss and reflect upon one’s collaboration experience in Early Intervention is believed to justify any potential risks.

The information that is obtained during this research project will be kept strictly confidential and locked in a storage cabinet in 526 DeGarmo office at Illinois State University.

Any sharing or publication of the research results related to this study will not identify any of the participants by name, geographical location, or agency.

My participation in this project is completely voluntary and I am free to withdraw my permission for participation at any time and for any reason without penalty or loss of benefits. My decision to participate or not will not affect my status within the Illinois Early Intervention system either as a provider or family.

I consent to voluntarily agree to participate in the research project described above. I will be provided with a copy of this Consent Form.

Signature

Date

I am a: _____ Caregiver _____ Service Coordinator _____ Service Provider/Discipline

As a service provider, I am employed by the following agency: _____

I do agree to have the interview audio taped for the purposes of transcription.

Signature

Date

Printed name: _____

If you have any questions or concerns about this study, please contact Dr. Sharon Doubet (dissertation chair) at (309) 438-8956 or via email at sdoubet@ilstu.edu. Or you can contact the Illinois State University Institutional Review Board at (309) 438-2529 or via email at ResearchOffice@IllinoisState.edu

Please mail the signed PARTICIPANT CONSENT FORM and the completed PARTICIPANT INFORMATION FORM in the stamped/addressed envelope provided.

If you have any questions, please contact Sara Edwards at sjedwar6@ilstu.edu

Or Sharon Doubet at sdoubet@ilstu.edu

Thank you very much!

APPENDIX E: PARTICIPANT INFORMATION FORM

Participant Information Form

If you are a caregiver (biological, foster, or adopted parent), service coordinator, or a service provider currently receiving or providing services or have received or provided services within the last year in the Illinois Early Intervention program and wish to be considered as a participant for an interview study, please continue to fill out this form.

This information will be kept confidential, filed separately from the interview transcriptions, and your name will be removed from the interview transcriptions.

1. Name _____

Please list the contact information where you wish to be contacted, either home or work.

Address _____

Phone/email _____

2. What is your primary position?

_____ Caregiver _____ Service Coordinator _____ Service Provider/Discipline

If a service provider, please indicate what agency you are employed by: _____

Please mail the signed PARTICIPANT CONSENT FORM
and the completed PARTICIPANT INFORMATION FORM
in the stamped/addressed envelope provided.

If you have any questions, please contact Sara Edwards at sjedwar6@ilstu.edu

Or Sharon Doubet at sdoubet@ilstu.edu

Thank you very much!

APPENDIX F: RESEARCH PARTICIPANTS

Table F-1

Research Participants

Name	Age	Ethnicity/Race	Role In EI	Years in current job	Type of Agency
Ann	34	Caucasian	Caregiver (CG)		
Samantha	31	Caucasian	Service Coordinator (SC)	6.0	State agency
Jenn	46	Caucasian	Developmental Therapist/Hearing (DTH)	10.0	Non-Profit
Jackie	41	Caucasian	Occupational Therapist (OT)	12.0	Independent

Note. Pseudonyms were assigned.

APPENDIX G: INTERVIEW PROTOCOL

Interview Protocol for Caregivers

Pseudonym:

Interview Location:

Date and Time of Interview:

1. Please tell me about your role in Early Intervention.
2. Are you currently receiving or have you received EI services for your child within the past year?
3. Please identify the EI services your family received, the location of where those services occurred, and frequency of visits.
4. The topic I want to talk to you about now is co-treating. Co-treating occurs when two or more therapists provide services at the same time. Do or did any of your therapists co-treat?
 - a. If yes, please describe the co-treating experience including how often and with whom the co-treats occurred.
 - b. If no, how was the decision made to not include co-treating?
 - c. If no, had you ever considered co-treating as an option?
5. Now I would like to discuss the scheduling of your child's therapy sessions. Are or were your child's therapy sessions scheduled at times when you could participate?
 - a. If yes, please describe where and when the sessions took place so that you could participate.
 - b. If no, how was the decision made regarding the times and locations of your child's therapy sessions?
6. Regarding the development of your child's IFSP goals, are or were the outcomes based on your family's concerns and priorities?
 - a. If yes, please describe how you were included in developing your child's goals.
 - b. If no, how are or were your child's IFSP goals developed?
7. Now I would like to discuss your role during the therapy sessions. Do or did your child's therapists include you in therapy sessions?
 - a. If yes, please describe in what ways you were included.
 - b. If no, would you have liked to be included and in what ways?
8. The topic I would like to discuss now is the use of household items and consideration of your child's daily routines.
 - a. Do or did your child's therapists suggest activities for you to do with your child throughout your daily routines?
 - i. If yes, please describe how the activities were decided.
 - ii. If no, would you have liked to receive suggestions as to how to work on skills within your child's daily routines and why?
 - b. Do or did your child's therapists use available toys or materials within the home during therapy sessions?

- i. If yes, please describe in what ways they used toys or materials already available within your home.
 - ii. If no, please describe what materials were used during therapy sessions.
 1. If the therapist brought in materials, then were they left in the home on loan or given to you (such as assistive technology funded by EI)?
9. In regards to playing with your child, do or did the therapists show you how to play with your child to meet his/her IFSP goals?
 - a. If yes, please describe in what ways they helped you play with your child so that he/she may achieve his/her IFSP goals.
 - b. If no, in what ways do you feel the therapists could have helped your family?
10. Now I would like to discuss your understanding of medical information and reports. Do or did your child's therapists help you understand medical information and reports?
 - a. If yes, in what ways did your therapists help you understand the medical terminology, your child's diagnosis, etc...
 - b. If no, in what ways do you feel therapists could have helped you understand the medical information you received from reports or appointments?
11. What suggestions do you have that would make therapies more beneficial for your child and family?

Interview Protocol for Early Intervention Service Providers

Pseudonym:

Interview Location:

Date and Time of Interview:

1. Please tell me about your role in Early Intervention.
2. Are you currently providing or have you provided EI services for (identified family) within the past year?
3. Please identify your area of discipline, where you provided services for (identified family), and frequency of visits.
4. The topic I want to talk to you about now is co-treating. Co-treating occurs when two or more therapists provide services at the same time. Do or did you co-treat with any therapists?
 - a. If yes, please describe the co-treating experience including how often and with whom the co-treats occurred.
 - b. If no, how was the decision made to not include co-treating?
 - c. If no, had you ever considered co-treating as an option?
5. Now I would like to discuss the scheduling of the child's therapy sessions. Are or were you able to schedule your therapy sessions with this child at a time when the caregiver could participate?
 - a. If yes, please describe where and when the sessions took place so that the child's caregiver could participate.

- b. If no, how was the decision made regarding the times and locations of this child's therapy sessions?
- 6. Regarding the development of this child's IFSP goals, are or were the outcomes based on the family's concerns and priorities?
 - a. If yes, please describe how the caregivers were included in developing their child's goals.
 - b. If no, how are or were the child's IFSP goals developed?
- 7. Please tell me about the caregiver participation level during therapy sessions.
- 8. The topic I would like to discuss now is the use of household items and consideration of the child's daily routines for implementation of strategies to work on particular skills.
 - a. Do or did you suggest activities for the caregiver to do with their child throughout their daily routines?
 - i. If yes, please describe how the activities were decided.
 - ii. If no, have you considered suggesting activities? Why or why not?
 - b. Do or did you use available toys or materials within the home during therapy sessions?
 - i. If yes, please describe in what ways you used toys or materials already available within the family's home.
 - ii. If no, please describe what materials were used during therapy sessions.
 - 1. If materials were brought into the home, then were they left in the home on loan or given to the family (such as assistive technology funded by EI)?
- 9. In regards to showing how the caregiver to play with their child to meet his/her IFSP goals, do or did you coach the caregiver in this area?
 - a. If yes, please describe in what ways you helped the caregiver play with their child so that he/she may achieve her/his IFSP goals.
 - b. If no, have you considered showing the caregiver how to play with their child and in what ways?
- 10. Now I would like to discuss the family's understanding of medical information and reports. Do or did you help the family understand medical information and reports?
 - a. If yes, in what ways did you help the family understand the medical terminology, the child's diagnosis, etc...
 - b. If no, have you considered helping the family understand medical information from reports and appointments and in what ways?
- 11. What suggestions do you have that would make therapies more beneficial for families?

Interview Protocol for the Early Intervention Service Coordinator

Pseudonym:

Interview Location:

Date and Time of Interview:

1. Please tell me about your role in Early Intervention.
2. Are you currently providing or have you provided EI services for (identified family) within the past year?
3. Please describe how often you contact or contacted the caregiver and service providers to monitor services, concerns, etc... and the type of contact that is or was made (telephone, in person, face-to face).
4. The topic I want to talk to you about now is co-treating. Co-treating occurs when two or more therapists provide services at the same time. Are or were you aware of any therapists co-treating with this child?
 - a. If yes, please describe what was shared about the co-treating experience for the caregiver and service providers.
 - b. If no, how was the decision made to not include co-treating as a strategy on this child's IFSP?
 - c. If no, had co-treating ever been discussed among the IFSP team members?
5. Now I would like to discuss the scheduling of the child's therapy sessions. Are or were you aware of therapy sessions being scheduled at times when the caregiver could participate?
 - a. If yes, please describe what was shared about the scheduling experience for the caregiver and service providers.
 - b. If no, how was the decision made regarding the times and locations of this child's therapy sessions?
6. Regarding the development of this child's IFSP goals, are or were the outcomes based on the family's concerns and priorities?
 - a. If yes, please describe how the caregivers were included in developing their child's goals.
 - b. If no, how are or were the child's IFSP goals developed?
7. Please tell me about the caregiver participation level during therapy sessions (if known) and IFSP meetings.
8. The topic I would like to discuss now is the use of household items and consideration of the child's daily routines for implementation of strategies to work on particular skills.
 - a. Are or were you aware of therapists' suggesting activities for the caregiver to do with their child throughout their daily routines?
 - i. If yes, please describe how the activities were decided.
 - ii. If no, have you considered suggesting activities? Why or why not?
 - b. Are or were you aware of therapists using available toys or materials within the home during therapy sessions?

- i. If yes, please describe in what ways therapists used toys or materials already available within the family's home to develop IFSP strategies.
 - ii. If no, please describe what materials were used during therapy sessions.
 1. If materials were brought into the home, then were they left in the home on loan or given to the family (such as assistive technology funded by EI)?
9. In regards to the caregiver playing with their child, are or were you aware of therapists showing the caregiver how to play with their child to meet his/her IFSP goals?
 - a. If yes, please describe in what ways therapists implemented strategies to help the caregiver play with their child so that he/she may achieve his/her IFSP goals.
 - b. If no, in what ways do you feel therapists could have helped the family?
10. Now I would like to discuss the family's understanding of medical information and reports. Do or did you help the family understand medical information and reports?
 - a. If yes, in what ways did you help the family understand the medical terminology, the child's diagnosis, etc...
 - b. If no, have you considered helping the family understand medical information from reports and appointments and in what ways?
11. What suggestions do you have that would make therapies more beneficial for families?