EXPLORATION OF FAMILY-CENTERED APPROACH TO EARLY INTERVENTION:

PERCEPTIONS OF EARLY INTERVENTION PROFESSIONALS

by

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The purpose of the present research study was to gain a better understanding of the framework of Family Centered Practice (FCP) in Early Intervention (EI). FCP is considered best practice in EI service delivery. Due to the lack of empirical research regarding FCP in EI, the current research study surveyed participants' perception of FCP in EI. Participants (N=53) were employees throughout sixteen Children's Developmental Services Agencies (CDSA) in the state of North Carolina. Participants completed a modified version of the Family-Centered Care Self-Assessment Tool (FCC-SAT). Consistent with former research, results highlight that EI professionals perceive that their own work is family-centered. Since EI is mandated by federal law, findings underscore the importance of FCP in this field, not only in North Carolina, but throughout the United States.

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CHAPTER 1: INTRODUCTION

Over the last few decades, the family-centered approach began to dominate service delivery of early intervention professionals. These professionals include both service coordinators and service providers. This family-centered approach began to guide the majority of services to young children and their families, especially in health and developmental environments such as early intervention agencies/services across the United States. Previously, early intervention (EI) was guided by a child-centered approach. Early intervention provides services for children and families when a child has a developmental delay or serious medical conditions that may lead to developmental delay or secondary disability (NC Infant-Toddler Program, n.d.). According to Part C National Program Data (2017), the number of children receiving EI services in 2016 was 357,715. Thus, the network of EI services for children and families is large in the United States of America, and is shown to be successful.

The recommended approach for providing services to young children and families is based on family-centered practice (FCP), since this is reported to be the best practice (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013; Tomasello, Manning, & Dulmus, 2010). According to the NC Infant-Toddler Program (n.d.), "The earlier you know, the better they'll grow" is the life strategy that encompasses the purpose of early intervention (EI) programs across the US. Moreover, these programs are designed to promote optimal development of children with disabilities, minimize existing developmental delays, prevent secondary disabilities, and promote the optimal development of children with developmental delays and/or disabilities.

By being enrolled in EI services, the child receives the direct service; however, family members are also involved. FCP is operationalized as acknowledging children with special

needs and recognizing the pivotal role that families play in this early intervention philosophy (Dunst & Trivette, 1996). As a result, in concurrence with FCP philosophy of EI services, professionals must recognize this pivotal role that families play in a child's life, while planning EI interactions and interventions. By doing so, EI professionals implement FCP by providing family support and allowing parents to make educated decisions.

According to Moeller, Carr, Seaver, Stredler-Brown, and Holzinger (2013), family-centered practices in early intervention often focus on families' strengths, while encouraging positive communicative interactions, family well-being, engagement, and self-efficacy. Research supports that a family-centered approach is most promising for addressing developmental delays and other problems due to the process of early identification because parental concerns are as accurate as other screening methods and questionnaires (Hielkema, de Winter, de Meer, & Reijneveld, 2011). Therefore, FCP is relevant because one purpose of early intervention is acknowledging developmental delays as soon as possible, and enhancing the development of these infants and toddlers, by developing an Individualized Family Service Plan (IFSP) (P. L. 108-446).

Through the development of the IFSP, service coordinators are responsible for implementing and delivering the services in line with FCP. The purpose of this study is to explore EI professionals' perceptions of family-centered practices, and investigate the extent to which EI professionals implement family-centered practices in EI services, by specifically reviewing EI professional's perceptions of decision making and family support. By understanding these perceptions, this research will help to explore gaps in FCP service delivery and guide the family-centered service delivery approach to its full potential, which will align with best practices for early intervention.

CHAPTER 2: LITERATURE REVIEW

Throughout the past few decades, early intervention has shifted from a child-centered approach to a family-centered approach (Ponzetti, Charles, Marshall, & Hare, 2008). When early intervention was considered child-centered, the child was the focus of the intervention. As early intervention has become family-centered, the child receiving early intervention services is not the only focus, the family is also involved. For example, through a family-centered approach, EI professionals can teach families how to be an advocate for their child. This is beneficial since the family is the one that will be with the child majority of the time, not the EI professional (Jung & Baird, 2003). EI professionals include both service coordinators and service providers. While the service delivery approach has changed over past decades, so have the laws regarding ages of those that receive early intervention services (Malone, McKinsey, Thyer, & Straka, 2000; Raver & Childress, 2015).

History of Early Intervention Laws

Early in the history of special education, there was the passing of the Education of the Handicapped Act Amendments of 1986 (P. L. 99-457). This introduced family-centered services for young children with developmental delays; thus, early intervention was formally recognized and established in 1986. Throughout the years, there have been many changes in laws regarding family-centered services for early intervention (Table 1). The first change, Part H of the Education of the Handicapped Act (P. L. 99-457), provided services for children birth to two years of age that were diagnosed with disabilities (Malone, McKinsey, Thyer, & Straka, 2000). The most recent modification in legislation was from Part H of the Education of the Handicapped Act (P. L. 99-457) to Part C of the Individuals with Disabilities Education Act (IDEA; P. L. 108-446). Moreover, P. L. 108-446 includes early intervention to be provided to

children birth to three years of age (Raver & Childress, 2015). There is a need for research to ensure that professionals are following recommendations and requirements set forth by Part C of the IDEA because there is much research that finds inconsistencies in the way early intervention is provided (Hallam, Rous, & Grove, 2005; Ponzetti, Charles, Marshall, & Hare, 2008; Votava & Chiasson, 2015). Therefore, the current research study will fill this gap by examining perceptions of EI professionals in the field of early childhood intervention.

Table 1

History of Early Intervention Laws

Education Act	Law	Description of Law
Education of the Handicapped Act Amendments of 1986	Public Law 99-457	Early Intervention formally recognized and established for children three to five years of age
Part H of the Education of the Handicapped Act	Public Law 99-457	Law updated to provide early intervention services for children birth to two years of age
Part C of the Individuals with Disabilities Education Act (IDEA)	Public Law 108-446	Law provides early intervention services for children birth to three years of age

Early childhood intervention, also referred to as early intervention (EI), is a field of study that focuses on supports for infants and toddlers, from birth to three years of age, who have developmental differences, delays, or disabilities (Raver & Childress, 2015). Since providing early intervention services to young children and families is a federal law, each state has a mandated early intervention program; however, all states do not follow the same criteria. One major difference among states regarding early intervention is that some states include children

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with risks for a developmental delay, along with children that already have a developmental delay or established condition, in their eligibility determination (Scarborough, Hebbeler, & Spiker, 2006; Raver & Childress, 2015). As of 2009, only nine states included children at risk for developmental delays in their eligibility determination, and as of 2015, only five states included these children: Illinois, Massachusetts, New Hampshire, New Mexico, and West Virginia. Although there are differences between early intervention programs practices, all states are directed to implement family-centered practices per P. L. 108-446 (Tomasello, Manning, & Dulmus, 2010; Wrightslaw, 2015). Due to P. L. 108-446, early intervention services must occur in the child's natural environment and services are to use a family-based approach since the family plays a crucial role in a child's success.

Family-Centered Practice

To better meet the diverse needs of families receiving early intervention services and ensure that high quality services are being provided, a family-centered approach is needed because family-centered practice is considered best practice (Bulkeley, Bundy, Roberts, & Einfield, 2016; Guralnick, 2011; Tomasello, Manning, & Dulmus, 2010; Yang, Hossain, & Sitharthan, 2013). Based on the understanding that parents spend more time with their child than an early intervention professional does, and that visits only occur during scheduled times, it is pertinent for early intervention to be family-centered so that parents can be better educated to promote their child's development even outside of scheduled EI visits (Jung & Baird, 2003). There is also the notion that families know their children the best. Thus, family-centered EI is justified because of the many benefits, such as improved long-term development of a child, reduced stress for parents, and positive impacts on cognitive and motor development for the child (Geurts, Boddy, Noom, & Knorth, 2012; Westrup, 2015).

There has been scrutiny in early intervention programs across the United States and Canada in recent years, caused by a philosophical shift from client-centered to family-centered practices because some scholars argue that coaching families is not as beneficial as focusing solely on the child (Ponzetti, Charles, Marshall, & Hare, 2008). While some professionals believe family-centered practices enhance child and family outcomes, there is growing literature that the benefits and implementation of family-centered practices still need to be clarified in the field of early intervention (Dunst, Johanson, Trivette, & Hamby, 1991; Jung & Baird, 2003; Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013).

Organization of Early Intervention

Due to federal law, systems of early intervention are organized based on required components, such as services being provided in the child's natural environment, and each child being assigned a service coordinator. Service coordinators are responsible for maintaining the Individualized Family Service Plan (IFSP) for each family. Each child has an IFSP, which illustrates the measurable results or outcomes that are expected for both the child and the family, and how to reach those results (Sheldon & Rush, 2014). Based on several descriptions of service coordinators, they are the main point of contact that is responsible for scheduling evaluations and assessments, facilitating IFSP meetings, assisting families to receive the supports and services as described in the IFSP, and guaranteeing families' rights throughout the early intervention program (King & Chiarello, 2014; Raver & Childress, 2015; Shelden & Rush, 2013). Moreover, it is crucial that service coordinators monitor the IFSP to ensure FCP in EI. In order to meet the diverse needs of families receiving early intervention services and ensure that high quality services are being provided, a family-centered approach is the best practice (Bulkeley, Bundy,

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Roberts, & Einfield, 2016; Guralnick, 2011; Tomasello, Manning, & Dulmus, 2010; Yang, Hossain, & Sitharthan, 2013).

Although service coordinators play the key role in developing IFSPs and service providers play a role in helping the child reach a goal listed on the IFSP, neither group receives adequate education and training (Jung & Baird, 2003). According to Hallam, Rous, and Grove (2005), the main educational backgrounds that service coordinators had were in nursing (30%), early childhood education (27%), and social work (26%). Moreover, research shows a lack in the amount of training an individual receives before beginning work as a service coordinator. Since the majority of service coordinators do not have degrees in special education, it is essential that FCP training is provided for service coordinators (Jung & Baird, 2003). Although research shows that service coordination training is required in 37 states, research reported that the average length of this training is only 2.9 days (Harbin et al., 2001). Additionally, there is limited research supporting what type of skills are needed for service coordinators (Hallam, Rous, & Grove, 2005). As a result, service coordinators in the field of EI do not have clear guidance of what skills are essential in order to provide family-centered practice. Regardless of a service coordinators background and training, parents should be key decision makers for their children in order to maintain a family-centered approach (Dinnebeil, Hale, & Rule, 1999; Edwards & Gallagher, 2016; Nolan, Young, & Hebert, 2005). Thus, it is important for EI professionals to be able to recognize the importance of providing family education and support, as well as allowing family members to be the decision makers.

Service Delivery

Service providers consist of a group of professionals who deliver services such as speech therapy, occupational therapy, physical therapy, special education, and service coordination

(Raspa, Hebbeler, Bailey, & Scarborough, 2010). Local early intervention agencies utilize service providers to ensure the child is meeting the goals outlined in their IFSP. Sometimes service providers are part of an EI agency, but this is not always the case. Since most professionals do provide services for all categories of residents, not only children, their style of service delivery may not be in line with family-centered practice, which is so important for early intervention services (Raspa, Hebbeler, Bailey, & Scarborough, 2010). Thus, the current research is important to examine FCP practice of providers/coordinators alone, and not in comparison to families.

Research conducted by Yang, Hossain, and Sitharthan (2013), suggests that service providers are aware that a family-centered, collaborative approach is beneficial for children and their families. Despite being aware that a family-centered approach is needed in early intervention services, this does not always occur. For example, research conducted by Yang et al. (2013) acknowledges the effectiveness of service providers delivering family-centered practice; however, perception does not equate to actual service delivery. Additionally, research conducted by Dyke, Buttigieg, Blackmore, and Ghosa (2006), found that service providers understood the importance of family-centered practices; however, they reported not always implementing a family-centered approach in practice. These results suggest that service providers need to work towards implementing genuine family-centered services (Dyke, Buttigieg, Blackmore, & Ghosa, 2006; Yang, Hossain, & Sitharthan, 2013). Therefore, the current research is important because this study focuses on perception of FCP practices among EI professionals. After understanding the perception of FCP, recommendations can be made for better service delivery.

Collaboration Between Service Coordinators and Service Providers

Service coordinators must work closely with service providers to ensure a family-centered approach is being followed. Due to the large number of children needing early intervention services, service coordinators cannot do the work alone. As a result, early intervention programs also require service providers. Service providers are important members of interdisciplinary team in early intervention services delivery because they provide necessary services required in the IFSP. Although service providers typically specialize in a specific area, they usually serve a variety of age groups; this leads to providers overlooking the family-centered approach (Tomasello, Manning, & Dulmus, 2010). Therefore, the field of early intervention is in danger of falling back to a child-centered approach, which is what the foundation of EI was in previous decades, because many early intervention professionals lack the necessary training for implementing FCP, unfortunately (Hallam, Rous, & Grove, 2005; Ponzetti, Charles, Marshall, & Hare, 2008; Votava & Chiasson, 2015). This is when the job of a service coordinator plays a major role in ensuring FCP approach is followed in service delivery of providers. While early intervention policies, such as IDEA, promote family-centered practices, not all early intervention professionals implement these practices, possibly due to the lack of training provided (Tomasello, Manning, & Dulmus, 2010). Such inconsistency in services and this disconnect from philosophy to practice is what guided the current research study.

Theoretical Framework

The theoretical framework that was used to guide the current research study is Bronfenbrenner's ecological theory. Bronfenbrenner's theory describes a child's development through the concept of integrated systems: microsystem, mesosystem, exosystem, macrosystem,

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and chronosystem (Bronfenbrenner, 1976). The child is at the center of the model, and is surrounded by the microsystem. The microsystem includes the child's immediate surroundings, such as the child's family.

Next, the mesosystem is made up of relationships that exist between the variables in the microsystem. In the field of early intervention, an example of the mesosytem would be the relationship between the parents and service providers because service providers and parents are parts of the microsystem and communication between these two creates the mesosystem (Guralnick, 2001; Guralnick, 2008). Furthermore, service providers should implement family-centered practices in order for the mesosystem, including the relationships within, to positively impact the child receiving services (Bulkeley, Bundy, Roberts, & Einfield, 2016).

Bronfenbrenner (1976) describes the next level, the exosystem, to include social policies, laws, and regulations that impact a child indirectly. The federal laws and policies regarding early intervention services form the exosystem. Although policy makers do not attend early intervention sessions, they create these policies based on best practices, which is considered family-centered early intervention (Bulkeley, Bundy, Roberts, & Einfield, 2016).

In order to implement family-centered services, it is important for service providers to be mindful of the family's culture, which makes up the macrosystem. This likely looks different for each family that a service provider works with.

Finally, the chronosystem was generated to characterize changes over time. In EI, these changes include the likelihood of secondary disabilities and delays (Ackar & Appiah, 2011). Therefore, Bronfenbrenner's theory is important when understanding the benefits of FCP in EI. When examining EI services, it is imperative to use Bronfenbrenner's theoretical framework

because a child should be observed throughout the many systems that impact the child's development as a whole (Bronfenbrenner, 1976; Guralnick, 2001; Guralnick, 2008).

Early intervention services are proven to be effective because early identification of developmental delays allows caregivers and professionals to employ appropriate interventions early and prevent secondary disabilities (Ackar & Appiah, 2011). Another reason early intervention services are successful is that EI services follow an ecological systems perspective, highlighting the importance of family and all people, and factors, creating the environment that influence a child's development (Guralnick, 2011).

Ecological Approach to Early Intervention Services

Prior to establishing early intervention services, developmental needs for children under the age of five were not considered significant because in 1986 EI was only recognized for children three to five years of age (Malone, McKinsey, Thyer, & Straka, 2000). Due to P. L. 108-446, EI is now provided to children birth to three years of age as of 2004. Since research in recent decades have emphasized the importance of early intervention services, legislation has evolved as a result of recognizing the importance of services for young children that have developmental needs. Developmental areas include cognitive, physical, social/emotional, adaptive, and communicative skills (Malone, McKinsey, Thyer, & Straka, 2000). Moreover, early detection and interventions prevent secondary disability and decrease the need for special education later (Ackar & Appiah, 2011; Sonuga-Barke, Koerting, Smith, McCann, & Thompson, 2011).

When deciding what type of care to provide for children, an ecological theoretical approach is used because the child's source of support comes from the contexts in which the child lives, with family usually being the child's primary source of support (Eichner & Johnson,

2012). In order to support families and implement effective early intervention strategies, it is important to examine families, by conducting in-depth interviews, in the context of their ecology (Swafford, Wingate, Zagumny, & Richey, 2015). By gathering this data, researchers will also better understand the importance of FCP in EI.

Benefits of Family-Centered Practice

Research has demonstrated that FCP has many benefits for families, including improved long-term development of a child, positive impacts on cognitive and motor development for the child, and empowerment and reduced stress for parents (Geurts, Boddy, Noom, & Knorth, 2012; Westrup, 2015). Thus, in a recent study, 204 parents of children diagnosed with cancer were surveyed and the outcomes showed that family-centered practice is beneficial because parents reported lower levels of burden when caregiving, increased quality of life, more opportunities for empowerment, and increased life satisfaction (Crespo, Santos, Tavares, & Salvador, 2016).

Additionally, another study indicated that a family-centered approach showed promise when attempting to reduce the impact of target behaviors of children with autism because families could coach their children (Bulkeley, Bundy, Roberts, & Einfield, 2016). One way families can coach their children is by implementing what is learned during a child's EI session so that children have more exposure to the intervention. Moreover, several studies have reported family support being an effective aspect of family-centered practice in early intervention (Bulkeley, Bundy, Roberts, & Einfield, 2016; Crespo, Santos, Tavares, & Salvador, 2016; Eichner & Johnson, 2012; Fox, Nordquist, Billen, & Savoca, 2015; Westrup, 2015). Since family-centered practice yields positive results, the present research study is important because research is needed to determine the extent to which service coordinators are implementing family-centered practice.

Parents Participation in Family-Centered Practice

While early intervention professionals are required to follow a family-centered approach, parents may have different views on this approach and practice. Ingber and Dromi (2009) examined 120 mothers and 60 service coordinators perceptions of actual versus desired family-centered early intervention programs in Israel. Their study focused primarily on family-centered early intervention services for children with hearing loss, which was associated as a developmental delay. Initially designed in the United States, the Family Orientation of Community and Agency Services (FOCAS) questionnaire was used to explore the collaboration between mothers and professionals in early intervention programs. In research conducted by Inger and Dromi (2009), the FOCAS questionnaire was used to explore caregivers', specifically mothers', perceptions.

The results supported that mother's perception of a professional's actual approach was characterized as family-centered; however, mothers expressed concerns that professionals did not encourage the family to take charge in decision-making (Ingber & Dromi, 2009). At the same time, professionals reported their struggle in implementing family-centered practices and reported that parents should be involved, but not in charge, during the early intervention process, which contradicts family-centered philosophy (Ingber & Dromi, 2009). Moreover, the mother's perception and the professionals' perception supported the same idea of parental decision making; however, they were viewed in a different light.

This finding is important because it supports that professionals in EI are not allowing families to be in charge of their child's EI services, which is not compliant with the decision making and family support aspects of family-centered practice. While this research studies professionals in EI, it would be beneficial to examine subgroups of professionals providing EI to

determine if the disconnect from FCP lies in a specific subgroup. The current study will add to this research by determining if a particular group of professionals, service providers, are implementing FCP, particularly decision making and family support, properly.

Another qualitative study by Swafford, Wingate, Zagumny, and Richey (2015) examined data by conducting one-on-one semi-structured interviews with 17 families regarding their experiences in family-centered early intervention. During these interviews, each family discussed how the microsystem (child and family) was impacted by the mesosystem (neighborhood, school, and religious groups), exosystem (policies and regulations) and macrosystem (culture and values). In this research, families reported that effective service delivery included professionals implementing family-centered practice because this was resourceful for the child, as well as the family (Swafford et al., 2015). This is another benefit of family-centered practices (Leite & Pereira, 2013). This finding is important because it suggests families agree that FCP is the most effective way of service delivery. As a result, the current research study will enhance previous research by determining if, and to what extent, EI professionals are providing FCP in their service delivery.

Factors Preventing Delivery of Family-Centered Practice

There are several factors that can interfere with EI professionals implementing family-centered practices, including communication styles, educational backgrounds, and differences in policies and procedures among states (Dinnebeil, Hale & Rule, 1996; Geurts, Boddy, Noom, & Knorth, 2012). Due to these factors, it is important to research the differences and results of these interferences. After examining the differences, researchers can then attempt to combat these interferences to improve the use of FCP in EI.

Education and training

        Dinnebeil, Hale and Rule (1996) acknowledge that trait characteristics, such as communication styles, can influence the collaboration with EI professionals and families. Geurts, Boddy, Noom, and Knorth (2012) point out that a disadvantage of family-centered practice is that it is not easily achievable. Moreover, all families are unique and culturally different, thus, sensitivity to values, including variability in desired various outcomes make it a challenge to implement family-centered practice (Geurts, Boddy, Noom, & Knorth, 2012). The current research will add to literature by determining what EI professionals see as challenges to implementing FCP.

State and federal discrepancy

        While federal law requires some uniformity among states, there are variations in Part C EI programs across the country (Edwards & Gallagher, 2016). Some of the flexibilities among states are cost options, standardized measures that determine eligibility, and the location in which the early intervention services take place. Another variation in early intervention programs across states includes background and training. Edwards and Gallagher (2016) suggest continued analysis of early intervention programs to understanding gaps existing within Part C programs on a local and national scale.

        In discussion of policy, research conducted by Harbin, et al. (2004) suggests that policies should be more specific in order to guide family-centered services because there is disconnect between philosophy and practice. Part C coordinators from all 50 states and the District of Columbia were participants in this study, resulting in a 100% response rate. The instrument that was used to explore Part C coordinators perceptions consisted of 30 multiple-choice questions and three Likert-style questions. Results found that state policies do not provide enough

specificity to be helpful in service coordinators' understanding what their job entails, such as providing family-centered practices, due to differences among states (Harbin, et al., 2004). Although federal law requires family-centered service coordination, many states still face challenges with following this law due to varied interpretations of family-centeredness (Harbin, Bruder, Adams, Mazzarella, Whitebread, Gabbard, & Staff, 2004). Because of these varied interpretations, the present study will attempt to understand EI professionals' perception of FCP.

While there has been a lack of clarity of roles in the practice of family-centered early intervention, research conducted by McBride, Brotherson, Joanning, Whiddon, and Demmitt (1993), found that more than half of the families reported feeling like they had the final decision for the child. Although results of the study support family-centered early intervention philosophy, many professionals reported understanding that the legislation requires family-centered early intervention; however, some of them are still reporting being child-focused in practices (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). This research is valuable; however, it was conducted over two decades ago. In order to add to literature, the current study will determine if EI professionals are perceiving that they are implementing family support and allowing the family to make decisions.

Another study conducted by Ziviani, Darlington, Feeney, Rodger, and Watter (2014), discussed family-centered practices and perceptions of FCP among early intervention professionals. While ten early intervention staff were interviewed via telephone or face-to-face, all participants, early intervention service providers, believed they implemented family-centered practices. Most of the staff reported that they implemented family-centered approach in early intervention, at the same time, emphasizing the need for information to be continually focused on the needs of each family, as well as highlighting the importance on training to implement family-

centered practice (Ziviani, Darlington, Feeney, Rodger, & Watter, 2014). The present study will add to current literature by examining if early intervention service providers/coordinators perceive they are implementing family-centered practice.

To better understand the perceptions of EI service providers, The Measure of Processes of Care (MPOC-SP) survey can be used. The MPOC-SP is a tool that can be used for researchers to understand parents and service provider's perception of family-centered practices. Sometimes, these surveys are used at the same time to compare views of parents and service providers. For the MPOC designed for service providers, the four variables include showing interpersonal sensitivity, treating people respectfully, communicating specific information about the child, and providing general information, with parents and service providers labeling providing general information as least positive while they rate treating people respectful as the most positive (Dickens, Matthews, & Thompson, 2010; Jeglinsky, Autti-Ramo, & Carlberg, 2011). While this tool examines perceptions of service providers, the current research study aims to add to current literature by exploring perceptions of service coordinators also.

In relation, the Family-Centered Care Self-Assessment Tool (FCC-SAT) is a tool that can be used to investigate the perceptions of EI professionals. For example, research conducted by Zajicek-Farber, Lotrecchiano, Long, and Farber (2015), explored families' perceptions of primary care pediatric providers (PCPP) use of FCP by using the FCC-SAT, and found that only 31% of parents were satisfied and 85% of parents indicated they wanted more help with providing services to their children. As a result, this study suggests that PCPP are much more child-centered than family-centered. In conclusion, parents want to be more involved with helping their children, but since parents are being left out of the care, EI is becoming child-centered. This raises a concern because early intervention recognizes FCP as best practice,

rather than child-centered care. In this research study, researchers modified the FCC-SAT by

deleting questions related to adolescent children, which will also be done in the current study

since the current study will focused on children ages birth to three years (Zajicek-Farber,

Lotrecchiano, Long, & Farber, 2015). Since parents report weaknesses in lack of coordination,

follow up, and support, the current study looks at perceptions of EI professionals to understand if

their perceptions differ.

Purpose of the study

Bronfenbrenner's ecological theory and recent research suggest that family-centered

practice is essential in service delivery of early intervention services. Therefore, the current

study will explore perceptions of family-centered services in early intervention, including

decision making and family support. These two subscales were chosen based on the literature

recognizing decision making and family support as important aspects of family-centered

practice. The research questions that guide this study are:

1) What level of family-centered practice do EI professionals perceive they use in early
   intervention?

2) Does family support predict perception of family-centered practice being delivered by
   CDSA staff?

3) Does decision making predict perception of family-centered practice being delivered
   by CDSA staff?

CHAPTER 3: METHODOLOGY

The purpose of this research was to examine the insights of professionals in early

intervention (EI) by paying specific attention to EI professionals' perceptions of decision making

and family support. The North Carolina Early Intervention Branch is the lead agency for the

North Carolina Infant-Toddler Program (NC ITP). The NC ITP is a federally funded statewide

program that is responsible for providing Part C of the IDEA, which is the law responsible for

providing early intervention services to children 0-3 years. There are 16 Children's

Developmental Services Agencies (CDSA) across North Carolina that are responsible for

providing early intervention services outlined by the NC ITP. Each CDSA determines

eligibility, provides service coordination, and work with local service providers to ensure the

IFSP goals are being met. In collaboration with the state Early Intervention Branch Head,

service providers/coordinators throughout North Carolina were invited to participate in this

research through cooperation with the CDSAs.

Participants

Participants were EI professionals at CDSA's across North Carolina who work closely

with families to provide service coordination and early intervention services such as speech

therapy, physical therapy, occupational therapy, and additional services, through the NC Infant

Toddler Program. Participation in this research was voluntary. The online survey took

participants about twenty minutes to complete. Table 2 fully describes participants' gender,

ethnicity, education levels, connection to CDSA, and primary role. Participants ($N = 53$) were

primarily female (96.2%, $n=51$), and White/European American (83%, $n=44$). Additionally,

most participants had achieved at least a bachelor's degree (69.8%, $n=37$), but had only received

less than five trainings on family-centered early intervention (58.5%, $n=31$). Participants were

predominantly from the Winston-Salem CDSA (52.8%, *n*=28). Additionally, about 9% of

participants were from both Cape Fear and Charlotte CDSAs, and about 6% of participants were

from each of the following: Blue Ridge, Durham, Elizabeth City, and Morganton CDSAs. The

remainder of participants were from the Greensboro and Sandhills CDSAs (1.9% and 3.8%,

respectively). Participant's primary positions from most to least were service coordinators

(*n*=37), evaluation team members (*n*=6), therapists (*n*=5), supervisors (*n*=4), and psychologist

(*n*=1). Twenty-three participants were excluded from analyses due to several survey responses

missing, which resulted in missing data.

Table 2

Demographic Characteristics of Participants

Characteristics	Category	Number	Percent
Gender	Male	1	1.9
	Female	51	96.2
	Other	1	1.9
Ethnicity	White/European American	44	83
	Black/African American	6	11.3
	Asian	1	1.9
	Other	2	3.8
Education	Associate's degree	3	5.7
	Bachelor's degree	37	69.8
	Master's degree	27	50.9
	Doctorate degree	2	3.8
Connection to CDSA	Blue Ridge CDSA	3	5.7
	Cape Fear CDSA	5	9.4
	Charlotte CDSA	5	9.4
	Durham CDSA	3	5.7
	Elizabeth City CDSA	3	5.7
	Greensboro CDSA	1	1.9
	Morganton CDSA	3	5.7
	Sandhills CDSA	20	3.8
	Winston-Salem CDSA	28	52.8

Procedure

A cross-sectional online survey was utilized to describe trends, perceptions, and practices of CDSA staff who provide early intervention services for children and families in North Carolina. After receiving IRB approval (see Appendix A) through East Carolina University, participants were recruited through an email (see Appendix B) sent out by the North Carolina Early Intervention branch head. The survey was distributed using the survey software Qualtrics, a web-based tool used by the researchers' university. Informed consent and the questionnaire were completed through Qualtrics. Participants were also informed that their answers will be kept confidential, and participants were made aware of the minimal risk associated with this study. Data collection occurred from June 20, 2017 until August 22, 2017. No compensation for participation was provided.

Instruments

Demographic survey

Service providers/coordinators were asked to indicate if they were an employee located within the CDSA or if they were a network provider through the CDSA; gender; age; services provided; length of time in the field of early intervention; education and/or training received; and effective ways of communication with families served. In addition, some of the open-ended questions included: "What is your role in early intervention?", "How comfortable do you feel communicating with families that you serve?", and, "What ways are the most effective in terms of communications with the families you serve?". See Appendix C for demographic questions used in this research. Even though service providers/coordinators may perceive their early intervention practices to be family-centered, the data shows that their actions may not always support high levels of FCP.

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Family-Centered Care Self-Assessment Tool

The Family-Centered Care Self-Assessment Tool (FCC-SAT) includes ten components of FCP, and was used to understand the perceptions of CDSA staff in North Carolina (see Appendix D for survey questions that were analyzed for the purposes of this study). The ten components of family-centered practices measured in this tool include: 1. acknowledges the family as the constant in a child's life, 2. builds on family strengths, 3. supports the child in learning about and participating in his/her care and decision-making, 4. honors cultural diversity and family traditions, 5. recognizes the importance of community-based services, 6. promotes an individual and developmental approach, 7. encourages family-to-family peer support, 8. supports youth as they transition to adulthood, 9. develops policies, practices, and systems that are family-friendly and family-centered in all settings, and 10. celebrates successes (Family-Centered Care Self-Assessment Tool, 2008).

While this tool provides ten components of FCP, the current study only focused on the two components to measure EI professionals' perceptions of FCP: family support, and decision-making roles in early intervention services. The family support component consisted of questions 13-16, 20, 22-23, 25-28, and 30, while the decision-making roles component consisted of questions 17-19, 21, 24, and 29 (see Appendix D). The FCC-SAT questions were revised to focus on the participants in this study and their current positions. The main researcher analyzed the data. Participants responded to survey items by a 5-point Likert type scale, ranging from "never", "some of the time", "half of the time", "most of the time", and "always", where never =1, some of the time =2, half of the time =3, most of the time =4, and always =5. Scores were computed by summing the individual items with the higher scores indicating a greater perception of family-centered practice.

To test the reliability of this measure, previous research used Cronbach's alpha to determine internal consistency of the FCC-SAT (Zajicek-Farber, Lotrecchiano, Long, & Farber, 2015). The coefficient alpha was 0.96 for the total scale, meaning the scale has high internal consistency. Moreover, for the variables used in this research study, the overall coefficient alpha was 0.92, the family support subscale coefficient alpha was .91, and the decision-making subscale coefficient alpha was .77 (see Table 3). Although the total scale was not used in analysis, the subscales still have high internal consistency. Additionally, validity analyses support the face validity of the FCC-SAT (Zajicek-Farber, Lotrecchiano, Long, & Farber, 2015). Therefore, the structured measure used in this current study was both reliable and valid.

Table 3

Reports of FCP Perception, Family Support and Decision Making Variables: Correlations and Descriptive Statistics (N = 53)

Variables	# of items	α	Mean	Std Deviation	Range
FCC Total Perception	20	.92	2.75	.48	1-3
Family Support	12	.91	1.98	.80	1-3
Decision Making	6	.77	1.87	.73	1-3

Data Collection/Management

The link and invitation to participate in the online survey were sent out once by the NC EI Branch Head. The email was sent to all CDSAs directors requesting them to forward the email to all service coordinators. The survey link was available for a two-month period. By clicking on the link, participants consented their voluntary participation. Additionally, the first question asked if participants consented to continue the survey to complete the questionnaire. If

the participant consented, he/she clicked yes; however, if the participant did not consent, he/she clicked no. The participants who clicked "no" were excluded from the study. In order to ensure complete anonymity and confidentiality, participants were instructed not to provide any identifying information during survey completion. The data was downloaded from Qualtrics and stored in a password protected file on the principal investigator's computer. Only the research team members had access to the data.

Data Analysis

Numerical data was analyzed using SPSS version 24. The data from study instruments were downloaded from Qualtrics and were used to examine CDSA's staff's perceptions of family-centered practice. Frequencies, means, standard deviations, and reliability coefficients were calculated and reported as part of the quantitative analysis. These descriptive analyses are appropriate due to the Likert-type-scale data. The results of these analyses are reported in Chapter Four. Results were obtained using linear regressions. Two linear regressions were conducted to determine if family support and decision-making involvement is able to predict perception of family-centered practices by EI professionals. The data were modified and converted as needed. Participants were provided with an open-ended response to the question "How many early intervention orientation sessions, classes, and/or trainings focused on working with families did you receive prior to starting your work with the CDSA?" Responses to this question varied with responses, so the researcher recoded these responses to the options of less than five classes, five to ten classes, ten to twenty classes, and more than twenty classes. Additionally, a total score for each participant was compiled for data analysis by adding responses to each question. Information from the data gathered may be used to improve the use of family-centered practice in early intervention.

Table 4 illustrates the three research questions that guide this research study. The research question "What level of family-centered practice do EI professionals perceive they use in early intervention?" was analyzed using descriptive statistics. Additionally, the other two research questions "Does decision making involvement predict perception of family-centered practice being delivered by CDSA staff?" and "Does decision making involvement predict perception of family-centered practice being delivered by CDSA staff?" were analyzed by using the statistical test known as linear regression.

Table 4

Research Questions

Research Question	Variable Names	Items on Survey	Statistical Test Used
What level of family-centered practice do EI service professionals perceive they use in early intervention?	FCP Perception	Demographic Survey FCC-SAT	Descriptive Statistics
Does decision making involvement predict perception of family-centered practice being delivered by CDSA staff?	Decision Making	Demographic Survey FCC-SAT: 17-19, 21, 24, 29	Linear Regression
Does family support predict perception of family-centered practice being delivered by CDSA staff?	Family Support	Demographic Survey FCC-SAT: 13-16, 20, 22-23, 25-28, 30	Linear Regression

CHAPTER 4: RESULTS

The current study used an exploratory nature to examine perception of FCC in EI professionals implemented practice. The results are described in three sections: 1) demographic characteristics of participants, 2) decision-making, and 3) family support. The results reported are based on North Carolina EI professional's responses to a demographic survey, as well as the FCC-SAT. Data were analyzed using descriptive statistics and statistical analyses to determine the levels of FCP implemented. Each participant had a total score of FCP, along with individual scores for family support and decision-making.

Demographic Characteristics of Participants

The sample was predominantly female ($n=51$) and White ($n=44$) with remaining participants identifying as Black ($n=6$), Asian ($n=1$) or Other ($n=2$). Three participants (5.7%) held an Associate's degree, 37 participants (69.8%) held a Bachelor's degree, twenty-seven participants (50.9%) held a Master's degree, and two participants (3.8%) held a Doctorate degree. Further demonstration of the demographic characteristics of participants can be found in Table 2.

Most participants were service coordinators at the CDSA; however, service coordination was not the primary role of all participants. Many participants (66%, $n=35$) listed service coordinator as their primary role, while six participants (11.3%) report the primary role of evaluation team member, five participants (9.4%) report the primary role of therapist, four participants (7.5%) report the primary role of supervisor, two participants (3.8%) report the primary role of intake service coordinator, and one participant (1.9%) report the primary role of psychologist.

Family-centered early intervention training prior to beginning their position was low. For example, 31 participants (58.5%) reported having less than five classes of family-centered early intervention trainings, eight participants (15.1%) reported having more than twenty classes of family-centered early intervention trainings, and seven participants (13.2%) reported having five to ten classes of family-centered early intervention trainings, and seven participants (13.2%) reported having ten to twenty classes of family-centered early intervention trainings. Additionally, when reporting levels of comfortableness communicating with families served, forty-six participants (86.8%) reported being extremely comfortable, four participants (7.5%) reported being somewhat comfortable, two participants (3.8%) reported being extremely uncomfortable, and one participant (1.9%) reported being neither comfortable or uncomfortable.
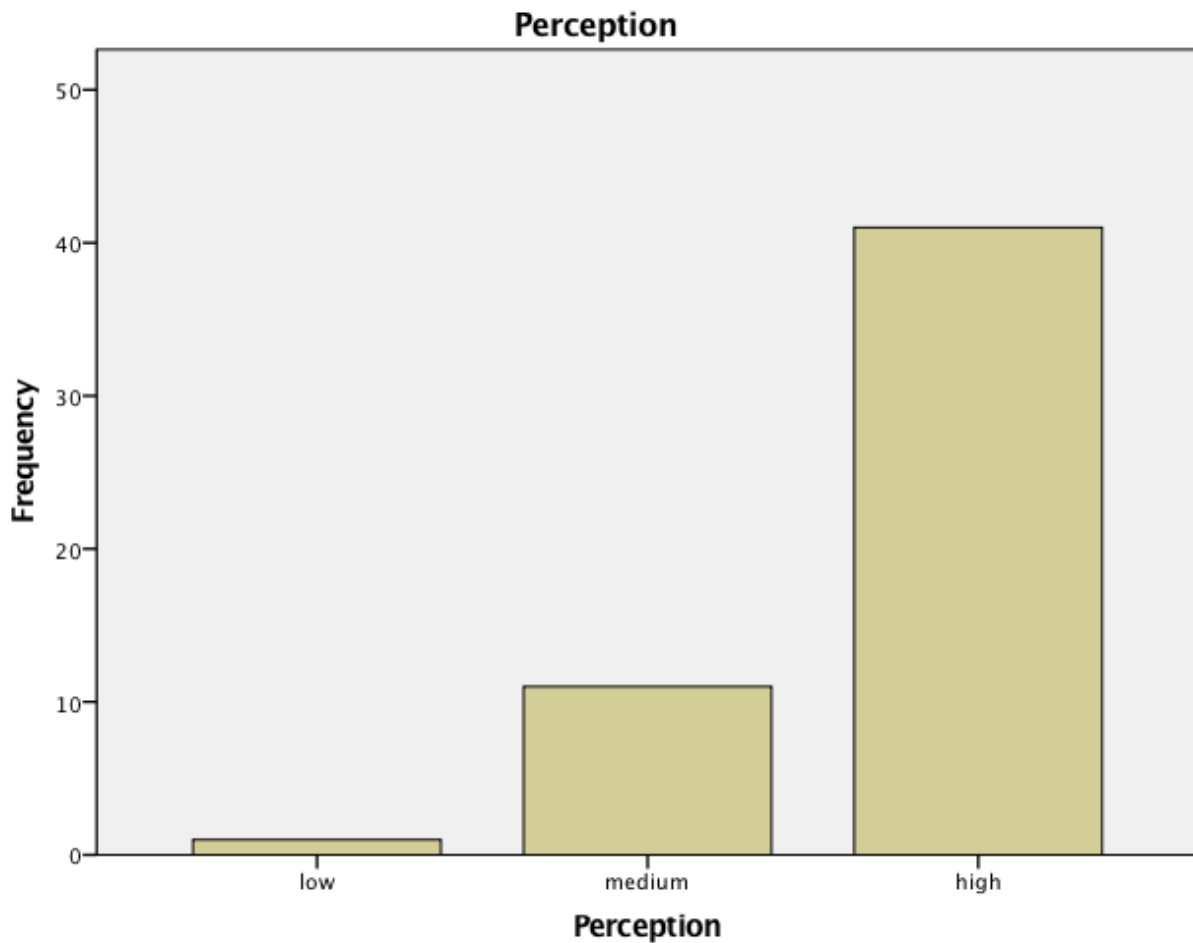
Perception of Family-Centered Practice

This study examined the effects of family support and decision making of EI professionals' perception of their use of family-centered practice in early intervention. The sample of participants included 53 early intervention professionals, with majority being service coordinators. Figure 1 illustrates the level of overall FCP perception of the participants. Scores were computed by summing the individual items with the higher scores indicating a greater perception of family-centered practice. Low scores (n=1) consisted of an average of never to some of the time responses, medium scores (n=4) consisted of an average of half of the time responses, and high scores (n=48) consisted of an average of most of the time to always responses. Therefore, majority of EI professionals reported having high levels of FCP. Table 5 shows the summary of simple regression analyses for both family support and decision making variables. Additionally, tables 6 and 7 illustrate the descriptive statistics for the family support subscale and the decision-making subscale, respectively. Interestingly, the survey question "Do

you work in partnership with families to make health care decisions?" yielded lower responses

(*M*=2.85, *SD*= 1.25), unlike the responses to the rest of the survey questions. This means that

CDSA staff partner with families to make health care decisions half of the time or less.

Figure 1

Levels of overall FCP Perception

Statistical Analyses

To examine if family support and decision-making predicted perception of family-

centered practice, two separate linear regressions were conducted. The correlation between

family support and decision-making variables was .76, which leads to a collinearity problem.

Therefore, two separate simple linear regressions were conducted. A simple linear regression

was calculated to predict family-centered practice perception based on family support. A

significant regression equation was found ($F(1,51)=566.32$, $p<.000$), and accounted for

approximately 92% of the variance of family support ($R^2=.92$, Adjusted $R^2=.92$). Additionally,

a simple linear regression was calculated to predict family-centered practice perception based on

decision making. A significant regression equation was found ($F(1,51)=149.88$, $p<.000$), and

accounted for approximately 75% of the variance of family support ($R^2=.75$, Adjusted $R^2=.74$).

Since the R Squares are closer to one than zero, these models are a better fit to this data.

Moreover, both family support and decision-making are statistically significant and predict

perception of FCP.

Table 5

Summary of Simple Regression Analyses for Family Support and Decision Making Variables

Predicting FCP Perception (N = 53)

Variable	Family Support			Decision Making		
	B	*SE B*	*β*	*B*	*SE B*	*β*
Perception	.08	.00	.96	.13	.01	.86
R^2		.92			.74	
F		566.32			149.88	

Table 6

Descriptive Statistics – Family Support Subscale (N=53)

	Min	Max	Mean	Std. Deviation	Variance
Family Support Subscale	1	5	4.38	.61	.37
13. define role	1	5	4.32	.99	.99
14. request for others to participate	1	5	4.75	.65	.42
15. help families advocate	1	5	4.51	.82	.68
16. support each family's chosen role	1	5	4.55	.77	.60
20. make sure family understands range of service options	1	5	4.66	.78	.61
22. family preferences	1	5	4.38	.88	.78
23. child's ability	1	5	4.42	.89	.79
25. family insurance	1	5	4.23	1.17	1.37
26. schedules	1	5	4.51	.72	.52
27. all questions answered before end of visit	1	5	4.77	.64	.41
28. make sure family feels comfortable letting you know if they disagree	1	5	4.53	.80	.64
30. does partnership change over time	1	5	4.04	.94	.88

Table 7

Descriptive Statistics- Decision-Making Subscale (N=53)

	Min	*Max*	*Mean*	*Std. Deviation*	*Variance*
Decision-Making Scale	1	5	4.19	.69	.48
17. partnership with families to make decisions	1	5	2.85	1.25	1.55
18. range of possible treatment	1	5	4.62	.71	.51
19. discuss which choices would be best for family and child	1	5	4.25	1.22	1.50
21. decisions on desired outcomes	1	5	4.47	.99	.99
24. follow up treatment	1	5	4.21	1.01	1.01
29. resolve disagreements	1	5	4.62	.71	.51

Summary of Results

The purpose of the present study was to determine EI professionals' perception of family-centered practice, particularly regarding family support and decision-making. The results demonstrated that EI professionals perceive they implement high levels of family-centered practice. Additionally, results show that family support and decision-making involvement predict high levels of perception of family-centered practice. EI professionals implement high

levels of family support and decision-making. Moreover, this means that EI professionals

perceive they implement high levels of FCP, and these high levels of family support and

decision-making predict perception of FCP. Table 5 shows both components of family-centered

practice (family support and decision-making) contributed significantly to family-centered

practice perception. While family support explained 92% in variability of FCP, decision making

contributed a bit less, explaining 74% in variability of FCP. This indicates that those EI

professionals who reported to perceive their practice as high FCP approach provide support to

the families they work with in a highly supportive manner, but allow the decision-making

process to be influenced by other factors, which could be family related factors, that account for

18%. Since this was an exploratory research study, additional research is needed to address the

difference.

CHAPTER 5: DISCUSSION

The findings of the current study were based on one completed demographic survey and an eighteen-question survey. Results from these surveys brought new data to the topic of family-centered early intervention, which currently has limited research. The findings from the current study indicated that EI professionals perceived themselves as implementing a high level of family-centered practice. Additionally, EI service professionals have high levels of family support and decision making involvement with families enrolled at the CDSA.

There were several similarities among the participants. One of the similarities were that majority of participants labeled themselves as White, female, service coordinators. Furthermore, most of the participants had similar educational backgrounds of either bachelor's or master's degrees. Additionally, there was a common response that the participants felt extremely comfortable communicating with the families served.

Previous research indicated the lack of service coordination training prior to working in EI (Hallam, Rous, & Grove, 2005; Jung & Baird, 2003; Ponzetti, Charles, Marshall, & Hare, 2008; Tomasello, Manning, & Dulmus, 2010; Votava & Chiasson, 2015). Similarly, the results of the current study support a lack in EI training. Although participants implemented high levels of FCP, majority of participants in this research study received less than five classes of EI trainings prior to working at the CDSA. This confirms what is already in the literature because previous research found that service coordinators receive less than three days of training (Harbin et al., 2001). Unfortunately, this lack of training can explain a potential disconnect from family-centered EI philosophy to practice.

The two variables of service delivery in this research included family support and decision-making involvement. The results of the present study support that EI service

coordinators perceive that they implement high levels of FCP. Additionally, results support that these perceptions are transparent in service delivery. This contradicts previous research by Yang et al. (2013) that found perception does not always equate to actual service delivery.

Family support is an aspect that is important to achieve for family-centered early intervention. The current study found that EI professionals implement high levels of family support. Since family support is an effective aspect of family-centered EI, it is crucial that service coordinators deliver high levels of family support.

In research conducted by Inger and Dromi (2009), mothers expressed concern that professionals did not encourage the family to be the primary decision-makers. The current study contributes to previous literature by addressing that EI service professionals implement high levels of family involvement of decision-making. This contribution addresses that there is a difference between EI professionals' perception and mothers' perception. Although EI professionals may struggle with allowing families to make the decisions, it is important for EI professionals to allow families to make the decisions because parental decision-making is a requirement of family-centered early intervention.

Family support and decision making are only two of the factors that make up family-centered early intervention. Research conducted over two decades ago found that professionals understand that they should be implementing family-centered EI, but some of them report not implementing family-centered EI (McBride et al., 1993). While this research was conducted over two decades ago, the current research study found results that contradict those findings because participants in the current study reported implementing high levels of FCP. Moreover, the current study extends previous research by concluding that EI professionals perceive they

implement high levels of family-centered practice overall, by implementing high levels of both family support and decision-making.

Limitations and Future Research

The current study had several limitations that could have influenced the results. Most importantly, this research observed new areas of EI research, where there was previously limited research on FCP service delivery. In this study, there was a small sample of participants that were eligible for data collection, which created a limitation because these results are not generalizable to the entire population of EI professionals. While there are some CDSA's that stand alone, there are some CDSA's that are contracted sites. However, there are also outside employees that CDSA's may contract with for children to receive services. Most participants were service coordinators that worked at various CDSA's, while there were no participants that were employees contracted outside of CDSA's. This caused a limitation because there was no way to compare the perceptions of the various types of EI professionals: service coordinators, service providers, employees working at the CDSA, and employees contracted through the CDSA, etc.

Additionally, not all CDSA's were represented due to lack of participation. Therefore, it is impossible to generalize these findings to NC CDSAs. Future research should encourage EI professionals from each CDSA to participate in data collection, as well as EI professionals that are contracted through the CDSA. This would allow for researchers to determine if certain areas of North Carolina implement more family-centered practices than others, and what other factors implement high levels of FCP. One of the factors should be training, and length of time working as an EI professional. Additionally, it would be beneficial for future research to see what type of trainings the western part of North Carolina implements since more than half of the participants

in this study were from the Western CDSA. Research should also do analyses to determine if the length of time at the CDSA influences family-centered service delivery. Moreover, future research should use staff from each CDSA, as well as EI professionals contracted through the CDSA, to allow for comparison, and to yield more results.

The current study used two questionnaires to complete data collection: a demographic survey, and a portion of the FCC-SAT survey. The portion of the FCC-SAT used for this research was family support and decision making involvement. This accounts for a limitation because the original FCC-SAT includes fifteen sections that address the ten components of FCC (Family-Centered Care Self-Assessment Tool, 2008). Future research should examine all portions of the FCC-SAT to determine which sections need to be strengthened. This would assist CDSAs in finding additional training their employees would benefit from.

Due to the design of this study, results were based on participant self-report, which could contribute to biased answers. Although the current study initiated the step for data collection, future research should add to the results of this study. Future research should follow up with participants by conducting an in-depth interview to gain clarity on perceptions. By using additional research designs, future research will strengthen the results of FCP in EI.

Lastly, access to the questionnaire was only available for two months. Researchers could use this as a guideline for future research. Although there was generous time for the surveys to be completed, perhaps extending the time of access would be beneficial. By allowing access to the questionnaire for a longer period, there would be more participants. Additionally, another way to have more participants would be for family-centered training requirements and/or incentives in the workplace. Moreover, data collection should occur for an entire year to expand on the current findings.

Despite the limitations discussed, this study is still valuable and it is important for future researchers to continue research on FCP in EI. While this study has limitations, it has also built a foundation for the importance of FCP in EI. By taking these limitations into consideration, researchers can expand on the perception of, and importance of, family-centered practice in early intervention. To expand the literature on FCP, future researchers must include larger sample sizes, longer length of access to the surveys, additional analyses, and/or the use of various research designs. In response, the objective for the future should be for all EI professionals to implement FCP.

Conclusions and Implications

The current study provided results that was consistent with previous literature, which confirms the importance of FCP in EI. Additionally, the study accentuated the gap that existed in the current literature by examining the perceptions of FCP, specifically through family support and decision making involvement. This study suggested that CDSA staff perceives they have high levels of FCP, and CDSA staff do not have high levels of family support and decision making involvement. It is important to have high levels of family support and decision making involvement since these are part of FCP. Moreover, these results allow future researchers to improve levels of family support and decision making involvement, as well as examine other aspects of EI that impact FCP. Service coordinators should consider the involvement FCP has in EI, and adjust their practices accordingly. This study suggested family support and decision making involvement are important factors that must be implemented to be compliant with FCP; however, with future research, several other aspects could be proven to be beneficial for EI professionals to ensure FCP is implemented.

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APPENDIX A: INSTITUTIONAL REVIEW BOARD APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · **www.ecu.edu/irb**

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Sheresa Blanchard
CC:

Date: 4/25/2017
Re: UMCIRB 16-002444
          Exploration of Approaches to Early Intervention Practices

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 4/24/2017 to 4/23/2018. The research study is eligible for review under expedited category #6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Consent template.docx	Consent Forms
Demographic Survey	Surveys and Questionnaires
Demographic Survey- revised for IRB .docx	Data Collection Sheet
FCP questions	Surveys and Questionnaires
Interview Questions_03.27.17.docx	Interview/Focus Group Scripts/Questions
Qualtrics Survey script	Recruitment Documents/Scripts
Survey questions	Additional Items

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

*Researcher, Kaylabeth Gudac VanBuskirk, used previously collected data for secondary data analysis; therefore, only the investigator, Sheresa Blanchard, is listed on IRB approval.

APPENDIX B: SOLICITATION FOR PARTICIPATION EMAIL

Q1 Dear Participant,

We are faculty members at East Carolina University in the Human Development and Family Science department, currently working with graduate student, Kayla Gudac. We are inviting you to take part in our research study, *Exploration of Approaches to Early Intervention Practices*.

The purpose of this research is to examine Children's Developmental Service Agency (CDSA) staff's beliefs about current practices. By doing this research, we hope to better understand practices implemented in early intervention throughout North Carolina. You are being invited to take part in this research because you are work for one of the CDSAs. The amount of time it will take you to complete this survey is approximately 20 minutes. If you agree to take part in this survey, you will be asked questions that relate to your work experiences with families. Your participation is completely voluntary.

This research is overseen by the ECU Institutional Review Board. *However, the information you provide will not be linked to you.* Therefore, your responses cannot be traced back to you by anyone, including me. You will have an opportunity to voluntarily participate in a follow-up interview. If you agree to participate in the interview, we will use contact information you provide and know your identity to set up the interview. Interviews will be audio recorded, but you will not be identified in summaries and recommendations provided after interviews are completed and transcribed.

If you have any questions about this research project, please contact Dr. Sheresa Boone Blanchard at 252-737-2075 or blanchardsh@ecu.edu. If you have questions about your rights when taking part in this research, call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (days, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, call the Director of ORIC, at 252-744-1971.

You do not have to take part in this research, and you can stop at any time. If you decide you are willing to take part in this study, continue with the survey below.

Thank you for taking the time to participate in my research.

Sincerely,

Sheresa Blanchard, PhD   Natalia Sira, PhD
Co-Principal Investigator

APPENDIX C: DEMOGRAPHIC SURVEY

Q2 How are you connected to the Children's Developmental Services Agency (CDSA)?

	Choose the answer(s) that apply	
	Employee located within the CDSA (1)	Employee contracted through the CDSA (2)
Blue Ridge CDSA (1)	○	○
Cape Fear CDSA (2)	○	○
Charlotte CDSA (3)	○	○
Concord CDSA (46)	○	○
Durham CDSA (47)	○	○
Elizabeth City CDSA (48)	○	○
Greensboro CDSA (49)	○	○
Greenville CDSA (50)	○	○
Morganton CDSA (51)	○	○
New Bern CDSA (52)	○	○
Raleigh CDSA (53)	○	○
Rocky Mount CDSA (59)	○	○
Sandhills CDSA (54)	○	○
Shelby CDSA (55)	○	○
Western NC CDSA (56)	○	○
Winston-Salem CDSA (57)	○	○

Q3 How many month/years have you worked in the field of early intervention (birth to three)?

Q4 What is your position with the CDSA?

Q5 What is your gender?
○ Male (1)
○ Female (2)
○ Other (please specify) (3) _____

Q6 What is your race?
○ Hispanic or Latino (1)
○ Non-Hispanic or Latino (2)

Q7 What is your ethnicity? (check all that apply or enter in Other)
- ○ White/European American (1)
- ○ Black/African American (2)
- ○ American Indian or Alaskan Native (3)
- ○ Asian (4)
- ○ Native Hawaiian or Pacific Islander (5)
- ○ Other (6) _____

Q7 What is your primary role with the CDSA?
- ○ Audiologist (10)
- ○ Intake (6)
- ○ Evaluation team member (3)
- ○ Nutritionist (8)
- ○ Physician or physician assistant (9)
- ○ Psychologist (7)
- ○ Service coordinator (1)
- ○ Supervisor (2)
- ○ Therapist (4)
- ○ Other (5) _____

Q8 What percentage of your time do you spend in the following roles with the CDSA?
_____ Evaluation (5)
_____ Occupational therapy (2)
_____ Physical therapy (1)
_____ Service coordination (4)
_____ Speech-language therapy (3)
_____ Supervision (6)
_____ Other (please enter) (7)

Q9 What level of education/degrees have you completed (choose all that apply)?

1) Associate's degree (enter degree area, specialization, major or minor) (1)
2) Bachelor's degree (enter degree area, specialization, major or minor) (2)
3) Master's degree (enter degree area, specialization, major or minor) (3)
4) Doctorate degree (enter degree area, specialization, major or minor) (4)

Q10 How many early intervention orientation sessions, classes, and/or trainings focused on working with families did you receive prior to starting your work with the CDSA?

Q11 How comfortable do you feel communicating with families that you serve?
- ○ Extremely comfortable (1)
- ○ Somewhat comfortable (2)
- ○ Neither comfortable or uncomfortable (3)
- ○ Somewhat uncomfortable (4)
- ○ Extremely uncomfortable (5)

Q12 What way(s) is/are most effective in terms of communications with the families you serve?

5) Email (1)
6) Driving to family's home (2)
7) Phone call (3)
8) Postal mail (4)
9) Text message (5)
10) Other (please enter) (6) _____

APPENDIX D: FAMILY-CENTERED CARE SELF-ASSESSMENT TOOL (FCC-SAT)

(FCC-SAT Decision-Making Team #1A)
Q13 Do you partner with families to help define their role in the infant/toddler's care?
- ⭕ Never (1)
- ⭕ Some of the time (2)
- ⭕ Half the time (3)
- ⭕ Most of the time (4)
- ⭕ Always (5)

(FCC-SAT Decision-Making Team #1B)
Q14 Do you honor families' requests for others (extended family, community elders, faith leaders or traditional healers that are designated by the family) to participate in the process that leads to decisions about care?
- ⭕ Never (1)
- ⭕ Some of the time (2)
- ⭕ Half the time (3)
- ⭕ Most of the time (4)
- ⭕ Always (5)

(FCC-SAT Decision-Making Team #1C)
Q15 Do you help families advocate for services and work to improve systems of care, if they so choose?
- ⭕ Never (1)
- ⭕ Some of the time (2)
- ⭕ Half the time (3)
- ⭕ Most of the time (4)
- ⭕ Always (5)

(FCC-SAT Decision-Making Team #1D)
Q16 Do you act to support each family's chosen role?
- ⭕ Never (1)
- ⭕ Some of the time (2)
- ⭕ Half the time (3)
- ⭕ Most of the time (4)
- ⭕ Always (5)

(FCC-SAT Decision-Making Team #2A)
Q17 Do you work in partnership with families to make health care decisions?
- ❍ Never (1)
- ❍ Some of the time (2)
- ❍ Half the time (3)
- ❍ Most of the time (4)
- ❍ Always (5)

(FCC-SAT Decision-Making Team #2B)
Q18 Do you talk about the range of possible treatment and service choices for the child?
- ❍ Never (1)
- ❍ Some of the time (2)
- ❍ Half the time (3)
- ❍ Most of the time (4)
- ❍ Always (5)

(FCC-SAT Decision-Making Team #2C)
Q19 Do you discuss which treatment and service choices would be best for the family and child?
- ❍ Never (1)
- ❍ Some of the time (2)
- ❍ Half the time (3)
- ❍ Most of the time (4)
- ❍ Always (5)

(FCC-SAT Decision-Making Team #2D)
Q20 Do you make sure the family understands the range of treatment and service choices?
- ❍ Never (1)
- ❍ Some of the time (2)
- ❍ Half the time (3)
- ❍ Most of the time (4)
- ❍ Always (5)

(FCC-SAT Decision-Making Team #2E)
Q21 When deciding on services, do you work with the family to decide what the desired outcomes are (e.g., improved health status, better childcare/preschool attendance, less pain, or better involvement with social or sports activities)?
- ❍ Never (1)
- ❍ Some of the time (2)
- ❍ Half the time (3)
- ❍ Most of the time (4)
- ❍ Always (5)

(FCC-SAT Decision-Making Team #3A)
Q22 Do choices of diagnostic and service approaches take into account family preferences for site of care, type of provider (gender, language spoken, etc.)?
- ○ Never (1)
- ○ Some of the time (2)
- ○ Half the time (3)
- ○ Most of the time (4)
- ○ Always (5)

(FCC-SAT Decision-Making Team #3B)
Q23 Do choices of diagnostic and service approaches take into account child's ability to tolerate the procedure?
- ○ Never (1)
- ○ Some of the time (2)
- ○ Half the time (3)
- ○ Most of the time (4)
- ○ Always (5)

(FCC-SAT Decision-Making Team #3C)
Q24 Do choices of diagnostic and service approaches take into account any follow up medical treatment the child will need?
- ○ Never (1)
- ○ Some of the time (2)
- ○ Half the time (3)
- ○ Most of the time (4)
- ○ Always (5)

(FCC-SAT Decision-Making Team #3D)
Q25 Do choices of diagnostic and service approaches/providers take into account family insurance status and economic situation?
- ○ Never (1)
- ○ Some of the time (2)
- ○ Half the time (3)
- ○ Most of the time (4)
- ○ Always (5)

(FCC-SAT Decision-Making Team #3E)
Q26 Do choices of diagnostic and service approaches/providers take into account family and child work and school schedules?
- ◯ Never (1)
- ◯ Some of the time (2)
- ◯ Half the time (3)
- ◯ Most of the time (4)
- ◯ Always (5)

(FCC-SAT Decision-Making Team #4)
Q27 Do you make sure all the family's questions have been answered before they leave the evaluation, session, or visit?
- ◯ Never (1)
- ◯ Some of the time (2)
- ◯ Half the time (3)
- ◯ Most of the time (4)
- ◯ Always (5)

(FCC-SAT Decision-Making Team #5)
Q28 Do you make sure the family and child feel comfortable enough to let you know if they disagree with medical advice and recommendations for treatment and services?
- ◯ Never (1)
- ◯ Some of the time (2)
- ◯ Half the time (3)
- ◯ Most of the time (4)
- ◯ Always (5)

(FCC-SAT Decision-Making Team #6)
Q29 Is there a respectful negotiation process to resolve any disagreements about a child's treatment and services?
- ◯ Never (1)
- ◯ Some of the time (2)
- ◯ Half the time (3)
- ◯ Most of the time (4)
- ◯ Always (5)

(FCC-SAT Decision-Making Team #7)
Q30 Does your partnership with families change over time as their experiences, knowledge, and skills change?
○ Never (1)
○ Some of the time (2)
○ Half the time (3)
○ Most of the time (4)
○ Always (5)