

FAMILY OUTCOMES AND EXPERIENCES AS A RESULT OF PARTICIPATING
IN EARLY INTERVENTION

BY

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DISSERTATION

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Abstract

This study examined families' experiences and outcomes as a result of participating in Part C early intervention services in Illinois. A total of 39 participants completed the Family Outcomes Survey-Revised[®] (FOS-R[®]) that focused on parents' (a) understanding their child's strengths, needs, and abilities; (b) knowing their rights and advocating for their child; (c) helping their child develop and learn; (d) having support systems; and (e) accessing the community. After completing the FOS-R[®], parents participated in an interview where they described the practices that early intervention professionals used to help them achieve their outcomes, as well as practices that were unsuccessful. Using a mixed methods data analysis approach, results showed that most of the parents who participated in this study reported high levels of satisfaction with their early intervention experiences. However, satisfaction ratings on the family outcomes items on the FOS-R[®] (Section A) were consistently higher than parents' satisfaction ratings on the helpfulness indicator items (Section B). This difference was echoed in the interviews. There were also some notable differences in parents' responses on the FOS-R[®] based on their reported residential location, race, income, and education level. Several themes emerged from the interview data including systems-level and provider-level facilitators and barriers, parental wishes related to their early intervention experiences, and factors related to parents' daily experiences in raising their children with a disability or developmental delay. While some families felt supported by their early interventionists, their experiences were not shared by the majority of families in the study.

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Chapter 1

Early Intervention and Family Outcomes

Part C of the Individuals with Disabilities Education Act (IDEA) provides for special instruction and related services for infants and toddlers with developmental delays and disabilities and their families (Individuals with Disabilities Education Act, 20 U.S.C., 2004). Ultimately, the goal of early intervention (EI) is “to understand what the family envisions for their child as part of their family and community, and help them achieve that vision” (Keilty, 2010, p. 8). The purposes of EI include maximizing a child’s potential, increasing family empowerment for their child, and reducing special education costs (IDEA, Sec 631). According to the *39th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act* (United States Department of Education, 2017), 357,715 infants and toddlers received Part C services in 2015. Approximately 23% of those children exited Part C without being eligible for Part B 619 preschool services. Thirty-nine percent of the children were eligible for Part B services, while the remaining 38% did not continue to Part B for various reasons including parental withdrawal, loss of contact, and eligibility not determined.

The Office of Special Education Programs (OSEP) of the U.S. Department of Education formed a workgroup to identify the necessary components for quality EI services. This workgroup generated three documents that were meant to be utilized by states, technical assistance providers, and early interventionists in their work with families. The seven principles described in the *Agreed Upon Mission and Key Principles for Providing Early Intervention Services in Natural Environments* (Workgroup on Principles and Practices in Natural Environments, 2008) document focus on the family as the central figure for the child, the role of the early interventionist as a support to the family, the importance of everyday experiences in

familiar contexts, and the use of evidence-based practices. These principles enable professionals to focus on the link to family outcomes, with the intention of ultimately leading to families to feel empowered to support their child.

The U.S. Department of Health and Human Services and the U.S. Department of Education recently released a joint policy statement on the importance of family engagement to remind programs, including Part C, to prioritize family engagement as a critical component of service delivery (2016). The policy statement emphasizes that a child's needs cannot be fully met without engaging the family. Family engagement strategies described in the policy statement that are relevant to Part C programs include establishing trusting relationships between families and professionals, supporting families' connections and capabilities, and developing relationships with community partners in support of families (2016). These strategies are central to the work of early interventionists and should be embedded within their practices with families.

Family-centered practices are key to high quality EI services (Bailey, Raspa, & Fox, 2012; McWilliam, 2010). When implementing family-centered practices, early interventionists become partners, consultants, and problem solvers with the family rather than experts who impart knowledge on the family (Espe-Sherwindt, 2008). Family-centered practices involve early interventionists treating the family with respect, individualizing intervention, providing full and unbiased information, and collaborating with family members (Division for Early Childhood, 2014).

When considering the goal of EI as stated by Keilty (2010) along with the OSEP Mission and Key Principles, it becomes clear how important it is to gather information from families as they participate in EI services. Families are the only ones who can share their perspective on family-centered services. While professionals can provide valuable input on whether they feel

that the services they provide are through a family-centered lens, it is important to understand how those services are received by the families.

Family Experiences in Early Intervention

Few studies address families' perceptions of their EI experiences, and many of the studies that do exist were published more than 15 years ago, during the first 10 years of Part H (precursor to Part C) of the Education of All Handicapped Children Act (Education of the Handicapped Act Amendments of 1986). Furthermore, many of those studies focused on a specific population of families within EI (e.g., children with hearing loss and children living in poverty). There are few published studies documenting families' experiences in recent years, particularly after the concept of family-centered services, rather than a therapist-directed approach, was emphasized. One exception is a study conducted by Campbell and colleagues (2009). However, these researchers focused on the concept of natural environments and not the families' overall EI experiences. The two most common topics addressed in the literature related to families' experiences in EI focus on their satisfaction with EI services and the quality of EI services.

Family satisfaction with EI services. Historically, family experiences with EI services have been measured through satisfaction surveys (Mahoney & Filer, 1996; McNaughton, 1994). Findings from those research studies have shown that families are often satisfied with the services they received. However, none of those studies examined the quality of services that families received.

McNaughton (1994) conducted a review of published research measuring parent satisfaction with EI services and found parent satisfaction to be "uniformly high" (p. 35). He, along with other researchers have expressed caution with measuring only satisfaction, as it can

be a consequence of *service access* rather than *service quality* (Bruder & Dunst, 2015).

McWilliam et al. (1995) found that families reported satisfaction with services if child-level goals and outcomes were addressed. Additionally, families who indicated high satisfaction also reported service gaps and needs.

Perceptions of quality of EI services. Bruder and Dunst (2015) investigated EI and early childhood special education (ECSE) services from the parents' perspective, focusing on perceived quality rather than satisfaction. They found that the majority of parents perceived early interventionists to be more confident than competent. They also noted that increased parental involvement correlated with higher ratings of confidence and competence.

Researchers who conducted the National Early Intervention Longitudinal Study (NEILS), a survey of a nationally representative sample of families who received EI services, collected data on many variables related to services (e.g., age at time of first IFSP, health status at 36 months, etc.). In an analysis of the NEILS data, Bailey, Nelson, Hebbeler, and Spiker (2007) examined the extent to which the quality of family supports was related to other variables, including quality of child services and confidence in parenting. They reported that parents rated EI services as high in quality, but the services did not impact their confidence in parenting their child with special needs.

Family Outcomes

Measuring family outcomes is one way that states have addressed accountability and to an extent, the efficacy of EI services. Bailey et al. (2006) define a family outcome as “a benefit experienced by families as a result of services received” (p. 228). It is important to emphasize that in EI, the outcome is not the service received, but rather the benefit or consequence of the service.

While individual program evaluations often consider family outcomes, it was not until 2006 that family outcomes and the helpfulness of EI services were systematically measured by states. Five family outcomes were identified through a process involving a literature review, expert consultation, stakeholder consultation, and consumer feedback (Bailey et al., 2006; Bailey, Hebbeler, Olmsted, Raspa, & Bruder, 2008; Raspa et al., 2010). The identified outcomes are that families should: (a) understand their child's strengths, abilities, and special needs; (b) know their rights and advocate effectively for their children; (c) help their child develop and learn; (d) have support systems; and (e) access desired services, programs, and activities in their community (Bailey et al., 2006; Bailey et al., 2008; Raspa et al., 2010). The Early Childhood Outcomes (ECO) Center developed the Family Outcomes Survey (FOS[®]) based on these identified outcomes and pilot tested the survey in Illinois and Texas in 2005-2006.

Based on the pilot data, the FOS[®] was revised for program planning and improvement purposes, as well as to assess the psychometric properties of the survey (Bailey et al., 2011). The survey format also was revised for clarity. After consulting with key stakeholders and piloting the instrument with families in Illinois and Texas, the Family Outcomes Survey-Revised[®] (FOS-R[®]) was created and implemented, beginning in 2010. Currently, 17 states use the FOS-R[®] annually as a measure for EI outcomes (Early Childhood Technical Assistance Center, 2017b). A full description of the revision and validation process is described in Bailey et al. (2011).

Gaps in Research

While measuring the helpfulness of EI services to families is a requirement for federal reporting purposes, and it is widely acknowledged in the field that understanding the importance of family outcomes is critical to program improvement, there continues to be a dearth of studies that examine outcome and helpfulness indicators. Furthermore, it is important to consider

families' perspectives on EI services they receive to help the field understand the extent to which these outcome indicators are indeed measuring families' experiences. There is also a need to conduct a systematic examination of practices used by early interventionists that can lead to achievement of these outcomes in order to further professionals' understanding and use of practices that lead to positive child and family outcomes.

Several researchers explored families' experiences in EI as they relate to a specific population such as families living in poverty (Swafford, Wingate, Zagumny, & Richey, 2015) or in rural areas (Ridgley & Hallam, 2006). However, no published studies have explored the extent to which outcomes were reflective of the families' experiences across diagnoses or income levels, and what practices early interventionists used to achieve those outcomes. Finally, Raspa et al. (2010) described a need to further investigate whether or not family outcomes change over time and how these changes are linked to the validity of the FOS®.

To date, much of the published research regarding family experiences in EI utilized surveys. While surveys provide valuable information, family voices describing the depth and breadth of their experiences are often lacking. Additionally, most of the research studies on family outcomes have focused on accountability. Bailey et al. (2006) argued that outcomes should go beyond accountability and also address quality. Highlighting the voices of families through their stories and the extent to which outcomes were or were not met and the quality of the EI services they received, may help professionals gain insights to the experiences of families who participate in the EI system. This may allow for a systematic examination of quality factors that can enhance EI services for young children with disabilities and their families.

Purpose of Study

The purpose of this study was to examine parents' experiences in early intervention and the practices that contribute to positive family outcomes. Specifically, the following questions were addressed:

1. What do families report as outcomes of participating in early intervention, as measured on the Family Outcomes Survey-Revised[®]?
2. What practices do families identify that practitioners use to produce the outcomes on the Family Outcomes Survey-Revised[®], including (a) understanding their child's strengths, needs, and abilities; (b) knowing their rights and advocating for their child; (c) helping their child develop and learn; (d) having support systems; and (e) accessing the community?
3. What additional practices and outcomes do families identify as part of their early intervention experience?
4. What family and child characteristics are related to differences and similarities in families' reported early intervention experiences?

Conceptual Framework

The conceptual framework upon which this study is built is based on a family-system framework, described by Trivette, Dunst, and Hamby (2010). The family-systems framework looks at (a) family strengths, (b) concerns and priorities, and (c) supports and resources as situated within professional help-giving practices. In this study these same ideas were examined with close attention paid to how family outcomes are related to professional practices. In order for children to have successful outcomes and meet their goals, families must be an integral part of the team, with their strengths and concerns recognized and reflected within the intervention. Family outcomes are dependent upon coordinated services and plans that recognize the family's desired outcomes for their children and work towards that goal. Early interventionists working with families' must have knowledge of EI principles and practices, child development, and

collaboration and teaming. Early interventionists must then utilize practices that support the family in achieving their desired outcomes for their child and themselves as a family.

Chapter 2

Literature Review

The aim of Part C early intervention (EI) services is to support the child and family in achieving family-identified outcomes, related to the child's developmental delay or disability. While child outcomes are frequently the focus of intervention and research, family outcomes have received less attention. Family outcomes have been identified as a necessary result of EI for several decades; however, federal legislation did not require formal reporting of these outcomes until IDEA 2004. As a result of the legislation, the Early Childhood Outcomes (ECO) Center was funded to study child and family outcomes, and make recommendations to meet the federal reporting requirements. Five family outcomes were identified through an extensive process, including a comprehensive literature search, focus groups with families, and pilot testing in two states (Bailey et al., 2006). Three helpfulness indicators also were identified and adopted by OSEP for federal reporting requirements.

The purpose of this study was to examine families' experiences and outcomes as a result of participating in Part C services. To inform the study, articles were reviewed that focused on key family outcomes related to Part C EI including and beyond those identified by OSEP, family-centered practices used in EI, and studies that focused on the Family Outcomes Survey-Revised[®] (FOS-R[®]). The guiding questions for the literature review were:

1. What potential family outcomes as a result of participating in Part C early intervention services are described in the literature?
2. How are family outcomes measured for children and families participating in Part C early intervention in the literature?
3. How are the voices of families of children with disabilities participating in Part C early intervention represented in the measurement of family outcomes?
4. What practices are identified in the literature that early interventionists use to support families in achieving family outcomes?

Search Criteria and Procedures

The primary criterion used to identify literature included in this review was that the article focused on family outcomes or family-centered practices in EI, as determined by the abstract, summary, or keywords. In order to identify relevant articles, electronic databases, including Scopus, EBSCOHost, ERIC, and Google Scholar were searched. Search terms included *early intervention*, *Part C*, *family outcomes*, or *satisfaction* in combination with ages (*infant*, *toddler*). A hand search of the table of contents of several journals, including *Infants & Young Children*, *Journal of Early Intervention*, and *Topics in Early Childhood Special Education* from 2006-present also were conducted. The criteria for the empirical studies included in this review were that the article: (a) addressed family experiences in EI; (b) provided a description of the intended family outcomes; (c) included information about the participants; (d) was conducted after 2006; and (e) described a study conducted in the United States and published in an English-language journal. 2006 was chosen as a criterion due to the initiation of requirements for states to formally measure and report family outcomes to the federal government. When identified articles met the search criteria, the reference lists as well as the articles that cited the originally identified articles were examined for additional articles. Additionally, databases were searched for articles published by significant contributors in the field including Donald Bailey and Carl Dunst. Through a combination of these methods, 19 empirical articles were identified and are included in this review. Additionally, four descriptive papers, literature reviews, and policy reports are included to provide background and context for the topics of interest. See Table 1 for a matrix of these 19 articles.

Study Description and Demographic Information

Across the 19 empirical studies, approximately 6,800 family members and 2,100 professionals served as participants. Several studies drew from the same data sources, but reported different number of participants and therefore it was difficult to determine how much overlap existed among the study participants. Additionally, several studies did not give clear descriptions or exact numbers of participants. Surveys, phone interviews, and face-to-face interviews were commonly utilized to gather information. Studies that utilized one or more surveys included 6,100 individuals, with 4,077 family members and 2,023 professionals (Aaron et al., 2014; Bailey et al., 2011; Broggi & Sabatelli, 2010; Bruder & Dunst, 2015; Bruder, Dunst, & Mogro-Wilson, 2011; Dunst & Dempsey, 2007; Epley, Summers, & Turnbull, 2011; Olmsted et al., 2010; Raspa et al., 2010; Stewart, 2011; Summers et al., 2007). Phone interviews were conducted with 2,681 family members, and face-to-face interviews were conducted with 36 family members (Bailey et al., 2007; Brotherson et al., 2010; Kellar-Guenther, Rosenberg, Block, & Robinson, 2014; Lee, 2015; Popp & You, 2016; Ridgley & Hallam, 2006; Swafford et al., 2015). Two studies utilized Q-sort procedures as one of several measures (Bailey et al., 2011; Noyes-Grosser et al., 2013). One study (Noyes-Grosser et al., 2013) was conducted across several phases and utilized multiple methods, including sorting and rating outcome statements; however, demographic information was not collected on all participants. For those individuals who shared demographic information, 25 family members and 52 professionals participated in one or more of the components of the study.

Nine research teams reported the ethnicity of the family member responding to a survey or interview (Aaron et al., 2014; Broggi & Sabatelli, 2010; Brotherson et al., 2010; Bruder & Dunst, 2015; Epley et al., 2011; Lee, 2015; Noyes-Grosser et al., 2013; Ridgley & Hallam, 2006;

Summers et al., 2007) and five teams reported the ethnicity of the child for whom the family member was describing (Bailey et al., 2011; Kellar-Guenther et al., 2014; Olmsted et al., 2010; Popp & You, 2016; Raspa et al., 2010). Of the 6,629 respondents for which ethnicity was reported, Caucasian respondents comprised the largest number of respondents ($n = 4,014$; 61%), followed by Hispanic respondents ($n = 1238$; 19%), African-Americans ($n = 930$; 14%), Asian or Pacific Islanders ($n = 112$; 1.7%); American Indian or Alaskan Natives ($n = 23$; 0.3%); and “Other” respondents ($n = 308$; 4.6%). Ethnicity for four individuals was not reported. In three studies participants were included who spoke languages other than English (Aaron et al., 2014; Kellar-Guenther et al., 2014; Olmsted et al., 2010). Thirteen studies included gender information about adult participants and seven studies included data on children’s gender. There were approximately 946 adult female and 73 adult male participants. The information pertaining to children included 2,414 females and 3,644 males, with three of the seven studies drawing from two non-overlapping data sets.

Income data were reported in 13 of the 19 studies reviewed. However, it is difficult to compare across these studies due to differences in how the data were reported. For example, in one study (Ridgley & Hallam, 2006), Medicaid eligibility was used as a criterion for participation. In another study, the author reported that 87% of respondents were above the federal poverty line (Epley et al., 2011). In yet another study, Lee (2015) reported that the family participating in the ethnographic study was middle-class. The other studies reported more detailed income data, with differing cut points, and included a wide range of income levels.

Identifying Family Outcomes as a Result of Part C Services

Across all 19 studies included in this review, researchers identified several family outcomes as a result of children and families’ participation in Part C Services. The ECO Center

identified five family outcomes based on an extensive literature review and meetings to gather input from stakeholders, including state level program administrators, researchers, family members, policy makers, and practitioners (Bailey et al., 2006). The family outcomes included: (a) understanding their child's strengths, needs, and abilities; (b) knowing their rights and advocating for their child; (c) helping their child develop and learn; (d) having support systems; and (e) accessing the community (Bailey et al., 2006).

Additionally, several researchers identified family quality of life (FQOL) indicators as outcomes, such as (a) family interaction, (b) parenting, (c) emotional well-being, and (d) physical/material well-being (Epley et al., 2011; Summers et al., 2007). Through survey research conducted with families in one state utilizing the Beach Center FQOL survey and the FOS[®], Epley and her colleagues (2011) found that the FQOL indicators measured the same constructs as the family outcomes identified by Bailey and his colleagues (2006). They also showed that families who reported higher scores on the FOS[®] also indicated higher scores on the FQOL, suggesting that attaining family outcomes through EI could lead to overall perceptions of higher quality of life for the family.

Noyes-Grosser et al. (2013) also shared findings from a study evaluating family outcomes specifically for children with autism spectrum disorder who were enrolled in Part C services in New York. In this study, parents and professionals prioritized outcomes using concept maps. The family outcomes included: skills and knowledge to support child development; anticipating child's needs and behavioral challenges; advocacy and collaboration with professionals; and family and community supports. Parents and professionals had similar responses, although parents identified broader outcomes as opposed to specific outcomes and skills identified by professionals. While this study did not identify the same family outcomes as

those identified by Bailey and colleagues, and indicated on the FOS-R[®], there was overlap in the outcomes, particularly regarding parental knowledge to support their child's development and access to community supports.

Quality of family services is a construct that is measured using different instruments that assess family outcomes (Bailey et al., 2006; Bruder & Dunst, 2015). However, a common definition of what constitutes quality was not included in the studies. Thus, parents completing a survey or responding to interview questions may interpret quality of services in different ways. Several research teams investigated elements that contribute to the quality of EI services.

First, in two studies researchers investigated parent participation based on location of service delivery. Stewart (2011) measured family support relative to therapy location, gathering perceptions from both family members and early interventionists. For both groups, the opportunity for family support was determined to be higher in center-based settings for outcomes related to meeting other parents of children with special needs, accessing additional services, and observing other children with special needs. Additionally, Stewart found that the opportunity for family support was higher in home settings for outcomes related to the ability for other relatives to learn from the early interventionist. These findings suggest that multiple factors may influence the impact of EI services for families and that service location should be individualized based on family and child needs.

Kellar-Guenther et al. (2014) measured parent involvement across home, clinic, provider office, and childcare settings. While parent involvement has not been considered a family outcome, the results of parent involvement, including the use of strategies to help their child, can be considered outcomes of services. Interestingly, Kellar-Guenther and colleagues found that parent use of strategies did not differ in home, office, or clinic settings. This suggests that factors

other than location may be more indicative of parent use of strategies and that location alone may not account for the level of parent involvement during the sessions.

Brotherson and her colleagues (2010) investigated emotional needs within parent-professional partnerships. They discussed scenarios in which the parent's and/or professional's emotional needs were met or not met. They found that it was important to consider the needs of both individuals in the partnership in order to produce successful outcomes. Parents reported that early interventionists were a source of hope and strategies, and they helped mitigate stress. However, this was only possible if the early interventionist's needs were met as well. This has important considerations for EI administrators in that early interventionist's well-being could be indirectly related to family outcomes.

The relationship between EI services and parenting confidence and competence needs further exploration (Broggi & Sabatelli, 2010; Dunst & Dempsey, 2007). Dunst and Dempsey did not find a statistically significant relationship between parenting competence or confidence and professional partnerships, nor did Bailey et al. (2006) find a relationship between quality of family services and parenting confidence. However, Bruder and Dunst (2015) found that parents who were more involved in their child's EI services rated those services as higher quality, with regards to both confidence and competence of practices. Broggi and Sabatelli found that a relationship only existed for those families who reported high levels of satisfaction with therapy in combination with a high degree of control over goals and services.

Measuring Family Outcomes Using a Family Outcomes Survey

Family outcomes are measured in a variety of ways. All 19 studies in this review measured at least one family outcome as a result of participating in Part C EI services. Researchers used a variety of measures to collect family outcomes data directly from parents.

Standardized surveys, such as the FOS[®], FOS-R[®], or FQOL were used in five studies, while five other studies used researcher-developed surveys with constructs focused on specific family outcomes, parental stress, or satisfaction. Phone interviews using a structured interview protocol with family members were used in two studies that mined the same data source (Bailey et al., 2007; Popp & You, 2016). Face-to-face interviews were conducted in four studies (Brotherson et al., 2010; Lee, 2015; Ridgley & Hallam, 2006; Swafford et al., 2015). Seven studies utilized multiple measures; five of those used multiple surveys while two utilized a combination of document review, focus groups, observations, or interviews (Brotherson et al., 2010; Lee, 2015).

The Family Outcomes Survey[®] (FOS[®]) or Family Outcomes Survey–Revised[®] (FOS-R[®]), developed by Bailey et al., was used in three studies (Bailey et al., 2011; Olmstead et al., 2010; Raspa et al., 2010). The FOS[®] was developed by a team of researchers who used the existing literature, expert consultation, focus groups with families, and feedback from stakeholders to develop the items (Bailey et al., 2011). Bailey and colleagues (2008) described the elements that were considered during the creation of the FOS[®], including the population that completed the survey and the method of completion, the outcomes measured, open-ended vs. closed-ended questions, wording of the items, and length of the survey. Olmstead and colleagues and Raspa et al. conducted two separate validation studies on the FOS[®]. These studies were conducted in two large states.

Researchers also found that the demographic information and questions related to perceived helpfulness of EI and family-centered practices were related to the measured family outcomes (Olmstead et al., 2010; Raspa et al., 2010). Raspa and colleagues analyzed 2,849 completed FOS[®] from two states and found that families reported positive outcomes overall.

Items with the highest ratings included having access to high quality medical care, helping their child practice new skills, comfort in meeting with professionals, and understanding their child's special needs. Psychometric validation showed that the three helpfulness indicators (knowing rights, communicating their child's needs, and helping their child develop and learn) reported to OSEP were strongly related to the five family outcomes (understanding their child's strengths, needs, and abilities, knowing their rights and advocating for their child, helping their child develop and learn, having support systems, and accessing the community).

Olmstead et al. (2010) analyzed a sub-set of data from a larger study (Bailey et al., 2011) focusing on the segment of families who completed the Spanish language version of the FOS[®]. They found that while there were slight variations in participant responses to each item, the majority of respondents had a similar response pattern as those who filled out the English language version. Based on feedback from respondents in both the English and Spanish language versions, several methodological issues were raised, including the use of a 7-point scale and the number of questions measuring each construct. For example, Olmstead and colleagues found that parents did not utilize the ratings of 2, 4, or 6. Thus, a revision process was undertaken and with further feedback from expert reviewers, stakeholders, and families, the FOS-R[®] was developed (Bailey et al., 2011).

While states receiving Part C federal support are required to measure and report family outcomes data, they have the option to choose a developed tool or develop their own tool. According to the Early Childhood Technical Assistance Center (ECTA; 2017b), for Federal Fiscal Year 2015, nine states and territories used the FOS[®], 17 states and territories used the FOS-R[®], 18 states and territories used the National Center for Special Education Accountability

Monitoring (NCSEAM) survey, and the remaining 12 states and territories created their own survey to report Part C data to OSEP.

Published articles describing the measurement of family outcomes using standardized tools, such as FOS-R[®] or NCSEAM, are limited to those that were carried out in conjunction with the ECO Center (i.e., Bailey, Olmstead). While the ECTA Center reports aggregated national data annually on the federally required helpfulness indicators and several states publish child and family outcomes data on their respective websites, there are no published articles analyzing Part C family outcomes data from within or across states.

While survey data are valuable in understanding families' experience with Part C services, survey data are often limited in describing the context of families' experiences. In nine of the studies reviewed, researchers gathered information directly from families through surveys. The information gathered through these studies provide the field with a broad look at a large number of families' reported outcomes as a result of their participation in EI. These studies allow for comparison across demographics, including language, as well as data across multiple states. Information gathered can begin to inform the validity of the survey items and general practice change for early interventionists. However, survey research does not allow for an in-depth look at the context behind the ratings provided by families. In order to understand the complete story of families' experiences in EI, methodology beyond survey research should be conducted.

Linking Family-Centered Practices to Family Outcomes

Family-centered practices in EI have been studied from a variety of angles over the past 30 years. In three studies (Bruder & Dunst, 2015; Bruder et al., 2011; Dunst & Dempsey, 2007), researchers examined aspects of family-centered practices; however, they did not directly relate those practices to family outcomes. Family-centered practices are defined as practices that are,

“individualized, flexible, and responsive” while sharing information and respecting family choices within a professional-family partnership (Dunst, 2002, p. 139). These practices include relational help-giving practices (i.e., active listening and beliefs regarding parental competency) and participatory help-giving practices (i.e., individualized support that actively involves the family in decision-making), as well as individualizing services to meet the specific needs of the family (Division for Early Childhood, 2014; Dunst, 2002). While the studies described family-centered practices in a general way, none of the studies defined the family-centered practices that were being studied. For example, Bruder and Dunst (2015) found that families who were the recipients of family-centered practices reported higher confidence in their early interventionists, but the specific family-centered practices that led to families’ perceptions of confidence were not identified.

Lee (2015) conducted an ethnographic study with a family for 6 months, beginning with their entry into EI, through initial eligibility, and during the first several months of service provision. The author did not provide an explanation or rationale for the timeline or decision regarding the end point of the study. Through observations and interviews, Lee examined the use and understanding of family-centered practices leading to the achievement of family outcomes. Several times, Lee reported that while the practices utilized may have been identified as family-centered, the description provided regarding the implementation of a particular practice was not family-centered. For example, the family was provided with information regarding their rights; however, Lee reported that the mother’s impression was that service recommendations could not be questioned and that she (the mother) wondered if many families did not exercise their rights.

Using data from the NEILS study, Popp and You (2016) explored the relationship between parent involvement in service planning and self-efficacy with regards to supporting their

child's development. They found that increased parental confidence and knowledge was correlated with earlier involvement in service planning. However, overall satisfaction with EI was not significantly related to increased parental confidence and knowledge. This suggests that while involvement in service planning is one important factor of self-efficacy, other factors may also play an important role. Further research is needed on factors related to increased parental self-efficacy and satisfaction with EI services.

Aaron et al. (2014) found that there was little discussion regarding family needs at initial IFSP meetings, nor were recommendations individualized based on child and family need. This is important to consider because if family needs are not discussed or documented at the outset of service delivery, they may not be regularly discussed. If family needs are not discussed, there is a good chance that these needs are not being addressed by early interventionists and therefore would not be measureable as an outcome of service delivery. Ridgley and Hallam (2006) also studied the presence of family concerns on the IFSP among rural, low-income families. Through interviews, these researchers found that discussions of family concerns occurred, but were not reflected in the written document. Rather, the IFSP contained mainly child-focused outcomes. These two studies highlight the importance of discussion and documentation of family needs and concerns.

While outcomes were measured across all 19 studies included in this review, there was variation in what was measured and how it was related to the provision of EI services. In general, parents reported positive outcomes or satisfaction as a result of participating in EI services; however, no data were reported that addressed specific practices that led to achieving those outcomes.

Gaps and Limitations

It is important to consider the conceptual and methodological limitations within each of the studies included in this review as we interpret the findings. While several limitations were identified, there are gaps and limitations related to methodology and family demographics. Fewer studies than expected were published that focused on measurement and analysis of family outcomes in EI. This is notable due to the importance of family engagement and outcomes in EI service process. Family outcomes related to specific questions, such as service delivery location, were measured. While there is a rich body of literature focused on family-centered practices, few research studies exist that focus on practices that are directly related to family outcomes. Clearly, there is a need to understand the extent to which family-centered practices lead to positive family outcomes in order to support practitioners through pre-service education and professional development in utilizing those practices that most positively impact children and families.

Epley et al. (2011) discussed the need for further research with families from varying socio-economic and racial backgrounds in order to ensure that information about outcomes and practices are gathered that represent all families who participate in EI. Furthermore, Noyes-Grosser et al. (2013) pointed out that individuals with different roles (e.g., parents and professionals) in the EI system may have different priorities and assumptions about service delivery and therefore it is important to hear from multiple perspectives. While several studies utilized qualitative methodology to better understand families' experiences, those studies often looked at one demographic characteristic, such as rural location or poverty. It is important to investigate if these same findings extend to families with different demographic profiles. Thus, future research should purposefully include families with varying demographics, including race, ethnicity, income, education level, and location. Additionally, demographics were not gathered

routinely across studies included in this literature review. For example, four of the studies reported demographic data regarding the child who was the recipient of EI services, while the other 15 studies reported demographic information about the adult who participated in the study. Information about the child's IFSP, including disability or type of service recommendations, was rarely included. The demographic information reported about adult participants inconsistently included educational background or income. Research with practitioners should include information on their educational background and experiences with different service delivery models.

Conclusion

Family participation in EI services is integral to the achievement of IFSP outcomes, both for the child and family. While there is a large body of literature focused on child outcomes and practices that early interventionists implement with children, little is known about family outcomes as a result of participation in EI. The studies included in this review measured various family outcomes utilizing surveys and interviews. Specifically, input was gathered from family members and professionals regarding the appropriateness of outcomes as well as specific aspects of how the outcomes are achieved.

While the specific outcomes that were measured differed across studies, there were similarities, including family members' understanding their children's development, feelings of confidence and competence in supporting their children, sharing information about their children's needs, and having a support system. Survey and telephone interview data allow for gathering of information from a large number of family members; however, the individual experiences related to participation in EI are not adequately captured through these measures.

Further research is needed to understand factors that serve as facilitators or barriers to achieving family outcomes.

Chapter 3

Methods

In this study, families' experiences and outcomes as a result of participating in early intervention (EI) services in one state were examined. Specifically, the following research questions were addressed:

1. What do families report as outcomes of participating in early intervention, as measured on the Family Outcomes Survey-Revised[®]?
2. What practices do families identify that practitioners use to produce the listed outcomes on the Family Outcomes Survey-Revised[®], including (a) understanding their child's strengths, needs, and abilities; (b) knowing their rights and advocating for their child; (c) helping their child develop and learn; (d) having support systems; and (e) accessing the community?
3. What additional practices and outcomes do families identify as part of their early intervention experience?
4. What family and child characteristics are related to differences and similarities in early intervention experiences, as reported by families?

Data gathered from the Family Outcomes Survey-Revised[®] (FOS-R[®]; Early Childhood Outcomes Center & U.S. Department of Education, 2010) and interviews were used to understand how and why families reported satisfaction or dissatisfaction with EI services and their achievement of family outcomes. Throughout the study, the term "early interventionist" is used to describe all professionals working within the EI system, regardless of role (i.e., developmental therapist, physical therapist, service coordinator, social worker). This study was approved by the Institutional Review Board (IRB) at the University of Illinois. Please see Appendix A for IRB Approval letter.

Study Design

The design for this study was based upon the complementarity purpose of mixed methods research (Greene, 2007). Complementarity refers to using findings from one data source in order

to enhance or clarify the findings from another source. Johnson and Onwuegbuzie (2004) stated that one strength of mixed methods research is that words can be used to add meaning to numbers, which was a primary goal of this study. Through the interviews, parents talked about their responses on the family outcomes survey, how those outcomes were or were not applicable to their experiences, and the rationale for their responses to the survey questions.

Participants

Participant criteria. To be included in this study, participants were required to have a young child who participated in Illinois' Part C EI services for at least 6 months or more at the time of recruitment. The children had to currently be receiving EI services or discharged within the 6 months prior to the start of the study. Participants also had to live or received EI services in Cook or DuPage counties in the State of Illinois. Cook and DuPage counties were chosen as a convenience sample, based on the large number of children receiving EI services in these two counties, relative to the other counties in the state, along with racial and economic diversity represented within the state (Illinois Department of Human Services, 2016b). Finally, parents were required to speak and read English fluently in order to participate in the study; however, it was not required that English was their primary language.

Participant recruitment. Participants were recruited from two Illinois counties, Cook and DuPage, through email, flyers, and social media postings. Recruitment information was distributed through the eight Child & Family Connections offices (CFC; the local level EI intake entity), via service coordinators and parent liaisons, early interventionists, Local Interagency Council meetings, family resource centers, the Early Intervention Training Program at the University of Illinois, the Early Intervention Clearinghouse, school district 619 or early childhood special education coordinators, advocacy organizations, Early Head Start programs,

and through location-specific parent groups on social media. See Appendix B for sample recruitment flyers and email text.

Initial recruitment efforts were for participation in a focus group. Several focus groups were scheduled on different dates in multiple locations across Cook and DuPage counties with which parents were potentially familiar, including an early intervention agency, two different CFC offices, a childcare/Early Head Start center, a community library, and a children's museum, with the potential to schedule additional focus groups based on participant availability. However, after approximately 70 contacts with potential referral sources, including leadership at the local CFC offices (managers, parent liaisons, social-emotional consultants, and lead service coordinators), early intervention agencies, individual early interventionists, parent advocacy or support groups, Early Head Start programs, local libraries, and other community locations where parents of young children frequent, only four parents responded to the invitation. Unfortunately, none of the families were available at the same time. Due to these factors, the decision was made with the support of the student researcher's dissertation committee, to complete individual interviews rather than focus groups. A revised IRB describing this modification was approved (see Appendix A).

Forty-five families indicated interest in participating in the study after the change to interviews was made; however, only 34 interviews were conducted. For the 11 families who were not included in the study, two did not meet the study criteria (i.e., discharged from EI more than 6 months prior, lived in a county not included in the study), two had unexpected family events that prevented from participating (e.g., illness, premature birth of next child), and the remaining seven families lost interest after learning more about the study or they did not respond to three or more follow-up contacts by the student researcher.

Participant demographics. Participants were 39 parents or guardians of 38 children who participated in Illinois' Part C EI services. The majority of the participants were female, over 30 years old, and married. Just over half of the caregivers listed Caucasian/White as their racial or ethnic identity, while 23% listed African American or Black, 15% listed Hispanic or Latino, and 8% listed Asian or Pacific Islander. Forty three percent of participants completed a graduate degree, 36% completed a bachelor's degree, and 21% of participants completed high school or some college credits. Annual income was under \$25,000 for 18% of families, \$25,001-\$50,000 for 21% of families, and over \$50,001 for 61% of families. Five interviews included two caregivers for the same child, therefore a total of 34 interviews were conducted. Four interviews discussed two children in the family who each met study criteria. See Table 2 for demographic information about the caregivers.

Participants also reported demographic information regarding their children, of whom 39% were female and 61% were male. This gender distribution is similar to the state's EI data (i.e., 35% female and 65% male; Illinois Department of Human Services; 2016b). Furthermore, the distribution of study participants by race/ethnicity (see Table 3) closely mirrors current state data (Illinois Department of Human Services; 2016b) except for Hispanic or Latino children who represent 28% of EI participants in the state, which is more than double the number of Hispanic or Latino children represented in this study (11%).

Eight percent of the children were under 12 months of age, 14% were 12-23 months, 53% were 24-35 months, and 26% of children were 36-42 months of age. Forty five percent of children had three or more services listed on their IFSP, 39% had 2 services, and 16% had one service listed on their IFSP. Thirty seven percent of children had been in EI for less than one

year, 29% of children were in EI for 12-17 months, and 34% of children were in EI for more than 18 months. See Table 3 for demographic information about the children.

The primary language in the majority of homes was English; however, 12% of families reported speaking languages other than English as their primary language. Additionally, Arabic, French, German, Hindi, Japanese, Spanish, and Urdu were spoken in 11 homes and American Sign Language was utilized as a secondary language in one home. Two caregivers self-identified as foster parents, representing three foster children. Families lived in 31 different zip codes, with all eight Child and Family Connections intake areas in Cook and DuPage counties represented. Although the city of Chicago is located within Cook county, for the remainder of the study demographic differences were analyzed with Chicago residents separated from suburban Cook county residents. Twelve of the families reported their residence in Chicago (CFC 8, 9, 10, 11), 14 families lived in suburban Cook county (CFC 6, 7, 12), seven families lived in DuPage county (CFC 5), and one family lived in Will county but received EI services in DuPage county.

In Illinois, families receive the FOS-R[®] within several months after their child is discharged from the early intervention system. Therefore, some families could have received the FOS-R[®] prior to participation in this study due to 29% of the children having already been discharged and several families having older children who participated in EI. However, only two families mentioned receiving the survey or that it looked familiar, with one family reporting that they had completed the survey previously.

Participant incentives. All participants received a \$25 Target[®] gift card in appreciation for their participation in the study. In addition, 29 participants received a \$10 Target[®] or \$10 Starbucks[®] gift card after they completed a member check. One family that responded to the member check declined the incentive.

Setting and Materials

The study was conducted in participants' homes or convenient community locations (e.g., University of Illinois Extension office, public library, participant workplace, local restaurant of participant's choosing). Each interview was conducted in person by the student researcher and audio recorded using a digital recording device.

Study Procedures

Research team. The research team was comprised of eight individuals, including the student researcher and one additional doctoral student who were early interventionists, two doctoral students who were familiar with qualitative data analysis, two master's students who contributed an outsider's view with a basic understanding of EI, the assistant director of the Early Intervention Training Program, and the student researcher's faculty advisor. Three members of the research team have worked in the EI system in Illinois as direct service providers and professional development providers.

Pilot. A pilot focus group was conducted with two parents who met study criteria, with the exception of not living in the recruitment area. The participants individually completed the demographic form and the FOS-R[®]. They then responded to the interview questions in a focus group format. After completing the focus group, the student researcher and two members of the research team utilized thematic analysis procedures to generate themes from the focus group data. No modifications were made to the protocol following the pilot.

Study. Participants registered for the study with the student researcher via telephone or electronic mail. Upon registering for the study, the student researcher confirmed with each participant the date, time, and location for the survey and interview. Upon arrival at the selected location, the student researcher explained the study (e.g., information shared will remain

confidential, participation is voluntary, survey and conversation expected to last approximately 60-90 minutes), and answered any participant questions. The participants read and signed a consent form, completed a demographic form, and completed the FOS-R[®]. See Appendix C for a copy of the consent and Appendix D for the study measures.

The student researcher began the interview portion by turning on the audio recorder and thanking participants for their interest and participation in the study. Participants were asked to talk about their entry to EI services. The student researcher then provided a handout with two hypothetical scenarios of experiences of families in EI and read the scenarios aloud while the families followed along with their copy (see Appendix D). The student researcher then asked participants to respond to the aspects of service delivery described and how the experiences depicted in the scenario were similar or different to what they personally experienced. Following the semi-structured protocol, the student researcher asked questions related to each of the five outcomes and asked probing questions when necessary to clarify responses and gather more information. Once all questions in the protocol were discussed, the student researcher gave participants an opportunity to share additional information they felt was important about their EI experience and that had not already been discussed. At the end of each interview, the student researcher asked the participants to review the FOS-R[®] they completed prior to the interview. She asked them to indicate any changes to their answers with a red pen and then turned off the audio recorder while they completed this task. Once the participants completed their changes to the FOS-R[®], the student researcher talked with them about their survey changes, thanked the parents for their participation, and provided them with the gift card incentive. She reminded participants that they would receive an email with a summary of the interview and a request to review the summary. Thirty-four interviews were conducted, totaling 1,501 audio-recorded

minutes. The average length of the audio-recorded portion of the interview was 44 minutes, with interviews ranging from 22 to 95 minutes.

A professional transcription company transcribed the audio recordings immediately following the completion of each interview. The student researcher compared each audio recording to the transcription and corrected any inaccuracies. NVivo[®] software was utilized to organize the data.

After the first round of data analysis was completed, a member of the research team compiled a brief summary of each interview, organized by outcome. The student researcher reviewed and edited the summaries. She then emailed each participant his or her summary with a request to review it and confirm that the summary accurately represented the conversation, or to note inaccuracies. Each participant was informed of an incentive of a \$10 gift card if they responded to the request. If a participant did not respond to the original email, a second email was sent. A response was received from parents representing 30 of the 34 interviews for an 88% response rate. Two participants requested minor changes to the summary while 28 parents indicated that the summary accurately reflected their interview.

Fidelity Check

A graduate student was trained to complete a fidelity check during the data analysis phase. The fidelity check ensured that all required components of the study were completed, including signed consents, audio recording, and survey distribution. Additionally, the fidelity check included required components and topics of the interview, to ensure that all participants had the opportunity to share the same information. See Appendix E for a copy of the fidelity checklist. All study procedures were completed, with 100% adherence to the checklist for all participants.

Measures

In order to address the research questions posed in this study, data were collected using the following tools: (a) a researcher-developed demographic survey, (b) the Family Outcomes Survey-Revised[®] (Early Childhood Outcomes Center, 2010), and (c) interview protocol. Each measure is described next.

Demographic survey. A demographic survey was developed by the student researcher to collect information about children's participation in EI services, as well as select family characteristics. Questions included the length of time in EI, type and frequency of EI services received, and racial and economic information. Two early interventionists, two EI professional development facilitators, and one family member reviewed a draft form of the demographic survey. Based on their feedback, as well as feedback from the student researcher's dissertation committee, revisions were made to the demographic form. The demographic form took approximately five minutes to complete. See Appendix D for a copy of the demographic survey.

Family Outcomes Survey-Revised[®]. The Family Outcomes Survey-Revised[®] (FOS-R[®]) is a tool that was developed by The Early Childhood Outcomes Center and is utilized in 17 states to measure family outcomes annually (Early Childhood Technical Assistance Center, 2017b). The Family Outcomes Survey (FOS[®]) was developed based on the literature, expert consultation, focus groups with families, and feedback from stakeholders (Bailey et al., 2011). Validation studies were conducted on the use of the FOS[®] in two large states and revealed that the demographic information and questions related to perceived helpfulness of EI and family-centered practices were related to the measured family outcomes (Olmstead et al., 2010; Raspa et al., 2010). Based on feedback from users, several methodological issues were raised, including the use of a 7-point scale and the number of questions measuring each construct. Thus, a revision

process was undertaken and through further feedback from expert reviewers, stakeholders, and families, the FOS-R[©] was developed (Bailey et al., 2011). Psychometric properties of the FOS-R[©] were measured, with a Cronbach's alpha ranging from .73 - .94 for each subscale (Bailey et al., 2011). The FOS-R[©] consists of 24 items measuring five family outcomes and 17 items measuring OSEP helpfulness indicators. See Appendix D for a copy of the FOS-R[©].

Interview protocol. Interviews are used to gather in-depth information about a particular subject. The semi-structured interview protocol was developed based on the data measured in the FOS-R[©] and designed to probe more deeply into each of the topic areas covered on the FOS-R[©]. The protocol included two scenarios and seven main questions, with probes included for further discussion regarding each question. Two scenarios describing differing hypothetical experiences of EI services were read at the beginning of the interview in order to give participants a tangible experience upon which to relate their own experience. One parent who previously participated in EI services served as an expert reviewer of the protocol and provided feedback regarding the content and structure of the questions. See Appendix D for a copy of the interview protocol.

Data Analysis

Descriptive statistics, including means and ranges of the aggregated data from the FOS-R[©] were calculated to analyze the survey data. Descriptive statistics also were utilized to examine demographic differences in survey responses, including participant residential location, income, race, and parental education level. Qualitative analysis procedures were used to analyze the interview data. A collaborative analysis approach was used to analyze the data from the interviews by a research team who was familiar with EI as well as research methods.

The transcriptions were coded to identify common, overarching themes. Each transcript was reviewed by two to five team members during the coding phase. Initial analysis began after

four interviews were complete, and the analysis and data collection period continued simultaneously. Analysis occurred in four stages. First, members of the research team coded the transcriptions independently. Several members of the team chose to simultaneously listen to the audio recordings as they read the transcripts in order to hear tone, inflection, and intonation of the parent's voice during the interview.

Second, members of the research team came together to discuss the themes and subthemes and arrive at consensus for coded segments of each transcript (Miles, Huberman, & Saldana, 2014). The identified subthemes provided a rich description supporting each of the overarching themes (Santos & McCollum, 2007). During this meeting, the student researcher shared context with the research team that was not evident from the transcript or audio recording. For example, two members of the research team commented that one parent's voice sounded monotone during the interview, that she spoke in a slow, measured pace, and that she referred to "the child" rather than by his name, and therefore questioned if there were concerns with attachment between this parent and child. The student researcher was able to explain that this was a foster parent who was very intentional about protecting the child's confidentiality, therefore she was very intentional in saying "the child" while the audio recording was on. After the first 17 transcripts were coded, the full research team came together for a discussion on consolidating codes. The remaining 17 transcripts were then analyzed with this set of consolidated codes and then the first 17 transcripts were re-analyzed using this same set of codes.

Third, members of the research team reviewed the coded segments organized by themes and subthemes across all interviews to determine if each code was appropriate for the segment and to ensure cohesiveness and consistency across coded segments. Minor changes were made to

the working set of themes and subthemes, and a final set of codes was developed (see Table 4 for the final codes).

Finally, two members of the research team independently evaluated the transcripts and surveys to determine if there was a match between information learned based on data source. There were three levels of coding: “complete match,” “partial match,” or “not a match.” After independently coding, the research members discussed each outcome and helpfulness indicator to come to consensus on the perceived match based on data collection method for all 39 participants. This mixed methods design allowed for a deeper and broader understanding than what could be generated from one method alone (Greene, 2007).

Trustworthiness and credibility. Trustworthiness and credibility of the findings were ensured through the use of triangulation, member checks, collaborative work, and development of thick, detailed descriptions (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Methodological and data triangulation occurred through the use of multiple data sources, researchers, and methods. Member checks, as described in the previous section, were conducted with interview participants. A document detailing the information gathered around each outcome was sent to each participant to provide them with an opportunity to respond to the accuracy of the interpretations of the data.

By utilizing a collaborative analysis process, bias and disconfirming evidence were discussed by the team members. Interpretation of data was arrived through consensus building (Santos & McCollum, 2007). Thick, detailed descriptions were pulled from each transcription and used as evidence for each theme.

This study addressed validity in that the student researcher was a former early interventionist who supported children and families as well as a member of the state’s

professional development team for EI. The research team was comprised of eight individuals who had backgrounds in EI and/or research methodology.

Reflexive Statement

Brantlinger et al. (2005) recommend that researchers should be “explicit about personal positions, perspectives, and value orientations” (p. 198) in order to ensure credibility within qualitative research. Thus, in this section I disclose my background, beliefs, and perceptions relevant to this study. I was an early interventionist and professional development provider. I believe that families participating in EI are entitled to receive high-quality services and support. Through participation in EI, families should receive information and strategies that help them support their child’s development and participation in family and community activities. Families should have a voice in how they perceive the quality of their EI services and how useful these services have been. I am a strong advocate for early interventionists who believe in and utilize a family-centered focus within their EI practice. Conversely, I struggle with early interventionists who utilize a child-centered focus and do not engage families as active participants within their child’s EI experiences. When listening to family stories, I must ensure that I do not show bias or disclose my personal feelings, so as not to make a family uncomfortable with or question their EI experiences.

Chapter 4

Results

The findings of this study are organized by the five outcomes from the Family Outcomes Survey - Revised[®] (FOS-R[®]). For each of the five outcomes, the following topics are discussed: (a) findings from the overall survey (Research Question #1), (b) survey results based on select participant demographic variables (Research Question #4), (c) interview themes (Research Questions #2 and #3), and (d) results based on a comparison of the interview and survey responses (Research Questions #1 and #2).

Data for the interview themes were derived from 1,496 uniquely coded segments pulled from across the 34 interviews. All 39 participants, including when two caregivers were interviewed simultaneously, contributed to each theme. The number of coded segments derived from each interview ranged from 24 to 98 unique segments. The five overarching themes that emerged from the interviews include: (a) early intervention facilitators, (b) early intervention barriers, (c) impact of disability on family life, (d) family advocacy, and (e) parents' "wishes" for their children's services. See Table 4 for a list of all themes and sub-themes. The coded segments included in the facilitators and barriers themes relate directly to the families' experiences with the early intervention (EI) system. The family life code was used when parents talked about factors beyond the EI system that impacted their experience of parenting an infant or toddler with disabilities or delays. Coded segments entered under the advocacy and wishes themes included topics both within and beyond the EI system.

For each outcome, representative quotes were chosen to expound on the themes. Each theme contained sub-themes and while all sub-themes are not discussed, those selected are the ones emphasized by families as important related to their experiences and family outcomes.

Additionally, quotes were chosen that represented common experiences shared by many of the participants. Finally, other quotes were selected because they were unique and at the same time important based on the families' particular experiences.

Understanding A Child's Strengths, Needs, and Abilities

Survey responses. Questions on the FOS-R[©] related to the outcome of parents understanding their children's strengths, needs, and abilities include parents knowing next steps for their children's learning, understanding their children's strengths, abilities, needs, and delays, and knowing when their children are making progress. Across the 39 participants, parents reported that their family "almost" or "completely" understood their children's strengths, needs, and abilities. There was a small increase in the overall average from pre-interview to post-interview.

Questions on the FOS-R[©] related to the helpfulness of early intervention in communicating their children's needs include early interventionists giving parents useful information, listening to parents and respecting parental choices, talking with parents about their strengths and needs, and developing a good relationship with the family. Across the 39 participants, parents reported that on average, they perceived early intervention as "very helpful" or "extremely helpful" in providing them with information and resources related to communicating their children's needs. There was no change from pre-interview to post-interview. See Table 5 for FOS-R[©] ratings.

Demographic differences. A closer examination of the FOS-R[©] items revealed several particulars that were worth noting based on the parents' reported residential location and income (see Tables 6, 7, 8, and 9 for additional details). When examining responses based on participants' residential location, the helpfulness of early intervention in communicating their

children's needs was lowest for residents of Chicago than for residents of suburban Cook or DuPage counties. Participants with incomes of \$25,000-50,000 reported the largest increase in understanding their child's abilities from pre-interview to post-interview, but also reported that early intervention was much less helpful than participants in all other income brackets.

Early intervention facilitators. When asked about specific practices or strategies that early interventionists used to support families related to "Outcome 1: Understanding Your Child's Skills, Strengths, and Needs," parents provided a variety of responses. The strategies most frequently mentioned revolved around having specific information for their children and engaging in open communication. Parents reported that demonstrating or modeling a specific strategy, brainstorming together, and giving information regarding development or recommended readings were useful.

Usually, the therapist will demonstrate something or we'll kind of brainstorm together because I realize, through doing therapy, that whatever new activities or skills we're trying to introduce, I need to know how to incorporate it in my everyday life. It can't be like hey, here's this. Go figure it out. Like I need to walk through. Like with diaper changing, would it be a good time to do it? Do we need to sit down and actually focus in on doing it? (C6.14.01)

I think it's helpful to get the information from the provider so that I can ask my questions right away. Also, having a tip sheet can be helpful. I think initially, when she was a baby, our DT-H [Developmental Therapist-Hearing] would actually give me little articles each week so I could read about her hearing loss and speech development. I thought that was really helpful. (D6.29.01)

The importance of communication was often mentioned, with parents reporting that they valued responsive communication from professionals. As one parent stated, "My coordinator was excellent. I called her if I had any type of issue or concern. She always called me back" (C6.15.01). Parents also noted the importance of early interventionists who were open to hearing concerns, engaged in conversations with parents about their child's skills and struggles, and who provided written information regarding what they could do throughout the week. Several parents

mentioned that early interventionists sent videos or text messages to them if the session was held at childcare or with a babysitter and that was a welcomed form of communication so that the parent was immediately aware of what happened during the session.

You know, I like the conversation because it becomes a task for me. And we text a lot, which is helpful because you can do it quickly or then, I can get a quick link. The other thing that I really like, because I like seeing my kid too, is sometimes my sitter will take. . . . They'll meet M (PT), like out, around to a park. So, I work from home, so when they're here, it's nice because I can join in, but then they'll go out and about and M will take videos and text them to me, which is awesome. Because, you know, I get to see R and then she'll explain like, "Okay, this is what we're doing and see how he's doing that? I noticed that." Then it's like, you know, 45 seconds, so it's quick for me to watch and it's specific to my child. (C6.16.01)

Additionally, parents mentioned early interventionists who were empathetic to and supportive of families' emotional needs.

They really just teach us to really just concentrate on those small victories and I feel like that is huge 'cause before I feel like when we do playgroups with other hearing children and everything like at the park and people through the library and my friends, like you almost can get completely just down on yourself over just your kid's just not there. (W6.14.01)

Connecting with him. All the therapists that came to the house connected with him. They had a real emotional connection to him. They connected with us. They were respectful to us. They taught us things to do during the week. They answered all of our stupid questions because we were clueless. We did not know what the heck was going on. We were scared out of our mind. (C6.26.02)

Early intervention barriers. Parents described several barriers including accounts of child-centered sessions where the early interventionist worked directly with the child, rather than coaching the family. One parent commented, "There was not really much time to talk about what I did or didn't do the previous week" (C6.22.02). With child-centered sessions, parents lamented that early interventionists did not help them figure out how to utilize therapeutic strategies in their daily routines. Interestingly, while parents expressed frustration with child-centered

sessions, they also frequently mentioned how much they liked and appreciated their early interventionists.

Sometimes, I wish our developmental therapist could just show me or help me figure out. . . . What she does is so great. It's one hour of intensive play. I don't know how to do that in my daily life with everything else. I mean I do play with the kids a lot. It's in 10 minute spurts here and there, 15 minutes. But not an hour of focused time, so sometimes I wish I could do what she does with him because when she leaves, he's super focused and really interested in everything. What she's doing works. I just don't know how to do that. (C6.14.01)

Additional barriers that families experienced included early interventionists who did not show up for scheduled sessions or return phone calls, did not take into account a family's values (e.g., regarding parenting choices around food for their child), or did not talk with families about expectations. Parents also mentioned that they did not receive any written documentation at the end of each session so that they could utilize strategies throughout the week or inform a non-attending caregiver (e.g., spouse who was away at work during EI sessions).

Even though we don't have that conversation every time she comes, they do come up periodically. . . . I think it would be great, coming back to your example of the two scenarios, the one with Mara and Shari, I wish I had more of a relationship like that with her because I do value her expertise. I think she's very good at what she does, and I think I could get more of the sessions if we had that conversation daily. (C6.23.01)

Father: Yeah I really, and I'll speak for you, we had no idea about the direction of where care was going.

Mother: No.

Father: We just didn't know. I mean we didn't know what was next, what timelines were, what the expectations should be. (D6.21.01-02)

Impact on family life. Families also mentioned how they gained new information about their children's skills, strengths, and needs in relation to their children's disability or developmental delay. Several parents mentioned that they learned about their children by being with them and observing them during sessions. As one parent stated, "I just compare to how she was before to things that I see her doing now, and that let me know that she progressed at some

levels of some things.” (C7.17.01). Parents mentioned how they were intentional about observing progress in skill development.

Well, just being with him. Talking with, we try not to get so fixated on like, what should a typical child at this age be doing because it’s just you’re fixing on what he’s not doing. We have been fortunate to see a lot of regular progress and most of the areas he’s working on. It’s obvious. Even though it’s like, they know smaller increments than you might see a typically developing child but they’re noticeable. (C6.30.01)

By observing him, I would say, and putting him, I mean involving him in other activities where he’s around other children his age and kind of just comparing what they’re doing versus what he’s doing, and then also what I read about based off of where he should be with development, but also when I started early intervention they did give me that chart that lists the milestones where he should be by different ages so that was helpful as well. (C6.30.03)

Parents talked about all of the sources of information that they accessed to gather information about their child’s development. While they learned from the early interventionists they also used additional sources such as books, websites, social media, parent groups, tip sheets, conversations with parents, and other professionals outside the EI system.

For me, I do feel very in-tune with what H is doing and obviously, then as a mom once everything happens with H, I’m the internet warrior. Everything with a grain of salt, though. I go this way. I look at this way. I look this way. I’m on the different Facebook groups and mom groups, and things like that with CVI [cortical visual impairment], I was trying to get involved with EI and everything. . . . EI helps though in that way. They’re letting me know. He’s under a microscope. He is with the therapists, so they’re letting me know, “Okay. Functionally, he’s here, but you know what? I’m seeing this bug-a-boo. We’re working on this, this week and this is a little difficult for H.” That’s always our conversation. (C6.27.01)

Family advocacy. Much of the advocacy efforts parents described in relation to Outcome 1 were specific to gathering information about their children’s diagnosis, services, or skills. However, one parent, who worked in the early care and education field talked about how she encouraged parents at her workplace to advocate for their children, relaying what she did to be involved in sessions for her child when those sessions occurred at home with the grandmother.

So I would advocate for them to advocate for their child, and speak up, and ask, and request information even if sometimes you're not able to be there. Me, in my situation, I feel like I'm fortunate to be able to get on the video chat to speak with these people, communicate with these people. I see a lot of people who don't do that. So one of the things that I've asked is that there be some type of tracking or written communication. (C7.20.01)

Family wishes. Several wishes that parents mentioned included having information available in multiple formats. Several parents mentioned that they learned differently from their spouse, so it was important that there were different ways used to gather information related to their children's diagnosis and development.

For me I much prefer to do research, like dig into it. I want to read something about it, whether it be in print or online. I like finding things and reading through things, whether it be something more formal like something published or even just a mom's blog. I know for my husband he prefers to get information auditorily. He likes when he has a chance to be home because he wants to hear that information directly from somebody. He's not into the research. (D6.28.02)

One parent described a wish for a video library that showed specific techniques or explained vocabulary development. The parent noted that she could then access this library when it was convenient for her, rather than only having access to the techniques and explanations during the EI visit.

If I'm still not getting this one technique, I could just type in the technique, it pulls up the library, and it shows me a video of like this. I feel like, if I had that kind from EI, that kind of access, it would just make it so much better because, I mean, like I said, the therapists do a great job of trying to tell me, but you know, not being a therapist myself, I may not always understand exactly what you mean by fine motor, gross motor. (C6.30.04)

Another parent described the importance of team communication and wished for a streamlined communication from one location. This wish included a way for her to communicate and document, as well as for her to receive information from her team members.

A trail, something that you can gauge, a stronger line of communication between just the whole system of therapists. Something that if everybody could do newsletters, and have access, or the team could have access to it, I think that would be beneficial for everybody.

. . . To be able to say, “Okay, this is what they were doing.” Maybe a reminder of some of the things that worked. I think it’s very helpful to everybody who’s involved with helping that child. . . . You know, where all your therapists can be there linked to it. They can what they do, communicate. It’s more solid because it’s one go-to place for information. Then if you need it to give it to your physician, or you need it to have some type of summary available to give to your social worker, or for court, it’s there. You don’t have to wait for six months. . . . Something that you can access, and you can comment, or notate. I can go in and add something, or express my ideas, or opinions, and give feedback, and reverse. (C7.20.01)

Overall, parents mentioned a variety of strategies that early interventionists utilized to help them learn about their children’s skills, strengths, and needs, including providing individualized information that was specific to their children’s current development and communication that was in the parent’s preferred mode based on their learning styles. Parents mentioned brainstorming, having input, modeling, and receiving coaching throughout the session as valued practices implemented by their early interventionists. The importance of communication and documentation were highlighted through examples of strategies that worked, barriers parents experienced, and wishes for improved services and supports.

Survey and interview comparison. Findings related to parents’ understanding their children’s strengths, needs, and abilities from the two data sources were highly consistent when results reported on the FOS-R[©] were compared to the results drawn from the interviews. See Table 10 for comparison between the survey and interview responses. Participants in 35 interviews relayed information that was consistent with their responses on the survey and participants in four interviews related information that appeared to partially contradict the responses they provided on the survey for the outcome of parents’ understanding their children’s strengths, needs, and abilities. There was less agreement between the survey and interview responses on the helpfulness of EI for parents in communicating their children’s needs. Twenty-three participants relayed information during the interview that was consistent with survey

responses while 16 participants' responses to the interview appeared to partially contradict their survey responses. Most of the discrepancies between the interview and survey responses were related to how EI services were not completely useful or specific to family needs, yet parents rated EI as "extremely helpful" on the FOS-R[®] questions related to parents understanding their children's strengths, needs, and abilities. One barrier frequently mentioned was related to child-focused services where parents' input was not invited, even though many of the participants responded that EI was "very helpful" or "extremely helpful" on the survey item, "How helpful has early intervention been in talking with you about what you think is important for your child and family?"

Knowing Your Rights and Advocating for Your Child

Survey responses. Questions on the FOS-R[®] related to the outcome of parents knowing their rights and advocating for their children include parents being able to find and use services available, knowing about their rights related to their children's needs, knowing who to contact with questions, and knowing about their transition options. Across the 39 participants, parents reported that their family "almost" or "completely" knew their rights and was able to advocate for their children. There was a very slight decrease in overall average from pre-interview to post-interview.

Questions on the FOS-R[®] related to the helpfulness of early intervention in parents knowing their rights include early interventionists giving families useful information about services and supports, providing useful information about parental rights, and explaining rights in ways that are easy to understand. Across the 39 participants, parents reported that on average, they perceived early intervention as "very helpful" in providing them with information and resources related to knowing about their rights. See Table 5 for FOS-R[®] ratings.

Demographic differences. A closer examination of the FOS-R[®] items revealed several particulars that were worth noting based on the parents' reported residential location, income, or educational level (see Tables 6, 7, 8, and 9 for additional details). When examining responses based on participants' residential location, the helpfulness of early intervention in relation to parents knowing their rights was higher for residents of DuPage county than for residents of Chicago or suburban Cook county. Participants with incomes of \$25,000-50,000 reported that early intervention was much less helpful than participants in all other income brackets. Participants with graduate degrees were the least satisfied when rating the helpfulness of early intervention as compared to participants with bachelor's degrees or who completed high school.

Early intervention facilitators. When asked about specific strategies that early interventionists used to help families know their rights, parents most frequently mentioned the importance and helpfulness of engaging in conversations with their early interventionists. They often spoke about knowing that they have rights within the system but that they were largely unaware of those specific rights. Many of the parents mentioned that they received a booklet that explained their rights, but they did not read it. However, they often mentioned the importance of engaging in conversations around parental rights. As one parent stated, "I'm quite sure that they understand that a lot of people don't read the book, so it's ear to mouth that they let you know also that you do have those options." (C7.17.01)

Additionally, parents talked about how the intake process was overwhelming, and that they did not remember learning about their rights from that meeting, beyond receiving the booklet. As one parent stated, "I think the first meeting can be kind of overwhelming. Just because it's so much information. And you're stressed, you're nervous, you're anxious."

(D6.28.01). Multiple parents said that they did not know their specific rights but that they had a general idea regarding rights.

I have no idea. I don't know what they are. I can make an educated guess. I don't know. That could be that first time that our coordinator came, we signed a ton of papers. Again, it was a much harder time in life where it was like so much information. Right. I can't say for sure that that was not communicated to us. I don't remember. (C6.30.01)

I don't know about technical rights, but I am a parent and I feel that I have the decisions. I make the final decision. What they kept telling me during the intake interview and all that stuff is whenever you feel that you don't want the service, all you have to do is call and say no. . . . I feel that I have input. I tell them. . . . What they ask is, what are your goals, what do you think she needs to work on? I tell them what I think. They give the technical terms, but I'm like I want her to do this and that. And, they're like, oh, okay, and that's it. (C7.26.01)

Often, parents did not appear concerned that they did not know their specific rights, as they felt that they could call or talk with their early interventionists if they had questions.

My coordinator. She helps me with a lot. If I don't know something I'll call her and ask her. And she is very open to giving me information that's needed or she'll refer me if she doesn't know, she'll refer me to another person to help me get things in order for them. (C7.26.02)

Unfortunately, other parents reported that rights were not formally discussed, nor was the importance of knowing their rights stressed by the early interventionists.

I feel like it was kind of glossed over. Like, "We just want you to have a copy of this." Kind of like the HIPAA thing, when you go to the doctor's office: "We have to give it to you, you'll never need it." (D6.28.01)

Parents referred to the support they received through the transition process as a helpful aspect of EI. During meetings with the school district, one parent referred to her service coordinator's helpfulness, "Oh yes, she set up everything. Oh my god, it was so awesome of her. She even called me afterwards just to make sure how it went and everything." (C6.23.02). Other parents wished that information beyond the school district would be provided, particularly if their children may not qualify for an IEP.

Early intervention barriers. In addition to not understanding their rights within Part C, a barrier frequently mentioned by parents was the length of time they waited for evaluations to be conducted or direct services to be implemented. The majority of parents indicated that at some point during their time in EI they were on some type of a waiting list, did not have an assigned early interventionist, or were frustrated by the lack of communication from their service coordinator regarding when a particular service would begin. Several parents mentioned a long waiting period for paperwork to come through, either regarding insurance or assistive technology. In these cases, parents did not know what to do beyond leaving messages with their service coordinators or following up with their early interventionist during a session. Most parents mentioned that they continued to wait. Several parents called the state agency's office, visited the regional office when phone calls were not returned, or contacted therapy agencies to seek potential services on their own. One parent mentioned that she knew she had the right to switch early interventionists but she did not want to tell her service coordinator that the speech therapist was not a good match for her family because they had waited a long time for speech therapy to begin initially and was afraid of having to wait again for a new speech therapist. One parent described her frustrations with more than a four-month waiting period for services,

I've called service coordinators, Springfield, individual providers, and then hospitals because my insurance was limited. Because I have military insurance, it was limited to hospitals. I couldn't just call the different therapy services that were offered in [town 1], the different companies, because they just didn't take my insurance, but hospitals took my insurance. I literally called every hospital and most of them all had waiting lists if you were going through EI . . . I got to the point, I'm taking EI off the table. She needs these services. I have insurance. Let them pay you. I didn't care who paid as long as she got the services. Then I did get to one service provider. She was out in [town 2]. She perturbed me a little bit because me going in, I don't care who's paying you. I don't care if it's my insurance or if it's EI. She literally asked me, "Well, could you sign this form so your insurance can pay me, because they pay me more?" I was like, "Is that really something that you should be speaking to me about? Shouldn't you be talking to my coordinator?" If that's your issue, that's your issue, but me as a parent, I don't think I need to know that as long as you're providing the service to my child. (C6.3.01)

Several parents wondered if the difficulties they encountered with the lack of timeliness for services were related to state budget issues.

And sometimes I think with the giant budget crisis, maybe they just don't have enough money, and so maybe the kids who are kinda borderline, maybe they ought to be getting speech therapy, maybe they just aren't because there isn't enough money? You know I wonder about that. (D6.22.01-02)

Parents shared how they learned about EI and the process that led up to the initial IFSP development. Several parents described the intake and initial evaluation process as overwhelming, while others talked about how unsure they were as to how each person fit into the overall experience. As one parent shared, "It was a little overwhelming to have all the therapists at my house. His initial assessment, there were four therapists here, which is really kind of intimidating." (C6.14.01). Another parent stated,

They came in probably four at once. So it was little bit overwhelming, 'cause we didn't understand. We didn't think anything of it, other than maybe, he's just gonna catch up eventually with his speech. They came in, they did an evaluation, so we had a speech, the DT, the OT, and two more, a coordinator, that was I guess assigned to me. And someone else I guess higher up. So probably it was between five and six people in the house. So basically it was just a little overwhelming because it was like busy with trying to figure out, you know, what maybe what N needed, to get a correct assessment for him and get him the correct services. (C6.15.01)

The importance of communication was brought up frequently. While some families reported that the frequency of communication between early interventionists and families was good, several parents expressed a desire for more communication. Most families reported that they did not receive a monthly call from their service coordinator and would only hear from them right before a scheduled meeting. Parents expressed wanting more frequent interactions with their service coordinators.

I think, too, the idea of checking in a month later would also be great just because we didn't get a check-in and we had a little bit of a rough start. I feel like I would've appreciated that. Not that we needed a new therapist but that it was just difficult timing.

We problem-solved it. We figured it out, but I would've been curious to see what that conversation would've looked like if it had happened. (D6.28.02)

Additionally, there was confusion regarding paperwork. Parents mentioned that they did not receive consistent paperwork throughout their children's time in EI. Some parents reported that they received copies of daily notes or documentation from therapists after each visit, while most did not receive anything except for the formal IFSP document. Parents also expressed frustration at the lack of real world applicability of parts of the IFSP process. In particular, one parent described the paperwork as "A means to get services" (C6.14.01) rather than something that was useful or that families could relate to.

I know goal setting needs to kind of be a big picture thing, but maybe something that's more related to his everyday life, not so much we want C to acquire language and blah, blah, blah, be able to use it, but like something more specific as like we would like C to express his wants and needs when it comes to taking care of himself and getting food and his basic needs. Or something really specific like that. (C6.14.01)

A barrier mentioned by several parents was the delay in referral to EI from a pediatrician. Several parents were told to wait until their child was 2 years old, even if after they had expressed concerns at an earlier time.

At 18 months, she did. She was concerned he wasn't talking much. He had a few words that he was using inconsistently like mama, dada and I think banana. That was like all he was saying. She had said, at the 18-month, if he wasn't speaking by two, she was going to recommend it. (C6.26.02)

Several parents who relayed stories similar to this have children who now have a diagnosis of autism. Parents eventually received a referral to EI but did not realize that they could have self-referred thus possibly enrolling in EI even sooner than they did.

Impact on family life. Much of the discussion related to parents knowing about their rights and advocating for their children revolved around parents' ability to gain new knowledge regarding the transition process and the worries that parents had as their children grew older. To

learn about the EI system or receive a referral, parents actively requested information or prescriptions from pediatricians, talked with therapists in their local communities, sought out advice from other parents, engaged with professionals in other home visiting programs, and attended local developmental screening events. After their children qualified for EI, several parents reported that they attended workshops on Individualized Education Programs (IEP), 504 plans or Americans with Disabilities Act (ADA) rights, as well as information sessions or conferences that were specific to their children's diagnosis. Several parents mentioned feelings of anxiety around the transition period, as they did not want EI to end and were unsure of the options for school district services. A parent of a child with multiple and complex disabilities mentioned the struggle between advocating for her child and waiting to learn about the process, "Since basically we've found out, I've been terrified about that transition. I feel like I'm almost hyper geared up to be an advocate and maybe I need to see what happens before I go out fighting" (C6.30.01). Several parents had family members or friends who worked in the education field or who had prior experience with EI and mentioned how those individuals were a source of support for them and their children. In particular, they noted how friends and family members became a sounding board when they had questions regarding their rights and next steps for the children.

Family advocacy. Many parents mentioned that their prior experiences, either personally or professionally, prepared them to advocate for their children in EI. Parents who did not have any advocacy experiences stated that they simply figured out what to do because their children needed it. Additionally, some participants expressed concern for other parents who they perceived to have fewer resources than themselves. They noted that they had the advantage of being able to access additional options, including privately paid services that were outside of the

EI system or personal contacts who helped to speed up processes. Again, they were worried for families who had less means and primarily dependent on state resources to access services.

I feel like how do families find out about it, they find out through their doctor. Us having a doctor who told us about it was good. If our other doctor would have told us earlier, that would have even better. How are other families finding out, I don't know. How are families who don't speak English finding out? How are people who don't have money to go to doctors finding out? I would like to see maybe more about this in public places, maybe at the library. I don't know. (C6.26.02)

One parent described how she was viewed as an advocate by her former service coordinator:

I still talk to her [SC]. She'll use me as a resource, which is pretty much how you got to me. She's like, "Can you go and just tell them what you experienced with us?" Like, "Maybe if other people talk, maybe we'll get the same resources that other areas have." It really, for them it wasn't like, "Oh, we don't care about our families." We do care about our families, we just don't have the resources and tools available to us that other areas have, and they really were very distraught. They didn't appreciate it, more so, that they know other areas in the city were getting all these things with no hassle, but they felt as if their families always had to go above and beyond, and for them, I was probably one of those parents that was like, "Look. My child needs it, she's going to get it. Either you're going to work and point me into the right direction or I'm going to work another system to get in through the back door, the front door, however." My child was going to get her services. (C6.3.01)

Family wishes. Wishes from parents included having EI supports until the beginning of the next school year for children with mid-year birthdays or EI lasting until age 5. The families who had already experienced the transition process into preschool expressed how grateful they were for the support from EI. When asked how EI could help support parents to better understand their rights, one parent's ideas included group discussions with other parents.

It's just like having a parenting group. It works better when you're with other people. If you're in a group or room with people and everybody is not a talkative person, but if you start to hear things, they're like, "Wait a minute. I agree with you, because I've experienced that, too." It gets us to come together and share our information. (C6.3.01)

Parents mentioned a variety of strategies that they felt could make their rights more accessible and meaningful including conversations focused on rights, not during the intake visit with all of the other paperwork. Other suggestions included a bulleted list or a one-page handout

with quick information regarding the “Top 5” rights and links to provide more information.

Access to information on rights via an electronic format also was brought up by parents as a way that they preferred receiving information.

Personally, maybe some of it being reviewed in person, because what parent of two kids have time to read and then to read something that isn't. . . . We don't have me time, so I feel like maybe incorporating it at the meeting in bullet points. Of course, you can't go over everything, like maybe one of the initial starts is these are your rights and it'll take less than five minutes to explain, so then therefore it's said out loud. If you need to reference in detail, here's the details, but at least maybe in their parents' brain it's gotten interjected verbally, because I feel like as much as going to technology and to paper resources, the human interaction is going to stick, so if my therapist or case worker's like, “Well, if you don't like your therapist, you have the right to change.” . . . I know I would be more the conversation person, maybe someone like my husband, like there was a website that you click, kindly ask questions, how do I blah, blah, blah, and he's obviously into computers and just click it, read it maybe. (C6.22.01)

I think probably a more effective way would probably be to have a video. I do a lot of online training. I find it typically to be more effective for things like that when you're able to watch it, have a breakdown of each component explained examples. Then maybe something to survey where you're at with each component in the booklet. So, I think something like that would probably be more effective than handing a book off. Then I wouldn't have to call all those people that I'm networking with who have the book now. (C7.20.01)

Survey and interview comparison. Information reported on the FOS-R[©] were consistent with the information generated from the interviews. See Table 10 for a comparison between the survey and interview responses. Participants in 30 interviews relayed information that was consistent with their responses on the survey in relation to the outcome of knowing your rights and advocating for your child, while eight interviewees shared information that appeared to partially contradict the responses provided on the survey. One participant in particular reported very different information in the interview when compared to her survey responses.

There was even less agreement between the survey and interview responses related to the helpfulness of EI in parents knowing their rights. Twenty-three participants shared information during the interview that was consistent with their survey responses. Notably, 16 participants'

responses to the interview appeared to partially contradict their survey responses. Most of the discrepancies between interview and survey responses were related to participants' report that they did not understand their rights, yet they rated EI as helpful on the FOS-R[®] (i.e., "How helpful has early intervention been in explaining your rights in ways that are easy for you to understand?"). In addition, parents mentioned difficulties related to the transition process, yet they often marked EI as "very helpful" or "extremely helpful" in relation to the question, "How helpful has early intervention been in giving you useful information about available options when your child leaves the program?"

Helping Your Child Develop and Learn

Survey responses. Questions on the FOS-R[®] related to the outcome of parents helping their children develop and learn include being able to help their child learn new skills, take care of his/her needs, get along with others, and work on goals during every day routines. Across the 39 participants, parents reported that their family "almost" or "completely" were able to help their child develop and learn. There was no change in overall average from pre-interview to post-interview.

Questions on the FOS-R[®] related to the helpfulness of early intervention in parents helping their child develop and learn include early interventionists giving parents useful information about how to help their children get along with others, learn new skills, identify things to do to help their child take care of needs and share ideas for including their child in daily activities. Across the 39 participants, parents reported that on average, they perceived early intervention as "very helpful" in providing them with information and resources related to helping their child develop and learn. Across all five outcomes on the FOS-R[®], helping children

develop and learn had the largest difference between the outcome rating and the helpfulness indicator. See Table 5 for FOS-R[®] ratings.

Demographic differences. A closer examination of the FOS-R[®] items revealed several particulars that were worth noting based on the parents' reported residential location, race, income, or educational level (see Tables 6, 7, 8, and 9 for additional details). When examining responses based on participants' residential location, the helpfulness of early intervention in parent's ability to help their child develop and learn was lower for residents of DuPage county than for residents of Chicago or suburban Cook county. At both the pre- and post-interview phases, Asian and African-American participants' average ratings were lower than 4.0 on a 5-point Likert scale, and with less than 70% of the parents reporting that EI was "very helpful" or "extremely helpful" when considering how early intervention has been able to help their child develop and learn.

Participants with incomes of \$25,000-50,000 reported that early intervention was much less helpful than participants in all other income brackets. However, participants with incomes less the \$25,000 had the lowest ratings for the outcome of helping their child develop and learn but reported the highest level of helpfulness from early intervention, with a large difference between the numbers. Participants with graduate degrees were the least satisfied when rating the helpfulness of early intervention as compared to participants with bachelor's degrees or who completed high school.

Early intervention facilitators. When asked about specific strategies that early interventionists used to support families in helping their child develop and learn, similar responses to Outcome 1 were mentioned, including demonstrating strategies with feedback, brainstorming around specific concerns, and providing information on exercises or activities that

parents can implement throughout the week. Parents stated that providing ideas of strategies that could be incorporated into daily routines and coaching in the moment was helpful.

So they were able to give me suggestions that were easily incorporated in my day. Like, “You know what? We’re gonna put the high chair here.” Because all the direction and the noise and whatever is this way, so it’s naturally going to. . . . He’s gonna be interested to be this way and to use his vision in this way and so, it was. It was always easily accommodated, and per their suggestions, maybe I wouldn’t have thought of it, but it was just, “Oh. Turn him this way,” or “Put the center of the focus this way.” (C6.27.01)

We did this whole big game in our basement where there’s this like, plastic car that my sister-in-law gave me, of course, because she’s cleaning out her house. You know? So, we did this whole thing where like, we turned it into a garbage truck because R’s obsessed with garbage trucks. Had him like, step on it and go forward. Anyway, we did this whole big elaborate thing that he loved and we played that over and over again for the next month. So, and I could figure out then, how to take that same type of play and do other things like that, that gave him the same skills. (C6.16.01)

Parents also reported that it was important that the advice and strategies suggested by early interventionists were specific to their family. One parent described the differences between her developmental therapist and speech pathologist, “I feel like our speech therapist really tailors it to us.” (C6.14.01). She went on to give examples of how her son responded more positively to suggestions from the speech pathologist and how she was able to incorporate those strategies into their daily life. Another parent talked about the value in problem-solving with the early interventionists and learning specific methods to help redirect her daughter’s challenging behaviors.

Transitioning for S, from one routine to the next, has gotten better because that was a big issue. When you take her from something that she really likes to transition to something that she’s not so crazy about, it would be like meltdown city. We’re getting better and I think the therapists have done a very good job of finding ways to redirect her and teach you ways to redirect her so that when we’re transitioning, it gets better. (C6.30.04)

When the importance of providing strategies specific to the family were discussed, several parents mentioned the need to incorporate siblings into the therapy context or take into account factors that go beyond just the child targeted for EI.

But the therapists have been good sometimes about like, “Hey, this would be a good therapy that C [older brother] could do with A,” type thing. Or I’ll mention it like, “Oh, I bet you C would like to do this.” And they’d be like, “Yeah.” And then they’ll think of more things or they help me. (W6.14.01)

It’s about, what’s going on in this family, in this little ecosystem here that could impact the child? It never feels like, any of the therapists are trying to investigate what’s happening, but it’s all just in a very all-encompassing way because everything that happens in our life impacts the kids. (C6.16.01)

Several parents mentioned the benefit of working with an experienced early interventionist who can help them think through the family context while providing suggestions to support their children’s development. One parent described how her physical therapist has supported her family,

She’s, kind of, telling me what he needs because she knows that I’m probably a little afraid to push him, but if she tells me he needs it, then I’ll do it. You know, it’s kind of making it all about him, but it’s very good. She’s very experienced, you know? That’s the difference and what would worry me, if I didn’t have. . . . Like, I was a new grad once, we all were. But, I’m like, “Oh thank God, I have somebody who has a lot of experience because it’s a lot to manage the family aspects.” (C6.16.01)

Another characteristic that was highly valued and mentioned by several families was the positive attitude of the early interventionists and particularly their willingness to listen to parents’ concerns.

I think the most helpful thing is just the willingness of everybody. Whether it’s speech saying, “Oh, this isn’t working? Okay, let’s try this or let me reach out and try this.” Our service coordinator saying, “Oh, you want to do a nutrition eval? Great, let’s do it. You want OT? Great, let’s do it.” Then those evaluators coming in and even though we didn’t add nutrition, just being so helpful in terms of, “I don’t recommend service but here’s a book you can read. Here’s two flyers I have. Here’s some resources. If it’s still not working call me in three months, we’ll reevaluate.” (D6.28.02)

One parent described the language an early interventionist used when discussing ideas and strategies to try with her child.

Every now and then we have like a brainstorming session where it’s kind of like this is working or this isn’t working. We throw out some ideas, she throws out some ideas. Nine times out of ten it’s an idea I wasn’t thinking of, which is helpful. Sometimes it’s like, “I

think that's gonna work," and other times it's a, "I don't know. I think that was a crazy left field suggestion but we'll try it anyways," which we usually do. . . . She suggests, "I wonder if we try this . . ." or something like that. "I've seen other kids have success with this," is usually how she phrases it. Not a, "Do this." (D6.28.02)

Constant communication among early interventionists, parents, and childcare providers also was mentioned as an important strategy. One parent explained her rationale for wanting EI supports at the child care center, "But I guess for me since, honestly, the childcare provider's spending most of the time, like it's best for me if the childcare provider can do it." (C6.30.02). Another parent who was unable to attend sessions with her child described how her early interventionists sent text messages to her with video clips the early interventionist recorded during the session.

They send me videos and tell me what they're working on and what should I be working on at home. . . . And it actually helps. . . . I follow what they're telling me to do, so I know what to do and then they also give these to the teachers at the daycare so they can know what to do and how to do it, which has worked. (C7.26.02)

Early intervention barriers. Parents mentioned several barriers including early interventionists who did not help families make connections between skills they worked on in sessions and the families' daily routines. They also reported that they did not receive any form of documentation from their early interventionists. One parent stated, "But there was kind of a disconnect sometimes about what he was doing in his therapy sessions and what we could then kind of integrate into the rest of the week" (D6.28.01). Another parent described the shift from having EI sessions at home to the childcare setting.

Now I don't always get that feedback. I think the therapist will speak with her teacher, but because I pick her up later on in the day sometimes that teacher's not there, so I can't get that feedback. . . . I know that her speech therapist does a fantastic job with her, because her speech development has really blossomed. At the same time, I'm not always sure what she's working on with her. . . . I might just be really old-fashioned, but having something written down each time about what to work on next would be helpful. (D6.29.01)

Many families reported that they did not receive weekly visit notes. Multiple families also mentioned they did not receive copies of evaluation reports or their IFSP documents. Parents said that receiving weekly documentations of their children's intervention would have been useful in knowing what to do throughout the week. One parent mentioned that she received daily notes from sessions but found them to be unhelpful, as written.

When I'm reading through the notes, I'm like, I don't know what that means and I think another thing, too. The therapist's handwriting is sometimes hard to read and, too, some of the language they use is like they understand what they're saying, but a parent who is not an OT or a DT is going what is that supposed to mean? (C6.30.04)

Another parent described her frustration with early interventionists who did not take into account her specific family's values and priorities.

There's some things I'm cool with that she isn't. I wish she was more flexible. I feel that she's a little bit old school. She feels that there is just one way of doing things. I get it, so I just go with the flow, I'm not going to fight with her. I mean, when she's not here I do thing my way. She's not here, he eats on the floor, and that's fine. See, I've learned to be less rigid then I used to be. He does eat his three meals, let's just give that example. I tell the social worker, "He does eat his three meals at the table and with us as a family. I'm cool with snacks. I don't care. Snacks are not done at the table," and she then insists, "No, every single meal must be done at the table," I'm like okay. Inside I'm like whatever. It's fine. (C6.23.01)

Impact on family life. Parents described activities in which their children participated beyond EI, and how they thought through their children's needs as they engaged in those activities. These activities were often part of the family's daily routines or classes available in the community, such as swimming lessons. When they chose the skills or strategies to focus on, parents considered their children's specific disabilities within the context of typical developmental milestones for children of the same age. One parent described how she supported her son's developing language during such activities,

I feel mostly confident. There's times, and I think this is probably like the age where we're in the grocery store and he's telling me, "Don't want to," sit in the cart, and we've gone over what my expectations are for the grocery store and it's probably me giving

him, "Oh, you want to talk?" Then, I regret that. Then, there's 10 tantrums, and so most of those are behavioral at that age. (C6.22.01)

For the most part, parents expressed confidence in helping their children develop and learn. However, some parents also discussed the multiple responsibilities they have and the struggle with balancing everything. "I work. We do the best we can. It's hard to do it all and also just have fun and be a family." (C6.30.01)

Family advocacy. Advocacy efforts described by families in relation to helping children develop and learn generally concerned finding additional services and supports, either while their children were in EI or as their children approached their third birthday and prepared to transition out of EI services. One parent described how they identified an early interventionist who subscribed to a specific philosophy to support their current team, "We're bringing the second therapist. Let's bring in someone who has more of floor time way of doing things. We added that therapist." (C6.26.02)

A parent of a child with a low-incidence disability talked about their family's efforts to have access to early interventionists who had expertise in her child's disability and their family's preferred communication methods. "And then A since August of 2016 has been attending a toddler group at [agency], so I drive her up there twice a week for that" (W6.14.01). This driving entailed 140 miles every week because early interventionists with relevant expertise were not available closer to her home. Another parent described her efforts to receive documentation,

So when he first started early intervention, we contacted the agency because we weren't getting obviously, those sheets [session summary notes] anymore, because they weren't leaving them. And the person who handled it was like: "Oh no one's really asked for that before." Which surprised me because we would read them every week, and then we'd text back and forth with the speech therapist. (D6.28.01)

Family wishes. Parents' wishes included having more information about EI available to parents and the public. Parents noted that if information about EI was more commonplace and

widespread it would have enabled them and other families to learn about available services sooner, or at least be reminded of its availability to families. A parent of a child who learned about EI when her son was discharged from the Neonatal Intensive Care Unit (NICU) did not receive services until he was about 16 months old. She mentioned that she would have wanted someone to have checked in on her sooner.

But had someone contacted me when he was a year old and been like, “Hey, just wanted to check in. We know that he has the cleft palate. We know that speaking on time could be an issue. Did you want someone to come in and see if he’s where he should be at right now? Or did you want to wait on that?” Maybe something like that would have been nice. (C6.26.01)

Other parents did not learn about EI from the NICU providers but rather from a pediatrician, home visiting nurse, WIC office, or through friends.

Survey and interview comparison. Data related to children’s development and learning were consistent across the surveys and interviews. See Table 10 for a comparison between the survey and interview responses. Participants in 37 interviews shared information that was consistent with their responses on the survey while two participants provided information that appeared to partially contradict their responses on the survey for helping their child develop and learn. There was less agreement between the survey and interview responses with regards to the helpfulness of EI in supporting parents to help their child develop and learn, with 28 participants relaying information during the interviews that was consistent with survey responses and 11 participants providing interview information that appeared to partially contradict their survey responses. Most of the discrepancies between the interviews and survey responses were related to participants stories of how their EI services did not connect to their daily routines or how the early interventionist did not help them make the connection. Many of the parents reported that they sought out information related to daily routines on their own. However, this contradicted

participants' rating of EI as "very helpful" or "extremely helpful" on the survey item, "How helpful has early intervention been in giving you useful information about how to help your child learn new skills?"

Having Support Systems

Survey responses. Questions on the FOS-R[©] related to the outcome of having support systems include having friends or family members who listened and cared, being comfortable talking to friends and family members about their children's needs, talking to other families of children with similar needs, and taking care of their own needs. Across the 39 participants, parents reported that on average, they perceived early intervention as "very helpful" in providing them with information and resources related to having support systems. Responses remained stable from pre-interview to post-interview. There was no corresponding helpfulness indicator on the FOS-R[©] related to having support systems. See Table 5 for FOS-R[©] ratings.

Demographic differences. A closer examination of the FOS-R[©] items revealed several particulars that were worth noting based on the parents' reported educational level (see Tables 6, 7, 8, and 9 for additional details). As educational level rose, parents' reported satisfaction with having support systems decreased. There were no other noteworthy differences based on other demographic factors.

Early intervention facilitators. When asked about specific strategies that early interventionists used to support families with regard to support systems, several parents expressed that they enjoyed getting to know other parents who they met through their early interventionists. A parent whose child was newly diagnosed with autism stated, "I was hooked up through my DT [developmental therapist] with a person from [nearby town] whose son has autism. I did reach out to her to maybe organize a small play group." (C6.26.02). One parent

specifically mentioned that it was helpful when her early interventionist talked with other early interventionists who were new to the team and followed up on paperwork for assistive technology. Several parents mentioned the importance of early interventionists who provided information regarding childcare, playgroups, family events, community supports, and advocacy events. One parent noted, “Her DT-H was really great about telling us about resources that we could use and told us about an institute down south. Those things were really great and helpful to meet other families” (D6.29.01).

Parents appreciated when early interventionists helped them explain specific developmental needs or diagnoses to extended family members and friends. Other parents said that they did not know this was something that EI could help with and that they thought the hour with their early interventionist could only focus on their children’s immediate skills.

Family events organized by the Child and Family Connections (CFC) were not mentioned by many families, but for those who knew about these events regarded them as valuable for connecting with other families. Several parents talked about difficulties attending events due to time, location, or transportation, but expressed a desire to attend, when possible.

Early intervention barriers. Many of the barriers parents mentioned related to support systems revolved around not knowing what EI could provide in terms of support, and what services were beyond the purview of EI. Parents were unsure if early interventionists could help connect them to other families, find support networks, or explain their child’s disability to others.

I think what would be helpful in general is outside of just our therapist, what else does EI provide? I don’t think I ever got [that information]. For example, he’s getting a medical diagnostic next month. I had no idea, A, what it was, or that it was covered by EI until I talked to, it was a roundabout way that I heard about it. (C6.30.01).

When asked if and how EI helped them explain their children’s disability to extended family members, a parent commented,

I think everything can always be improved, but I think that's something that definitely can be improved. I think in the beginning when people were asking about M's hearing loss, from my perspective, I struggled to explain it in a way that they could understand it. (D6.21.01-02)

One parent explained the need for support from early interventionists, and how she felt she could not ask her speech therapist for assistance to meet other families.

If there were ways to connect parents who are in similar circumstances, I think that would have been helpful. Sometimes you can feel like you're the only one who knows what your going through, and it's your child so it's really personal to you. To have maybe more of a support system. Our service coordinator, we only really talked to like when we had a meeting coming up, so I don't know. She could have helped bridge some of those gaps of like: "This is what you're doing in speech but this is what you could be doing outside of speech." Just maybe more communication amongst everybody. I sometimes felt when our speech therapist was here, we didn't want to talk to her about those kinds of things because I felt like she wanted to focus on the speech and that was the first priority. So I think that's where I feel like we could have gotten more, maybe, out of our service coordinator. And I don't even know if that's a part of their responsibility or if this is a strange request but if they would have tried, then I think that would have been really helpful. (D6.28.01)

Impact on family life. In addition to previously mentioned supports provided by the EI system, parents identified the assistance provided by extended family members, friends, and extended network, including childcare providers and medical personnel as helpful. Several parents mentioned the importance of extended family members being able to attend therapy sessions or have a better understanding of EI supports.

When my mom and my dad, being a pediatric nurse, she's like, "You're overreacting. Blah, blah, blah." But, you know, I made her go to one of R's appointments and see what was happening, and I think as soon as they see the experience of it, they get it. That's been another thing that the therapist has talked to me about, how to manage family members who, kind of, have that attitude. Which is great because I just got so tired of hearing like, "Oh, he's just, Let him catch up." Just all the excuses, or we were too hard on him, or he's not feeling us, stop comparing. And that just drove me nuts. . . . I had good, fact based things to say back, where it wasn't such a battle anymore. (C6.16.01)

Several families mentioned that they have not met other parents whose children are served in EI or other families of children with disabilities. Many noted that they did not know

where they could meet them. The desire to meet other families was mentioned frequently, from parents of children with specific diagnoses as well as children who are enrolled in EI due to a developmental delay. A parent of two children described the difference in the quality and level of support from friends who do not have children with disabilities:

You can see it in their face, they just don't get it. There's some things that they want to understand, and they're very eager to learn and everything, but when you explain to a family that does not have a special needs child how tired you are, their conception of tired is very different from mine. (C6.23.01).

Parents often talked about the support from their extended network, including friends, childcare providers, community members, and medical professionals. Parent-to-parent networks and support groups specific to their children's diagnosis were mentioned as strong sources of support and information. One parent turned to another parent of a child who had a similar diagnosis as her child for help with struggles she had with her own child. She and this other parent problem-solved together on conversations she planned to have with her early interventionists and extended family members. Another parent talked about how she used social media contacts when she had a concern about her son's development. Through those connections she learned about developmental screening and eventually received a referral to EI.

Well, on social media, I joined a couple groups with the moms of different suburbs in my area. And someone suggested, you know, "Where can we get some speech information for my son? He's around, almost two, he's not speaking yet or he's not saying much. Where should I go?" So the moms in our neighborhood put something that helped me too, in [town] there's a library. And they're like if you have issues with your child having maybe some type of speech delay or developmental issues, then come to the library near here, and we'll do an assessment. (C6.15.01)

Many parents mentioned that extended family members were their primary sources for getting emotional support, receiving assistance with daily needs such as babysitting, or accessing information to support their children. "My sister, other sister, she's also a daycare teacher. So she is always sending me videos or things on how to help with sensory or speech and she's always

finding things” (C6.27.02). Parents often mentioned family members who had a background in education or who had other experiences with children with disabilities as a source of additional support.

I have a great support system. I have my mom, my sister, they help me out a lot. They understand him, and they both were teachers. So whatever I miss, or he’s doing something, they try to redirect him. So to me, that’s great, because I don’t have to tell them “Oh he has to do this.” They already know. (C6.23.02)

However, differences in understanding of their children’s needs sometimes served as a source of stress or disagreement between parents and extended family members.

Our babysitter is my in-laws. They do an amazing job with the girls. My only concern is my mother-in-law is really in denial over their diagnosis of autism. She admitted that it might be more a self-coping thing for herself to just deny it than to embrace it and accept it. I understand her, but I feel like because she’s not accepting of the diagnosis, she’s not always accepting of the fact that they need these therapies. . . . If you want to live in denial, fine, but I think because she’s in that denial, she’s kind of not always quick to [help]. Like, because the therapists end up talking to her, sometimes more than me because when I’m at work, she’s here. . . . I feel like for some things, she’s more accepting to follow the technique and for some things she just isn’t able to go along with the technique. Well, no, they don’t need that, but yes, they do. I feel like that’s the only small hesitation I have with her and in the family support is that sometimes she’s a little bit quick to reject the support when we need it. That kind of creates a little bit of a, I feel like, an issue. (C6.30.04)

Two study participants from different geographical areas, who both identified as foster parents, described how they relied on extended family for support. Additionally, both felt that there was good communication and support from all of the professionals involved, including the early interventionists, Department of Children and Family Services caseworkers, social worker, Guardian ad Litem, medical personnel, and childcare staff.

Worries that parents mentioned most included finding babysitters or childcare providers. Several parents raised concerns with finding babysitters or childcare providers who knew what to do with children who had a feeding tube, cochlear implants, tracheostomy tube, or ventilator. A

parent of a child with challenging behaviors also mentioned concerns about her child possibly being kicked out of the childcare center that he recently began attending.

Family advocacy. Advocacy efforts parents described included finding services or supports in the community for their children and passing information along to other families. One parent attended a disability resource fair and shared information about the organizations represented at the fair to her service coordinator. She did this so that the service coordinator could pass this information on to other families she served.

When asked about their experience when they first entered EI, several parents commented that they advocated for their children's pediatrician to make a referral for EI. "My younger son, when we said he wasn't really talking, they were like: 'Oh, boys will be boys. He'll get there.' And we really kind of had to push for it" (D6.28.01). One parent mentioned that she called EI directly, but only after she talked with friends. Two parents commented that they called their service coordinators for their older children and asked if they could have their younger children evaluated. Several parents encouraged friends to have their child evaluated through EI. "I've had friends ask about it and my answer's always, 'You should do it. You should at least be evaluated. There's no harm in it'" (C6.30.02).

Family wishes. Parents of children with a specific diagnosis wished that professionals from the medical community provided support or linkages to other parents. Several parents also mentioned the idea of having online support and meeting families through social media if they were not able to meet each other in person. One parent, described how parents provide supports that professionals cannot:

I think that when you have someone coming into EI, it will help them navigate. It will help them understand better. It's one thing to talk to a coordinator, but the coordinator's never walked in your shoes in any form or fashion, but if you're talking to a person who

doesn't have your exact issue but knows what the medical barriers are, know how to navigate the system, what you might need. (C6.3.01)

When asked what EI could do differently to support parents, one parent suggested social work supports to help families through the initial entry into EI and the diagnostic period.

I guess if you are looking, they could give you a list of maybe more support groups. Or maybe, this might be useful, is maybe talk about social work to all families because we didn't hear about social work until H started having behavioral issues. Having a social worker may become, at least as a visit perhaps, because it is really stressful when you first do it and get the diagnosis. (C6.26.02)

Survey and interview comparison. Data reported on the FOS-R[®] related to parents having support systems were consistent with information generated from the interviews. See Table 10 for comparison between the survey and interview responses. Thirty-three participants shared information that was consistent with their responses on the survey while six participants related information that appeared to partially contradict the responses provided on the survey.

Accessing the Community

Survey responses. Questions related to accessing the community included families' ability to participate in social, recreational, or religious activities, do things together as a family, and have their child care, medical, dental, transportation, food, and housing needs met. Across the 39 participants, parents reported that their family could "almost" or "completely" access the community. This outcome had the highest ratings for the group of 39 participants, as compared to the other four outcomes, and the ratings remained stable from pre-interview to post-interview. There was no corresponding helpfulness indicator on the FOS-R[®] related to accessing the community.

Demographic differences. A closer examination of the FOS-R[®] items revealed several particulars that were worth noting based on the parents' reported income (see Tables 6, 7, 8, and 9 for additional details). Participants with incomes less than \$25,000 had the lowest ratings in

terms of accessing the community, while participants with incomes greater than \$50,000 rated this outcome highly. There were no other noteworthy differences based on other demographic factors.

Early intervention facilitators. Much of the conversation regarding accessing the community was related to family life, rather than how EI has supported families. While all families were asked specifically about EI, this was not a focus of conversation between many families and early interventionists. However, this was also the outcome with the highest overall ratings on the FOS-R[®] and which generated a high proportion of positive comments across the interviews.

When asked about specific strategies that early interventionists used to support families in accessing their community, the most commonly mentioned strategy was the willingness of early interventionists to meet parents at locations other than the family's home.

She's up for anything, which I love, like, "Hey, it's warm outside, did you want to meet at the park?" So it's cool because then it's not just in our house, we'll stop at the park, "What park do you guys want to be at?" So we'll go to the park and then she takes her to different things and shows us almost like different things that you could use to work on her speech and everything. (W6.14.01)

Parents appreciated early interventionists who initiated meetings in the community rather than parents being compelled to ask the early interventionists if it was something that could happen. One parent mentioned the importance of how her early interventionist adjusted their times to meet at home and at the childcare so that both the family and childcare provider participated in their child's EI services. Another parent shared how she and her early interventionist engaged in conversations to help her son access the community and assistive technology. She also described how these conversations allowed her to discuss difficult choices one makes as a parent.

We started talking about a walker and we're trying to hold back. There's a balance between what we hope and what we're seeing when we believe will happen, but also you want him to be able to keep up with his peers and experience things. (C6.30.01)

Early intervention barriers. When asked if early interventionists offered to meet families out in the community or went with them during challenging routines outside of the home, several parents mentioned that they did not know that was a possibility. As one parent stated, "I've never had any of them offer to go with me. I don't know if they're allowed to" (C6.30.04). Another parent said, "I don't think I would ever step on their toes in that way" (C6.27.01). These parents not only described child-focused sessions but they were unaware of other ways that EI could have supported their family. Interestingly, once the idea was mentioned, parents responded that they felt they could ask in the future. On the topic of problem-solving strategies that could help families successfully participate in community activities, a parent mentioned that she would have liked "to use their knowledge to be able to give me some different ideas on things that I can work on" (C.6.30.03). For this parent, having early interventionists brainstorm ideas with her of skills to work on while participating in community events would have been helpful in supporting her child's development, but this type of brainstorming was never offered.

Impact on family life. Most parents remarked that they felt confident in accessing community resources and participating in daily activities in the community. Often, there were additional considerations, but parents identified factors that prevented them and their children from participating in their community. One parent of a child with complex medical needs commented,

Oh, I just figured it out. I just take her pump with me. I take her suction machine. I take her diaper bag for everything that she needs, put diapers, wipes, extra change of clothes. Whatever it is that she needs. She has a pillow that I put in her stroller to help manage her

head, a fan to keep her cool. She has all the assets that she needs, and we're on our way. (C7.17.01)

Another parent commented:

She's like one of the other kids. She's got her water wear for her ears so she's fully hearing even if it's raining, she could run outside with the kids in puddles. She has to have me around a little bit more to put her ears back on when they fall off 'cause she still isn't at that age yet but even everything in the community like whether it's at the park or whether it's something downtown going on, she's right there with her brother. (W6.14.01)

Parents mentioned that when they selected activities in which to participate, they considered factors such as opportunities for a wide age range or ability levels.

We tend to do stuff that there's a wide variety of kid ages. So, if we do a library class that was like one to three year olds, or something, he could fit in kind of, with somebody there, even if maybe he wouldn't necessarily have fit it with the other kids in his age group. (D6.28.01)

A parent of twins mentioned that she was comfortable taking her children when she ran errands and utilized specific strategies when her daughter engaged in challenging behaviors.

There are some days that there's just no touching S, looking at, you know, if she's going to act a fool in public no matter what we do. We've kind of learned some strategies to try to curb that. It's not all the time so it makes you feel comfortable that you can try to go out and 95% of the time it's going to go okay. You just run that 5% that she's just having an off day and it's just going to be bad. We've learned from strategies on redirection when she's really making a scene in public or the first-then kind of thing and just trying to figure out what is it that's triggering her at that moment. (C6.30.04)

Other families remarked that they chose where and when to go places, such as the zoo or library, so that they would not be as crowded. For other activities, they did not stay for as long of a time as they initially intended or would have with other children.

Several parents commented that they accessed the broader community rather than their neighborhood, but that was due to safety concerns rather than their children's abilities. As one parent stated, "Yeah, I'm happy overall, going out. I don't go out in my neighborhood because

the neighborhood itself is not healthy.” (C6.23.02). Another parent who lived in a different area expanded on that idea,

This isn’t the best neighborhood. My only concern is because of the violence and stuff. Opposed to me going to a park here, I would drive to [nearby town]. The museums and stuff, I have no problem doing that with her. But just going to sit on the porch, that’s not a good idea. When we’re here I try to stay in the house, because it’s much safer. Nobody wants to bury their kid. (C6.29.01)

Several parents commented about an informal network of information regarding community activities in which their children participated. While some parents were pleased to find out about resources in their community in this way, others expressed frustration that had they not asked the right questions with the correct person and that they may have missed out on important information.

I think I’m very good at finding out those things, actually. I’m not shy of asking questions. I think I’m very good at finding the people who know. It’s not necessarily the person who has the role of knowing, but it’s more that you know this neighbor that’s really active in this area, or they refer you to some other woman that’s doing this and that over there. (C6.23.01)

Family advocacy. Advocacy efforts that parents described related accessing the community focused on activities for their children. One parent talked about how after they attended a disability resource fair she became involved with other organizations that she learned about through the fair. “Then, while I was at AccessChicago, there was a company called Lekotek. I found them, and we participated with them for a couple of months” (C6.3.01).

Another parent relayed a story of how she called the town’s attention to safety concerns at her local park so that her son would be able to play there without fear of him running into traffic. “So now its safer and I don’t have to really worry about ‘Hey is N going to run out?’ He can’t reach the latches” (C6.15.01).

Family wishes. When asked how EI could support her around accessing the community, one parent talked about how EI facilitated parent-to-parent support which allowed her to access the community and share resources.

When I think about how . . . this journey that he went through with Early Intervention, I think that it would have been wonderful to be part of an Early Intervention parenting group where, "Okay, this is the beginning of your child receiving services. And this is just an intro session. And all parents that are beginning this journey might join you." Maybe parents who have children, just having some type of support group. I don't know if we'll meet once a month, but just having . . . or once every two months, just having these, and then a goal what the session is all about, like, using your resources around the community, like your libraries, your, you know. I think that that might have been helpful, because then it keeps us more focused on, "Okay, how can I support my child with some of the needs that they may need," which might be speech, for some parents. For some, it might be a different area. I think that might have been very, I guess, not so separate. That might have made it feel more like there's a support group. . . . I'm not sure if other families have expressed that that's a need, but I think that that helps me to just refresh my memory, refresh my mind of what's going on, by going to sessions and hearing out, "Oh, the session's all about literacy." Or, "This session's all about how you can reach out to your local library." (C6.22.02)

Survey and interview comparison. When responses on the FOS-R[©] related to community access were compared to the information generated from the interviews, there was strong consistency across these two data sources. See Table 10 for a comparison of the survey and interview responses. Participants in 38 interviews relayed information that mirrored their responses on the survey, while one parent shared information that appeared to partially contradict the responses she provided on the survey.

Chapter 5

Discussion

This study examined parents' reported experiences and outcomes as a result of participating in Part C early intervention (EI) services. Parents of children enrolled in EI completed the Family Outcomes Survey-Revised[®] (FOS-R[®]) and participated in an interview where they shared their experiences while in the EI system. The interviews provided parents the opportunity to contextualize their responses on the FOS-R[®]—to explain the “why” behind the “what.” Parents in this study shared many stories and provided examples of what worked and did not work for their family. While family outcomes data are required in federal reporting annually, there is scant research on the quality of the data from the FOS-R[®] or how the data generated can be used for program improvement. Researchers have also called for further examination of the extent to which family-centered practices are utilized by early interventionists and how those practices are modified to support families (Bailey, Raspa, & Fox, 2012). This study begins to help the field develop an understanding of why parents respond to the items in the FOS-R[®] in the way that they do, different practices that are used by early interventionists, and what practices support or do not support the families in achieving family outcomes. Finally, this study adds to the currently limited literature related to the validity and utility of the FOS-R[®] tool to support children and families from diverse backgrounds (Bailey et al., 2011).

Most of the parents who participated in this study reported high levels of satisfaction with their EI experiences. On the FOS-R[®], satisfaction ratings on the family outcomes items (Section A) were higher than parents' satisfaction ratings on the helpfulness indicator items (Section B). This difference was echoed in the interviews. The family outcomes for which most parents reported highest satisfaction was related to accessing the community, followed by understanding

their child's skills, strengths, and needs. The family outcome with the lowest satisfaction rating was related to parents knowing their rights. The helpfulness indicators showed a similar pattern with the item that received the highest rating related to how EI helped parents communicate their children's needs and the item that received the lowest rating related to how EI helped parents understand their rights. There were also some notable differences found in parents' satisfaction ratings of family outcomes and helpfulness of EI based on their reported residential location, race, income, and education level.

A closer examination of the data from the state's annual FOS-R[®] report reveal comparable results with the current study. Annually, Illinois reports family involvement data to the federal government through the Part C State Performance Plan and Annual Performance Report using data collected from the helpfulness indicators (Section B) of the FOS-R[®]. In FFY 2015, the Illinois Department of Human Services distributed surveys to 20,981 families of children who were discharged from EI statewide. A total of 1,736 surveys were returned, representing an 8.27% return rate (Illinois Department of Human Services, 2017). For the Helpfulness indicator 1: Knowing their rights, 74% of Illinois families who completed the 2015 survey indicated that EI was "very helpful" or "extremely helpful" which is slightly higher when compared to the 67% of families in the current study who rated EI as "very helpful" or "extremely helpful" in getting parents to know their rights.

For the Helpfulness indicator 2: Communicating their child's needs, 79% of Illinois families indicated that EI was "very helpful" or "extremely helpful" which is similar to the 77% of families from this study who rated this item similarly. For the Helpfulness indicator 3: Helping their child develop and learn, 77% of Illinois families indicated that EI was "very helpful" or "extremely helpful" compared to 72% of the families in the current study who

provided the same ratings (Illinois Department of Human Services, 2017). Similar to findings in the current study, the statewide data also showed differences based on respondents' geographic location. The similarities in the statewide data and findings from this study warrant further examination of parents' ratings on the FOS-R[®] and the apparent differences based on various demographic variables of respondents.

In the current study, several themes emerged from the analysis including (a) systems-level and provider-level facilitators and barriers, (b) parental wishes related to their EI experiences, and (c) factors that related to parents' daily experiences of raising their children with a disability or developmental delay. Parents' explanations for how they achieved or did not achieve the outcomes measured on the FOS-R[®] provide new insights into the family experience, beyond what is currently reported in the literature. While families who described family-centered practices felt supported by their early interventionists, their experiences were not shared by the majority of families in the study. Even with a large push in personnel preparation and professional development to move from child-focused services to more family-centered practices, this study confirms that more work is needed to ensure that early interventionists can successfully implement family-centered practices. Families also talked extensively about their prior or newly acquired knowledge of child development and disability, as well as their support systems. Assessing families' current knowledge and providing individualized support is a core component of family-centered practices, and findings from this study add to the existing literature base highlighting the importance of family-centered practices. Families in this study affirmed the need for them to have a voice in their children's EI services. Furthermore, they emphasized the importance of collaborative brainstorming and discussions with their early interventionists and further bolstered the idea that the strategies to support their children and

families should fit within their daily routines. Additionally, parents mentioned that their family's experiences, including their knowledge and support structures, further highlight the need to tailor and individualize EI to each family. Finally, a topic of extended conversation with many families related to their rights as parents within the EI system. Rights and procedural safeguards are described in legislation and policy, as well as in procedural documents for each state. However, there are few guidelines for best practices in relating this information to families, nor are there parent voices explaining how they want to access this information. Parents in this study contributed many valuable ideas to add to our field's practices on this topic.

In this section, I focus on four main issues that emerged from the findings: (a) families' qualified satisfaction, (b) early interventionists' implementation of recommended practices, (c) the importance of understanding parental rights, and (d) the process used to measure family outcomes. While each of the outcomes measured on the survey and themes generated from the interviews add to our understanding of how families experience the EI system, I selected these four particular issues to highlight given the broad impact each have on the quality of services families receive and the overall effectiveness of EI system.

Qualified Satisfaction with Early Intervention Supports

Generally, parents reported satisfaction with their experiences in EI. All of the interviews included a proportionally large number of positive statements from parents compared to their negative comments related to their EI experience. Specifically, parents talked about the positive relationships they had with their early interventionists and how grateful they were to receive supports and services. Families often mentioned how nice their early interventionists were to their family or how well the early interventionist worked with their children. This relationship with early interventionists was clearly valued by parents. Yet at the same time, parents were

reluctant to speak negatively about the services and supports they were receiving. For example, when parents were asked to describe a practice or behavior that did not match their families' needs or priorities, parents often prefaced his or her responses with statements similar to, "I like her, but . . ." or "I am happy, but" These types of responses from parents also surfaced when they were asked probing questions or prompted to provide specific examples of why they were happy with their EI supports. When parents described situations in which their needs were not met, they often were apologetic, feeling as if they should not criticize or speak negatively about services that were intended to support them and often delivered by early interventionists in their home. An undertone that was present in parents' hesitation to criticize their early interventionists or speak negatively about the services they received may also be linked to power issues within help-giving relationships where parents may perceive professionals having the power to give or deny their families' access to services. Researchers have long discussed concerns regarding validity in measuring family satisfaction with services due to the fact that parents were mostly appreciative of any services they received and that their lack of understanding of or exposure to alternate service delivery options may have skewed their perceptions of satisfaction (Bailey et al., 2006; McNaughton, 1994; McWilliam et al., 1995). Similar concerns were reported by Korfmacher, Green, Spellmann, and Thornburg (2007) when they found highly positive ratings of home visiting supports. Korfmacher and colleagues noted that parents felt grateful to receive services regardless of the quality of those services that were delivered. However, when probed further through semi-structured or unstructured interviews, parents provided a more detailed explanation of their satisfaction and lack of satisfaction with the services they received. Other researchers have found that parent satisfaction is related to the amount of parental involvement, as parents who were more involved with service delivery and decision-making reported higher

satisfaction and those with less involvement reported lower satisfaction (Coogle & Hanline, 2016; Jinnah & Walters, 2008). Despite these concerns, it is still important to measure family outcomes in order to gain families' perspectives and learn if their needs are being met by their current supports and services. Systematically and regularly gathering information is important as over time, families' priorities change and new stories and needs emerge. Parents' qualified satisfaction with EI suggests to researchers and policy makers that they need to be mindful of the information conveyed in these satisfaction measures and recognize that what is often left unsaid is just as important to consider. Given that policy and procedural changes impact families and services, it is critical that these changes are made based on information provided by families to ensure that policies and procedures are developed with their needs in mind.

Some parents who received EI supports at childcare centers or through another caregiver such as a nanny, mentioned feeling disconnected from services or that they did not know what was happening. They attributed much of the progress their children attained to EI, but without an acknowledgement of the active role they played in facilitating their children's development and learning. Other parents mentioned that they took specific steps to ensure they were as involved and aware as possible. The parents who described active and regular communication and collaboration among their childcare providers, early interventionists, and family members also reported higher satisfaction with supports and feelings of involvement with EI services. These findings highlight the need for early interventionists to strive for increased communication across systems in order for all caregivers to gain access to important information regarding the children they serve. Indeed, families who feel supported by the EI system can be more effective in supporting their children.

In this study, many families spoke about wanting additional support from EI, but not necessarily related to receiving direct services. Rather, parents were interested in meeting other families of children in EI, as few parents who participated in this study knew of other families similarly enrolled in Part C services in their area. The desire to meet other families is not unique to families in this study. Similar to findings by Summers and colleagues (2007), parents in this study spoke highly of early interventionists who offered to put them in contact with other families. When the student researcher mentioned the EI system role of parent liaison, very few families knew of any one who was in that role nor the possibility that connecting with other parents can be a part of their EI services. Turnbull et al. (2007) stated that while family-centered practices are essential, often parents are not aware of what these supports can look like as they likely have not had the opportunity to talk with other families. This lack of connection with other families leads to parents not knowing what to ask for when developing IFSP outcomes. While the importance of connecting with other families who experience EI is well documented in the literature, there is a lack of structure to put this into practice (Dunst, 2002; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). Parent support and input from other parents who have previously accessed the EI system can meet both emotional and informational needs (Turnbull et al., 2011). While professionals can also provide emotional and informational support (McWilliam & Scott, 2001), their support comes from a different standpoint as they cannot bring the same lens and perspective to families as would another family member who has experience receiving EI services.

Parents' qualified satisfaction came through in the interviews but was not fully captured in the survey responses. Satisfaction and quality of supports were the areas of greatest discrepancy between the survey ratings and what parents revealed in the interviews. While

survey data on family outcomes (Section A of the FOS-R[©]) appeared to match what parents described during the interviews, the helpfulness indicators (Section B of the FOS-R[©]) did not have as close of a match and should be further explored. The specific practices that families reported as helpful aligned with the family-centered practice literature. The findings from this study align with previous literature regarding measuring satisfaction via a survey, in that while satisfaction with EI supports was high, this appeared to be a result of service access rather than quality (Bruder & Dunst, 2015). Additionally, the information gathered from the interview provided details that could not be captured simply through a survey. Ensuring that early interventionists truly support families with regard to their priorities is important and taking the time to ask how a practice is working or why an outcome is a priority is essential. If families are only able to mark their satisfaction on a check box, and not given the opportunity to explain their full experience and why they are satisfied or dissatisfied, the field loses valuable information about what practices work in what situations and under what circumstances.

Early Interventionists' Use of Recommended Practices

Across the majority of interviews, parents described practices utilized by their early interventionists that closely matched provider-led, child-focused practices. This is in direct contradiction to current research and knowledge in the field that recommends services for young children and their families incorporate family-centered practices (Division for Early Childhood, 2014). Parents who described provider-led, child-focused sessions also mentioned that early interventionists verbally reviewed the session with them during the last few minutes of their visit. Parents also shared that they were only encouraged to ask questions of their early interventionists at the end of sessions. Notably, a handful of parents spoke about strategies they learned even though they were not active participants during the sessions. Researchers have

found that parents are more likely able to support their children and understand the intention of a strategy when they are engaged in purposeful teaching (Sawyer & Campbell, 2017). Swafford et al. (2015) found that while parents were physically present during EI services, they were often passive recipients of support provided by the early interventionists rather than actively engaged. The concept of incidental learning compared to purposeful teaching may need to be explicitly taught to early interventionists during both preservice and inservice training as many may believe that the mere physical presence of parents during sessions will result in them learning the strategies, which would lead to their active use of specific strategies when interacting with their children.

One parent described the difference between what she thought EI would look like (i.e., medical model) and what it actually looked like for her family because her early interventionist used family-centered practices. Through various examples, this parent mentioned how the family-centered philosophy was supportive of and beneficial for her and her family. While she also described frustration with completing system-required paperwork and experiencing delays in accessing assistive technology, she mentioned that she preferred EI because of its family-centered philosophy over seeking physical therapy at an outpatient clinic that followed a medical model. Another parent, when asked what she would like EI to look like for her and her family, described family-centered services, although everything that she described regarding how her EI services currently looked was child-focused and provider-driven. She had never experienced family-centered practices yet described that as the ideal approach after hearing the scenarios and talking through what she felt would support her with regards to family outcomes. While the field of EI widely promotes family-centered practices as the most effective way to support families of infants and toddlers with disabilities, the change from a medical model or child-focused sessions

to family-centered practice has been occurring slowly (Bailey, Raspa, & Fox, 2012; McWilliam, 2015). Family-centered practices emphasize a collaborative relationship and views the role of parents as full partners in the EI process (Bailey, Raspa, & Fox, 2012; Keilty, 2017). Families in this study who experienced family-centered practices placed high value on their time in EI. Furthermore, parents mentioned family-centered practices as a desired format of service delivery particularly those who had experienced provider-driven and child-focused services.

When asked if they could change anything about their EI experience, several parents who also described their services as provider-driven and child-focused, mentioned wanting an increased number of hours of EI services. In comparison, parents who described their services as family-centered did not express the same wish. The contrast between these two groups of parents may be due to the difference in their experiences with and understanding of the role of early interventionists and families in supporting children. McWilliam (2010) argued that “more is better” in EI as additional opportunities for intentional interactions by caregivers over time each day is better than more discrete hours of therapy. However, this idea is not universally understood nor accepted (Woodman, Demers, Crossman, Warfield, & Hauser-Cram, 2018), particularly when parents have only had exposure to provider-led, child-focused interventions.

Dunst (2012) described the changes in conceptualizing EI over the past several decades, from providing experiences that support a child’s development to providing prescribed services for infants and toddlers with developmental delays and disabilities. There is a large body of literature that found early interventionists did not utilize recommended practices or include the family as the primary agent of change (i.e., Cambray-Engstrom & Salisbury, 2010; Campbell & Sawyer, 2007). Furthermore, researchers have reported that family-centered practices were not covered in personnel preparation programs, which may strongly influence early interventionists’

ability to implement these practices (i.e., Bruder & Dunst, 2005; Campbell, Chiarello, Wilcox, & Milbourne, 2009). While some families in the current study described family-centered practices that focused on coaching the family, most participants described provider-led sessions that concentrated on skill acquisition for the child. When families heard, through the scenarios utilized in this study, of other ways that EI supports could be received, several parents reported that they never knew EI could look differently than what they experienced and that their concerns for their children could be a topic of focus during sessions. Information regarding recommended practices for infants and toddlers must be made more readily available to parents and other consumers of EI services. By providing this information to families, they can then expect family-centered services and engage in conversations regarding quality practices with early interventionists. Finally, knowledge and access to information regarding best practices and engaging in conversations with other families and early interventionists can build families' capacity to advocate for their children and families. As skilled advocates, parents can truly be the primary voice and support for their children throughout their lifespan.

Importance of Parental Rights and the Early Intervention Process

A key systems-related issue that emerged from this study was the notion that families did not understand the EI process or have a deep understanding of their parental rights. Parental rights and procedural safeguards, including the right to timely services and prior written notice, are built into legislation (Individuals with Disabilities Education Act, 20 U.S.C., 2004). While all of the parents in this study reported that they received information about their rights, many lamented that the information they were presented was not fully discussed nor was the importance of understanding their rights stressed. Many parents mentioned that they had received the *Infant/Toddler and Family Rights under IDEA* booklet (Illinois Department of

Human Services, 2016c), but did not know where it was or had filed it away and never read it. While not reading the book was a choice parents made, there were significant implications of parents not fully understanding their rights.

The topic of rights generated discussion with almost all of the parents in this study regarding how to provide information to families to ensure that they understood the meaning of their rights. Two areas frequently discussed by parents included the timing of the delivery of information and the format in which information was presented. While parents understood the need to receive the rights booklet during intake, several expressed that they would have preferred receiving information about their rights in smaller doses or at the point in time at which information about specific rights would be needed. For example, one parent said that she would have wanted information about her rights related to eligibility at the intake meeting. She noted that she received additional information regarding her rights and service delivery during the IFSP development process. Several parents thought that a conversation solely focused on rights would be beneficial but recommended that it be held several weeks after the initial conversation where rights were first introduced. Many parents also expressed the desire for the rights information to be offered in multiple formats, including through conversations and electronic documents.

Bruder and colleagues (2005) conducted a study with professionals and parents to determine the role and intended outcomes of service coordination. Several of the agreed-upon outcomes of service coordination generated from their study were related to families' understanding of their rights, which are reflected in Illinois state policies and procedures (Illinois Department of Human Services, 2016a). However, understanding their rights was one area in which families in the current study felt they were not proficient. Although several families reported that they did not know their specific rights and said that they were not concerned about

not knowing these rights during the interviews, parents described their frustrations and sometimes noted rights violations, along with an uncertainty for how to proceed when they realized that their rights were not being met. For example, several families mentioned feeling overwhelmed at intake and during the initial evaluation and IFSP development process. While it is possible that parents signed a waiver of prior written notice, allowing the development of the IFSP to occur on the same day as the eligibility evaluation, the implications of that may not have been fully described and therefore parents did not realize how the process for receiving EI services may have been impacted. As a field, we need to consider how federal and state policies, or the implementation of such policies, could in fact be hurting families even though these policies were designed to support and protect families (Hebbeler, Greer, & Hutton, 2011).

Many families in this study, regardless of income level and residential locations mentioned that they waited for an extended period between the time their children were found eligible for EI services and the time they started receiving services or after one early interventionist stopped and before the next one started. State reporting data indicate that 97% of families experienced timely services, defined as services starting within 30 days of signed consent on the IFSP (Illinois Department of Human Services, 2017). While this appears to be a significant contradiction, parents may have different interpretations of delay than what is reported in the state data. For example, an IFSP may indicate that the family will receive support from three separate professionals, such as a developmental therapist, physical therapist, and speech-language pathologist. The developmental therapist may start within 30 days of IFSP development, but there may be a longer wait for the physical therapist and speech-language pathologist. Another scenario mentioned by several families was that they were receiving speech therapy and a change in their early interventionist was required, either through family request or

due to the early interventionist no longer being available. This waiting period for a new early interventionist would not be captured in the state data, but certainly impacts families' experience with the EI system. Several families described advocacy strategies they used to minimize the delay including repeated contact with their service coordinator, hand delivering documentation, directly contacting their pediatrician to request a prescription, or finding information regarding services on their own. However, other families knew of their rights to have services, yet they did not have specific strategies that they utilized beyond calling their service coordinator to ask for an update. During the interview, several parents reported that they did not know of their right to seek therapy services outside of the system if timely services could not be provided, with the EI system supporting the cost of services. By not knowing of these rights and the questions to ask, parents described frustrations with the system that could have been mitigated through other options.

Additional areas in which families expressed concern or a lack of understanding of the EI process was related to documentation and transition. Many families reported that they did not receive session notes in a timely manner, while some reported that they did not receive assessment or evaluation reports and/or IFSP documents. With regards to transition, almost all families mentioned that discussion regarding the transition process focused solely on the transition from Part C to Part B 619 services. Several parents mentioned that they would have appreciated more comprehensive information regarding other options, including community classroom settings or outpatient therapy. Researchers have long documented the need for early interventionists to support families through the transition process and consider all transition options, including community-based services (Hanson et al., 2000; Rous & Hallam, 2012; Rous, Myers, & Stricklin, 2007). While IDEA requires only a formal transition process to Part B 619

services, best practices (Division for Early Childhood, 2014; Hebbeler, Spiker, & Kahn, 2012), as well as state procedures (Illinois State Board of Education and Illinois Department of Human Services, 2007) recommend that a comprehensive transition plan should be established in order to find the most appropriate placement for each child.

Findings from this study highlight the important role parents play in making decisions about their children's education and intervention support (Turnbull et al., 2011). Parents' perspectives on the ways access to information can be improved to increase their understanding of their rights is not new (Burke & Sandman, 2015; Turnbull et al., 2011). When discussing rights with parents in the current study, the idea of "people don't know what they don't know" was evident across many participants. The scenarios shared at the beginning of the interview included examples of family-centered practices and child-focused practices to stimulate discussion regarding practices that early interventionists used with families. However, the scenarios did not include specific information about parental rights, and therefore parents did not have an example upon which to compare their own experiences of knowing about rights. Findings from the current study further emphasize the need for early interventionists to implement best practices to ensure that every family that is enrolled in Part C services has access to and knowledge about their rights within the EI system and beyond.

Parents experience the impact of EI policies and procedures differently from professionals and therefore creating opportunities to gain advocacy skills is important. Part C is unique in that parent advocacy and input is encouraged through participation in state interagency coordinating councils (Smith, Gundler, Casey, & Jones, 2011). Supporting parents' advocacy efforts during their time in Part C could lead to strong advocacy skills that parents can utilize throughout their children's life.

Measuring Family Outcomes

While interviews and surveys are designed to capture different types and depths of data, it is important to know what is being measured by each tool. Some of the issues that arose in this study that impact family experiences were not explicitly measured in the FOS-R[®]. For example, while documentation can be captured on “Helpfulness item 6: giving you useful information about your child’s delays or needs,” as parents select a value on the Likert scale in response to this item, they would have to decide the relative weight of verbal information shared by early interventionists during sessions, written information provided by early interventionists after each session, and the quality of the written and verbal information regarding evaluation and assessment results. Administrators reviewing the results of the survey would have no context to situate their understanding of the types of information and documentation that families have received or should have been provided to help them gain useful information about their children’s delays or needs. Additional topics frequently mentioned during interviews included the importance of team communication, collaboration, and desired qualities of early interventionists. Desired qualities mentioned by parents included having a positive attitude, being flexible in delivering services (e.g., rescheduling when children had medical appointments or supporting a child at childcare), and communicating with other professionals, all of which are aligned with recommended practices for early interventionists (Keilty, 2017). These constructs were not measured on the survey, yet clearly have a direct impact on family outcomes. Families who experienced EI where there was poor team communication or early interventionists who were not flexible to meet families’ needs may not have received the full benefits of EI services. States may want to consider adding these constructs to formal measurements of the quality of EI services provided to families in their state so that professional characteristics and behaviors can

also be evaluated. Once quality is formally measured, program supervisors or professional development providers can use this information to better support early interventionists in the field.

Moreover, parents in this study noted that the FOS-R[®] did not include an option to indicate “not applicable.” This would have been particularly useful on the helpfulness indicators. From the interviews, it was evident that not all of the survey questions were relevant to all families. The question most frequently skipped or that parents included commentary noting a lack of relevance was “Helpfulness item 12: giving you useful information about how to help your child get along with others.” Several parents who commented on this item had children under 12 months of age or children who had complex medical needs. These families did not consider peer interaction a top priority. Adding a “not applicable” option is a simple adjustment that could be made to the survey form that could provide a more accurate picture of families’ experiences with EI. The National Early Intervention Longitudinal Study (NEILS; Hebbeler et al., 2007) asked families if they received a service with options of “yes,” “no, needed,” and “no, not needed” which provided parents with a way to indicate the reason for the “no” response. Since states have the option of creating their own measurement tool or adapting the FOS-R[®] form, adding the “not applicable” to the scale may yield a more exact picture of families’ experiences in EI.

As described earlier, a topic of frequent conversation during the interviews was that parents wanted to meet other families who were also enrolled in EI. The FOS-R[®] does not explicitly measure how helpful EI has been in connecting parents with other parents of young children with disabilities. While there is an outcome statement in Section A of the FOS-R[®], “Item 16: We are able to talk with other families who have a child with similar needs,” there is

no corresponding helpfulness indicator to measure how early interventionists are supporting families to achieve this outcome. Engaging with other families of young children with disabilities contributes to families' quality of life (Summers et al., 2007) and having support systems is often used as a mediating variable and/or as an outcome measure (Bailey, Nelson, Hebbeler, & Spiker, 2007). However, if there are no systematic and consistent ways to measure family support variables such as in the helpfulness indicators on the FOS-R[®] and these data are not required for reporting by federal (US Department of Education) and state agencies, it is impossible to hold EI accountable or fully support families in engaging with other families.

Limitations

While an attempt was made to include families representing a wide range of backgrounds in this study, several limitations in the recruitment and data collection methods must be noted. First, the study criteria, which were largely influenced by constraints in time and funding resources limited recruitment efforts to an urban and suburban area of one state. All qualified participants were required to speak English, although it was not required that English was a parent's primary language. Based on these two criteria, experiences of families residing in rural areas of the state or families who accessed EI system resources primarily through the use of language interpreters were not represented.

Second, participants in this study may or may not be similar to the overall parent demographics in the state. In fact, participants reported a higher income and higher education level than what may be present across all EI system participants. Illinois does not collect parental education levels nor does it publicly release family income data for EI participants. According to the latest census data, 33% of Illinois residents over 25 years of age have obtained a bachelor's degree or higher (United States Census Bureau, 2017). In contrast, nearly 80% of participants in

this study had a college degree. Moreover, in the NEILS study which utilized a nationally representative sample (Hebbeler, Spiker, Mallik, Scarborough, & Simeonsson, 2003), the parental education and income levels were lower than those of participants in the current study. Finally, many of the families in this study were educators or knew someone in the educational field. Therefore, participants may have access to information or resources that went beyond what may be available to many of the families participating in EI.

Third, during the recruitment and the consent process, I disclosed that I formerly provided EI services within the state. I did not collect the names of early interventionists, including service coordinators or direct service providers, so that parents were assured that I did not know who their early interventionists were unless they chose to share that information or if they were recruited for the study through a personal connection. Despite assurances to potential participants that I would maintain their anonymity and confidentiality and that their children's EI services would not be impacted, some parents may have decided to not participate or to self-censor the information they shared due to concerns with confidentiality. By not participating or self-censoring, there may be untold stories that are different from the stories shared by participants in this study.

Finally, parents reflected on their EI services during a one-time meeting that lasted 30 to 90 minutes, leaving many more stories left untold. All of the face-to-face meetings during which the interviews were conducted were the first and only time the student researcher met the participants. Thus, while the student researcher made a concerted effort to build rapport with each participant, the novelty of the situation may have impacted parents' responses. Multiple and long-term engagement with participants generally allows for deeper recollection and reflection. For example, Seidman (2006) recommends a series of three interviews over several weeks in

order for the interviewee to have time to reflect and build upon previous conversations. The time constraints and being fairly unacquainted with the researcher may have left parents selecting and limiting which instances of support and lack of support they shared. While they could have added information during the member check, none of the parents did so. Therefore, what parents may have shared during the interview might not be a full reflection of their experiences. However, it is also possible the stories they shared were the most salient given that they only had limited time to share their stories and selected those that most strongly impacted them and their families.

Future Steps, Recommendations, and Implications

During many of the interviews, the way parents responded made it seem like it was the first time that they had an opportunity to reflect on the supports they received and their overall experience with EI. For example, parents used phrases such as “now that you’re mentioning it” or “oh, I have no idea.” Several parents mentioned that they had never been asked these types of questions prior to this study. By creating opportunities for parents to think reflectively and critically about EI services, early interventionists can ensure that the supports and services they are providing are continuing to meet the changing needs of children and their families. Parents also frequently gave an automatic response of “everything’s good.” However, when pressed for examples of practices early interventionists used, or prompted to expand on why they described services as “good,” stories of situations that parents described as unhelpful emerged. Early interventionists should consider how to build this time of reflection into system touchpoints, such as during IFSP meetings, service coordinator monthly contacts, or direct service support visits.

Additionally, it is important for early interventionists to consider the family experience beyond the EI system. As parents in this study reported, seeking additional parent-to-parent

support was desired. This idea is echoed by Iversen and colleagues (2003), who found that early interventionists reported needing to learn more about helping families access parent-to-parent support.

Bailey, Raspa, and Fox (2012) wrote about the future directions of family outcomes and additional studies that are needed to add to the evidence base. While this study does not meet those specific needs, findings from this study add to the literature and bring up additional concerns regarding how and why we measure family outcomes. If a number is all that is needed to determine the impact of EI on children and families, then the field has that information. If quality of experience is what will help improve processes and systems and form a contextual understanding of factors that impact quality of experience in order to inform best practices, then the field needs to do more.

Nationally, states collect a variety of data related to children and families regarding their EI experiences. In addition to family outcomes data, states are required to annually report child outcomes data in their Part C State Performance Plan and Annual Performance Report. The three child outcomes data that are collected include (a) positive social emotional skills (including social relationships), (b) acquiring and using knowledge and skills, and (c) taking appropriate action to meet needs. Similar to family outcomes, each state develops a plan for data collection for child outcomes. In Federal Fiscal Year 2015, 43 of 56 states and territories used the Child Outcomes Summary Process (Early Childhood Technical Assistance Center, 2017a). The child outcomes process is intended as a performance measurement data point, in part to determine accountability and program improvement (Taylor, Hebbeler, Spiker, & Kasprzak, 2018). However, there is controversy regarding the use the child outcomes process data for program evaluation rather than to measure performance (Rosenberg, Elbaum, Rosenberg, Kellar-

Guenther, & McManus, 2017; Taylor et al., 2018). While it is essential to consider the data collection process and the quality of the data collected, it is equally important to recognize the limitations of the inferences that can be made from any one measure. The child outcomes data is similar to the family outcomes data in that it is one measure, but it does not capture the entire experience of a family and child during their time in EI.

Findings from this study highlight the fact that each family's lived experiences are more nuanced than what can be captured on a 5-point Likert scale such as the FOS-R[®]. How to effectively and efficiently capture the depth of the experience while also capturing the breadth of families served within each state, is a research issue that needs continued exploration. Further research in this area should include families from a variety of backgrounds (e.g., families living in rural communities; families who speak languages other than English) in order to understand if their reported experiences and outcomes are similar to the families represented in this study, or if different issues emerge that paint a more detailed picture of families' experiences with EI. Additionally, as this study was completed in a state with an independent vendor model, further research should include states utilizing other service delivery models (e.g., a primary service provider model).

Effective early interventionists implement and believe in family-centered practices. Higher education personnel preparation programs, professional development providers, credentialing entities, mentors, and supervisors can support early interventionists by ensuring that they understand recommended practices, including family-centered practices, and that they use them effectively within their daily practice. Additionally, these entities can ensure that all early interventionists understand families' rights in order to actively engage in conversations with families regarding their rights within the EI process.

Family outcomes as a result of participating in EI are important to measure and reflect upon. Policy makers, administrators, personnel preparation programs, and early interventionists have the potential to positively impact children and families as they enter the special education service delivery system through Part C. In order for families to have the best experience with the EI system, their unique needs and values must be embraced and addressed. Through family stories, we as a field can gain insights that can ultimately lead to improved supports and services for all young children and their families.

Tables

Table 1

Family Outcomes and Family-Centered Practices in Early Intervention: A Review of Literature

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Aaron, C., Chiarello, L. A., Palisano, R. J., Gracely, E., O'Neil, M., & Kolobe, T. (2014) Relationships among family participation, team support, and intensity of early intervention services. <i>Physical & Occupational Therapy in Pediatrics</i> , 34, 343-355.	Examine parent participation at initial IFSP meeting	ASQ; Family Needs Survey (FSN); Parent Participation Measure	63 families; 6 counties in NE & SE PA; concerns with motor or adaptive skills; 72 professionals - 7 PT, 7 OT, 6 ST, 16 ECE, 36 SC	FSN—need for information, explaining to others more than information to support child functioning; no parents rated as advocacy/ strongly voiced opinion during meeting	Recommendations did not appear to be individualized based on child and family need, rather other factors influenced intensity of service recommendation; limited discussion about family needs during IFSP meetings
Bailey, D. B., Nelson, L., Hebbeler, K., & Spiker, D. (2007). Modeling the impact of formal and informal supports for young children with disabilities and their families. <i>Pediatrics</i> , 120, e992-e1001.	Examine factors related to perceived impact of EI	Phone interviews from NEILS study	2100 parents	Quality of family services, family and community support, confidence in parenting; No evidence of confidence in parenting, optimism for future, or informal supports on positive family impact;	Not measured

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
				families in poverty less likely to have positive family impact	
Bailey, D. B., Raspa, M., Olmsted, M. G., Novak, S. P., Sam, A. M., Humphreys, B. P., . . . Guillen, C. (2011). Development and psychometric validation of the Family Outcomes Survey-Revised. <i>Journal of Early Intervention</i> , 33, 6-23.	Revise Family Outcomes Survey and evaluate statistical properties of new tool	Study 1: Researcher developed form; Q-sort procedure Study 2: Researcher developed survey from study 1	Study 1: 2 SPED researchers, 1 survey methodologist, 2 doc students, 2 Part C evaluation coordinators, 1 local EI program coordinator; 19 states' Part C evaluation or program coordinators, 3 ECO advisory board members, ECO staff Study 2: 265 parents from IL & TX	Study 1: resulted in revised survey Study 2: resulted in some revisions; families reported high level of helpfulness of EI	Study 1: Not measured Study 2: Helping family know rights, communicate child's needs, help child develop and learn—sub-items with specific questions/practices
Broggi, M. B., & Sabatelli, R. (2010). Parental perceptions of the parent-therapist relationship: Effects on outcomes of early intervention. <i>Physical and Occupational Therapy in Pediatrics</i> , 30, 234-247.	Examine types of parent-professional relationships and impact on parental outcomes	Parenting Stress Index; Measures of Processes of Care-56; Family Resources Scale; % of goals achieved; Satisfaction and control surveys	39 parents of children rec PT in CT EI	Parenting stress, competence; If relationship falls into collaborative or distant typology, impact on outcomes	Family-centeredness as measured by enabling and partnership, providing information, coordinating care, respect

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Brotherson, M. J., Summers, J. A., Naig, L. A., Kyzar, K., Friend, A., Epley, P., . . . , Turnbull, A. P. (2010). Partnership patterns: Addressing emotional needs in early intervention. <i>Topics in Early Childhood Special Education, 30</i> , 32-45.	Explore dynamics of emotional support in home visiting relationship	Interviews, observations, focus groups	3 EI agencies—22 practitioners and 16 families	Hope and urgency; challenges and stress; emotional needs and characteristics mutually impact relationship	Concrete strategies, use of modeling, source of support, parent appreciated child-focused visit
Bruder, M. B. & Dunst, C. J. (2015). Parental judgments of early childhood intervention personnel practices: Applying a consumer science perspective. <i>Topics in Early Childhood Special Education, 34</i> , 200-210.	Examine parents perceptions of practitioner confidence and competence and if parental involvement linked to use of practices	Investigator developed survey	124 parents of Part C and 144 parents of Part B-619	Parents who reported more involvement perceived practitioners as more confident and competent; specific practices varied, but confidence higher than competence in 5 of 6 (evaluation was exception)	Family-centered practices (not specifically identified); child assessments and evaluations, teaming and collaboration, IFSP and IEPs, instructional practices, natural environment and inclusion practices

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Bruder, M. B., Dunst, C. J., & Mogro-Wilson, C. (2011). Confidence and competence appraisals of early intervention and preschool special education practitioners. <i>International Journal of Early Childhood Special Education</i> , 3, 13-37.	Examine providers sense of own competence and confidence in recommended practices	Investigator developed survey	1892 practitioners in EI and ECSE	More confident than competent in 5 of 6 (teaming was exception)	Family-centered practices were one of six variables measured, using 2 questions for competence and 2 questions for confidence. Those questions not available in manuscript.
Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. <i>International Journal of Disability, Development and Education</i> , 54, 305-318.	Examine relationship between parent and professional partnerships and outcomes	Enabling Practices Scale, 2 researcher developed scales, Everyday Parenting Scale	150 parents of children birth-5; approximately half had children under 3	Parenting competence, confidence, enjoyment	Not measured
Epley, P., Summers, J. A., & Turnbull, A. P. (2011). Family outcomes of early intervention: Families' perceptions of need, services, and outcomes. <i>Journal of Early Intervention</i> , 33, 201-219.	Examine relationships between EI services and family outcomes	Early Childhood Services Survey, ECO Center Family Outcomes Survey, Beach Center Family Quality of Life Scale	N = 77 families of children in Part C or recently discharged	Family quality of life (family interaction, parenting, emotional well-being, physical/material well-being) + OSEP outcomes;	Not measured

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
				Degree of perceived need inversely related to parent ratings of EI services and FOS scores; FOS & FQOL positively correlated	
Kellar-Guenther, Y., Rosenberg, S. A., Block, S. R., & Robinson, C. C. (2014). Parent involvement in early intervention: What role does setting play? <i>Early Years</i> , 34, 81-93.	Examine effect of setting of EI services on parent attendance, parent participation, communication between parent & provider, instruction to parents, parent use of strategies	Telephone interview, adapted from items on NEILS	92 families in CO	Attendance, better communication, provider instruction better at home; participation and parent use of strategies higher at EI center; child care lowest for all except parent use of strategies Higher attendance related to higher levels of parent participation and communication	Asked parents to report on provider's frequency of suggestions about what they could do with their child, modeling of strategies, asking parent to demonstrate strategies

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Lee, Y. H. (2015). The meaning of early intervention: A parent's experience and reflection on interactions with professionals using a phenomenological ethnographic approach. <i>International Journal of Qualitative Studies on Health and Well-being</i> , 10, 1-10.	Explore how parent's partnership with professionals progresses and evolves throughout service provision	Interview, observations, document review	1 family over 6 months	Satisfaction with services, professional knowledge; parent advocacy; frustration with planning process and partnerships with providers; provider lack of sensitivity	Parents concerns – information gathering rather than dialogue; recommendations worded in authoritarian way; question about exercising rights
Noyes-Grosser, D. M., Rosas, S. R., Goldman, A., Elbaum, B., Romanczyk, R., & Callahan, E. H. (2013). Conceptualizing child and family outcomes of early intervention services for children with ASD and their families. <i>Journal of Early Intervention</i> , 35, 332-354.	Examine appropriateness of family outcomes specifically for children with autism spectrum disorder	Q-sort	300 stakeholders, including 216 professionals and 84 parents and family members	Skills and knowledge to support child development, anticipating child's needs and behavioral challenges, advocacy and collaboration with professionals, and family and community supports; parents had broader outcomes as opposed to specific outcomes and skills identified by professionals	Not measured

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Olmsted, M. G., Bailey, D. B., Raspa, M., Nelson, R. E., Robinson, N. D., Simpson, M. E., & Guillen, C. (2010). Outcomes reported by Spanish-speaking families in early intervention. <i>Topics in Early Childhood Special Education, 30</i> , 46-55	Examine reported outcomes from FOS for families who utilized Spanish language version	FOS—Spanish version	3140 families of children in IL & TX—Spanish version of FOS	Helping child develop and learn, communicating child's needs, advocating for rights, having support system, accessing community	Helping family know rights, communicate child's needs, help child develop and learn—sub-items with specific questions/practices
Popp, T. K. & You, H. (2016). Family involvement in early intervention service planning: Links to parental satisfaction and self-efficacy. <i>Journal of Early Childhood Research, 14</i> , 333-346.	Examine parental satisfaction with services and providers	Interviews from NEILS study	2586 families	Increased confidence and knowledge with earlier involvement in service planning; overall satisfaction not sig related to increased confidence and knowledge	Involvement in service planning with parents
Raspa, M., Bailey, D. B., Olmstead, M. G., Nelson, R., Robinson, N., Simpson, M. E., . . . Houts, R. (2010). Measuring family outcomes in early intervention: Findings from a large-scale assessment. <i>Exceptional Children, 76</i> , 496-510.	Examine use of FOS tool and program factors related to outcomes	FOS	2800 families in IL and TX	Generally high level of outcome attainment; outcomes clustered around family knowledge and ability (1-3) and family support and community (4-5)	Helping family know rights, communicate child's needs, help child develop and learn—sub-items with specific questions/practices

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Ridgley, R. & Hallam, R. (2006). Examining the IFSPs of rural, low-income families: Are they reflective of family concerns? <i>Journal of Research in Childhood Education</i> , 21, 149-162.	Examine needs and concerns identified by rural, low-income families and if those needs reflected in IFSP	2 semi-structured interviews	5 families—Medicaid, rural, rec EI for 6 months, at least 2 services	IFSPs generally included concerns related to parenting a child with disability; outcomes generally child focused—all 5 had child developmental needs as outcome; informational support was addressed; 4 families identified additional family concerns—only 1 IFSP addressed this	Not directly measured, but parents mentioned needs that their providers did or did not support, including flexibility in service delivery, information regarding toys and materials, connections with other families, and transition information
Stewart, K. B. (2011). Therapy locations in early intervention: A pilot survey of parents' and therapists' perspectives. <i>Journal of Occupational Therapy, Schools, & Early Intervention</i> , 4, 215-228.	Examine how differences in therapy locations provide opportunities for child's development, family support	Researcher developed surveys	39 families rec OT, PT, ST in 2+ locations 59 therapists (ST, PT, OT) provide services 2+ locations	Family support—center best to meet other parents, access additional services, observe children with special needs; home best for providing other caregivers to learn from therapist; overall family support 41% of families and therapists chose home, 54% of parents and 59% of therapist chose center	Practices measured on survey include parents learning new ways to play with child, parents and relatives learning from therapist

(continued)

Table 1 (continued)

Article	Purpose	Measures/Data sources	Participants / Family voice	Family outcomes / Findings	Provider practices
Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D. J., . . . , Kupzyk, K. (2007). Relationship of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. <i>International Journal of Disability, Development, and Education</i> , 54, 319-338.	Examine families' perceptions of levels of service, satisfaction with partnership, satisfaction FQOL	Services Inventory, Family-Professional Partnership Scale, FQOL Scale	180 families (86 with child 0-3 years)—results did not separate out by age	Families reported more child needs than family needs, but of those reporting family needs fewer report receiving enough services	Survey measured services (not practices), including parent training, information on where to get services, information on specific disabilities
Swafford, M. D., Wingate, K. O., Zagumny, L., & Richey, D. (2015). Families living in poverty: Perceptions of family-centered practices. <i>Journal of Early Intervention</i> , 37, 138-154.	Explore parent's perceptions of relationship with providers, ineffective strategies, effective strategies, EI support in quality of life	Researcher developed Interview protocol	N = 17; 12 families for 1 interview; 5 families for 3 interviews	Overall satisfied with EI experiences; quality of life—increased self-efficacy; challenges re location, service access	Practices that were helpful: Explaining child development and needs, being resourceful, collaboration, supporting entire family Practices that parents wished would occur: attending meetings, encouraging active participation in natural environment, family-to-family support, helping families to fully understand EI

Table 2

Demographic Table—Parents

Demographic	Percent
Gender	
Female	90
Male	10
Age	
Under 20 years	0
20-25 years	3
26-30 years	8
31-35 years	44
36-40 years	28
41+ years	15
Did not respond	3
Race	
African-American or Black	23
Asian or Pacific Islander	8
Caucasian / White	54
Hispanic or Latino	15
Highest Educational Level	
High School	13
Some college/vocational school	8
Associates degree	0
Bachelor's degree	36
Master's degree	38
Doctorate or terminal degree	5
Marital Status	
Married	79
Single	13
Divorced	8
Annual Family Income	
Under \$25,000	18
\$25,001-\$50,000	21
\$50,001-\$75,000	6
\$75,001-\$100,000	26
Over \$100,000	29
Languages spoken in home	
English as primary	88
Other than English as primary	12
Multiple languages (Arabic, ASL, French, German, Hindi, Japanese, Spanish, Urdu)	38

Note. $n = 39$.

Table 3

Demographic Table—Children

Demographic	Percent
Gender	
Female	39
Male	61
Age	
Under 12 months	8
12-23 months	14
24-35 months	53
36-42 months	26
Race	
African-American or Black	24
Asian or Pacific Islander	5
Caucasian / White	42
Hispanic or Latino	11
Multiracial	11
Did not answer	8
Number of services on IFSP	
1 service	16
2 services	39
3 or more services	45
Children with therapeutic services in addition to EI (ABA, aquatics, feeding, duplicative to increase number of sessions/week)	8
Length of EI involvement	
6-11 months	37
12-17 months	29
18-23 months	13
24-29 months	13
30+ months	8

Note. $n = 38$.

Table 4

Interview Themes and Sub-themes

Theme	Sub-Theme
Early Intervention Facilitators	System Provider
Early Intervention Barriers	System Provider
Family life raising a child with a delay or disability	Knowledge and experiences - Prior Knowledge and experiences - New because of child's delay or disability Relationships and support - Nuclear family Relationships and support - Extended family Relationships and support - Extended network Relationships and support - Absence of Emotional Impact - Worries Emotional Impact - Confidence Actions - As a direct result of EI Actions - Parents in daily life, not necessarily related to child's disability
Advocacy	Actions taken on behalf of own child / family, EI system, or others Potential future actions
Wishes	Regarding EI, child/family, community

Table 5

FOS-R® Responses—All Respondents

Item	All; <i>n</i> = 39 Average, Range		All; <i>n</i> = 39 Percent 4+*	
	Pre	Post	Pre	Post
Section A				
Outcome 1 (4 sub-items)	4.31 1-5	4.41 1-5	79%	87%
Outcome 2 (5 sub-items)	4.27 1-5	4.25 1-5	79%	74%
Outcome 3 (4 sub-items)	4.47 3-5	4.46 1-5	82%	82%
Outcome 4 (5 sub-items)	4.39 1-5	4.39 1-5	82%	79%
Outcome 5 (6 sub-items)	4.68 1-5	4.68 1-5	95%	92%
Section B				
Helpfulness 1 (5 sub-items)	4.15 1-5	4.10 1-5	69%	67%
Helpfulness 2 (6 sub-items)	4.41 1-5	4.43 1-5	77%	77%
Helpfulness 3 (6 sub-items)	4.16 1-5	4.16 1-5	72%	72%

Note. Average and range of all sub-items; *Percentage of responses at average of 4 or higher on 5-point Likert scale for sub-items. Outcomes: “almost” or “completely”; Helpfulness: “very helpful” or “extremely helpful.”

Table 6

FOS-R[®] Responses by Location

Item	Chicago; <i>n</i> = 13		Suburban Cook County; <i>n</i> = 15		DuPage County; <i>n</i> = 11	
	Pre	Post	Pre	Post	Pre	Post
Section A						
Outcome 1	4.25 (77%)	4.25 (77%)	4.33 (87%)	4.52 (100%)	4.35 (73%)	4.43 (82%)
Outcome 2	4.4 (77%)	4.28 (77%)	4.09 (80%)	4.19 (73%)	4.35 (82%)	4.31 (73%)
Outcome 3	4.46 (77%)	4.41 (77%)	4.59 (93%)	4.57 (93%)	4.32 (73%)	4.39 (73%)
Outcome 4	4.54 (85%)	4.52 (85%)	4.32 (87%)	4.28 (80%)	4.31 (73%)	4.38 (73%)
Outcome 5	4.72 (100%)	4.64 (92%)	4.62 (87%)	4.64 (87%)	4.74 (100%)	4.78 (100%)
Section B						
Helpfulness 1	4.05 (54%)	3.92 (54%)	4.01 (73%)	4.0 (67%)	4.45 (82%)	4.44 (82%)
Helpfulness 2	4.27 (69%)	4.25 (69%)	4.43 (80%)	4.46 (80%)	4.57 (82%)	4.59 (82%)
Helpfulness 3	4.05 (62%)	4.0 (62%)	4.44 (80%)	4.44 (80%)	3.92 (73%)	3.97 (73%)

Note. Average of all sub-items; Percentage of responses at average of 4 or higher on 5-point Likert scale for sub-items. Outcomes: “almost” or “completely”; Helpfulness: “very helpful” or “extremely helpful.” Chicago nestled in Cook County; Data from participants in Chicago are not included with participants in Cook County.

Table 7

FOS-R[®] Responses by Race

Item	Asian; <i>n</i> = 3		African-American; <i>n</i> = 9		Hispanic/Latino; <i>n</i> = 6		White/Caucasian; <i>n</i> = 21	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Section A								
Outcome 1	3.5 (33%)	3.58 (67%)	4.33 (89%)	4.33 (89%)	4.46 (83%)	4.46 (86%)	4.26 (76%)	4.42 (86%)
Outcome 2	3.4 (67%)	3.4 (67%)	4.49 (89%)	4.49 (89%)	4.37 (83%)	4.33 (83%)	4.14 (71%)	4.11 (62%)
Outcome 3	4.42 (100%)	4.58 (100%)	4.48 (78%)	4.4 (78%)	4.58 (83%)	4.58 (83%)	4.45 (81%)	4.44 (81%)
Outcome 4	4.33 (100%)	4.53 (100%)	4.42 (78%)	4.42 (78%)	4.4 (83%)	4.4 (83%)	4.38 (81%)	4.35 (76%)
Outcome 5	4.43 (100%)	4.53 (100%)	4.61 (100%)	4.5 (89%)	4.5 (83%)	4.58 (83%)	4.8 (95%)	4.8 (95%)
Section B								
Helpfulness 1	4.27 (67%)	4.27 (67%)	4.13 (56%)	4.13 (56%)	4.0 (67%)	3.87 (67%)	4.1 (71%)	4.04 (67%)
Helpfulness 2	4.23 (67%)	4.23 (67%)	4.3 (78%)	4.3 (78%)	4.45 (83%)	4.5 (83%)	4.37 (71%)	4.39 (71%)
Helpfulness 3	3.9 (67%)	3.9 (67%)	3.92 (56%)	3.85 (56%)	4.35 (83%)	4.38 (83%)	4.11 (71%)	4.13 (71%)

Note. Average of all sub-items; Percentage of responses at average of 4 or higher on 5-point Likert scale for sub-items. Outcomes: “almost” or “completely”; Helpfulness: “very helpful” or “extremely helpful.”

Table 8

FOS-R[®] Responses by Income

Item	<25K; <i>n</i> = 6 households; 7 participants		25-50K; <i>n</i> = 7 households; 8 participants		50-100K; <i>n</i> = 11 households; 11 participants		100K+; <i>n</i> = 10 households; 13 participants	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Section A								
Outcome 1	4.46 (86%)	4.5 (100%)	4.0 (75%)	4.34 (88%)	4.48 (91%)	4.48 (91%)	4.27 (69%)	4.33 (77%)
Outcome 2	4.29 (86%)	4.4 (86%)	4.1 (88%)	4.25 (88%)	4.42 (91%)	4.44 (73%)	4.23 (62%)	4.02 (62%)
Outcome 3	4.14 (71%)	4.11 (71%)	4.66 (100%)	4.63 (100%)	4.66 (91%)	4.68 (91%)	4.37 (69%)	4.37 (69%)
Outcome 4	4.29 (86%)	4.31 (71%)	4.5 (88%)	4.48 (88%)	4.4 (82%)	4.4 (82%)	4.37 (77%)	4.37 (77%)
Outcome 5	4.3 (100%)	4.34 (100%)	4.65 (88%)	4.55 (75%)	4.81 (100%)	4.81 (100%)	4.81 (92%)	4.83 (92%)
Section B								
Helpfulness 1	4.54 (86%)	4.66 (86%)	3.68 (50%)	3.7 (50%)	4.33 (64%)	4.18 (55%)	4.08 (77%)	3.97 (77%)
Helpfulness 2	4.71 (86%)	4.69 (86%)	3.99 (63%)	4.13 (63%)	4.67 (100%)	4.67 (100%)	4.28 (62%)	4.27 (62%)
Helpfulness 3	4.69 (86%)	4.53 (86%)	3.9 (63%)	3.98 (63%)	4.32 (82%)	4.35 (82%)	3.91 (62%)	3.92 (62%)

Note. Average of all sub-items; Percentage of responses at average of 4 or higher on 5-point Likert scale for sub-items. Outcomes: “almost” or “completely”; Helpfulness: “very helpful” or “extremely helpful.”

Table 9

FOS-R® Responses by Parental Education

Item	Completed high school or some college; <i>n</i> = 8		Bachelor's degree; <i>n</i> = 14		Graduate degree; <i>n</i> = 17	
	Pre	Post	Pre	Post	Pre	Post
Section A						
Outcome 1	4.25 (88%)	4.25 (88%)	4.32 (79%)	4.54 (93%)	4.33 (76%)	4.37 (82%)
Outcome 2	4.13 (75%)	4.3 (75%)	4.39 (86%)	4.36 (79%)	4.24 (76%)	4.14 (71%)
Outcome 3	4.5 (88%)	4.48 (88%)	4.59 (93%)	4.61 (93%)	4.35 (71%)	4.34 (71%)
Outcome 4	4.6 (100%)	4.6 (88%)	4.39 (86%)	4.39 (86%)	4.29 (71%)	4.29 (71%)
Outcome 5	4.54 (100%)	4.58 (100%)	4.73 (93%)	4.67 (86%)	4.72 (94%)	4.74 (94%)
Section B						
Helpfulness 1	4.42 (75%)	4.53 (75%)	4.19 (64%)	4.13 (64%)	3.99 (71%)	3.87 (65%)
Helpfulness 2	4.46 (75%)	4.44 (75%)	4.48 (86%)	4.54 (86%)	4.32 (71%)	4.34 (71%)
Helpfulness 3	4.44 (75%)	4.3 (75%)	4.22 (79%)	4.27 (79%)	3.98 (65%)	4.01 (65%)

Note. Average of all sub-items; Percentage of responses at average of 4 or higher on 5-point Likert scale for sub-items. Outcomes: “almost” or “completely”; Helpfulness: “very helpful” or “extremely helpful.”

Table 10

Family Outcomes Survey-Revised[®] and Interview Comparison

Participant	O 1	O 2	O 3	O 4	O 5	H 1	H 2	H 3
C6.2.01	M	M	M	P	M	P	P	P
C6.3.01	M	M	M	P	M	M	M	M
C6.14.01	M	M	M	M	M	M	M	P
C6.15.01	M	M	P	M	M	P	P	P
C6.16.01	M	M	M	M	M	M	M	M
C6.22.01	M	P	M	M	M	P	M	M
C6.22.02	M	P	M	M	M	P	M	M
C6.23.01	M	M	M	P	M	M	M	P
C6.23.02	M	M	M	M	M	M	M	M
C6.26.01	M	M	M	M	M	P	P	M
C6.26.02	M	M	M	M	M	M	M	M
C6.27.01	M	M	M	M	M	P	P	P
C6.27.02	P	P	M	M	M	P	P	M
C6.28.01	M	M	M	M	M	M	M	M
C6.28.02	M	P	M	M	M	P	P	M
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C6.29.03	P	P	M	P	M	P	P	P
C6.30.01	M	M	M	M	M	M	M	M
C6.30.02	M	M	M	M	M	M	M	M
C6.30.03	M	N	M	M	M	P	P	P
C6.30.04	M	M	M	M	M	M	M	M
C7.12.01	M	M	M	M	M	M	M	M
C7.12.02	M	M	M	M	M	M	M	M
C7.17.01	M	M	M	M	P	M	P	M
C7.20.01	M	M	M	M	M	M	M	M
C7.26.01	M	M	M	M	M	P	P	P
C7.26.02	M	M	M	M	M	M	M	M
D6.21.01	M	M	M	M	M	M	M	M
D6.21.02	M	P	P	P	M	M	P	M
D6.22.01	M	P	M	M	M	P	P	M
D6.22.02	M	M	M	M	M	P	M	M
D6.28.01	P	P	M	M	M	P	M	M
D6.28.02	M	M	M	M	M	M	M	M
D6.29.01	M	M	M	M	M	M	P	P
D7.11.01	M	M	M	M	M	P	P	P
D7.11.02	M	M	M	M	M	M	P	M
D7.12.01	M	M	M	M	M	P	P	P
W6.14.01	M	M	M	M	M	M	M	M

Note. O = Outcome; H = Helpfulness; M = Match; P = Partial match; N = No match.

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Appendix A

Institutional Review Board Approval

Sunday, January 29, 2017 at 8:04:33 AM Central Standard Time

Subject: re: UIUC IRB Exempt Approval - IRB #17142
Date: Tuesday, September 13, 2016 at 1:19:25 PM Central Daylight Time
From: Banks, Ronald Alan
To: Santos Gilbertz, Rosa Milagros, Spence, Christine Marie

IRB EXEMPT APPROVAL

RPI Name: Rosa Milagros Santos
Project Title: Family Outcomes and Experiences as a Result of Participating in Early Intervention
IRB #: 17142
Approval Date: September 13, 2016

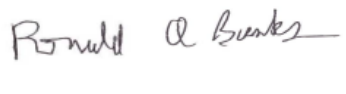
Thank you for submitting the completed IRB application form and related materials. Your application was reviewed by the UIUC Office for the Protection of Research Subjects (OPRS). OPRS has determined that the research activities described in this application meet the criteria for exemption at 45CFR46.101(b)(2). This message serves to supply OPRS approval for your IRB application.

Please contact OPRS if you plan to modify your project (change procedures, populations, consent letters, etc.). Otherwise you may conduct the human subjects research as approved for a period of five years. Exempt protocols will be closed and archived at the time of expiration. Researchers will be required to contact our office if the study will continue beyond five years.

Copies of the attached, date-stamped consent form should be used when obtaining informed consent.

We appreciate your conscientious adherence to the requirements of human subjects research. If you have any questions about the IRB process, or if you need assistance at any time, please feel free to contact me at OPRS, or visit our website at <http://oprs.research.illinois.edu>

Sincerely,



Ronald Banks, MS, CIP
Human Subjects Research Coordinator, Office for the Protection of Research Subjects

Attachment(s): Approved consent letter

Cc: Christine Spence

Office of the Vice Chancellor for Research | Office for the Protection of Research Subjects
University of Illinois | Urbana-Champaign
528 E. Green Street, Suite 203, MC-419 | Champaign, IL 61820
Phone: (217) 333-2670 | Fax: (217) 333-0405 | Email: irb@illinois.edu
Website: <http://oprs.research.illinois.edu>

RE: OPRS approval for research amendment for #17142

Banks, Ronald Alan

Sent: Tuesday, June 13, 2017 11:16 AM
To: Spence, Christine Marie
Cc: Santos Gilbertz, Rosa Milagros
Attachments: 17142_ApprovedICD_06132017.pdf (121 KB)

Dear Christine and Amy:

This message serves to supply UIUC IRB approval for the minor modification being made to your protocol <IRB 17142 - Family Outcomes and Experiences as a Result of Participating in Early Intervention>. This amendment approves the following changes:

- 1) Changing from focus group interviews to individual interviews; supplied the updated consent document and interview protocol to reflect this change.

Attached is the approved stamped copy of the updated individual interview consent document. This revision does not affect the exempt status of your application. If you have any questions please don't hesitate to ask!

Ron

Ron Banks, MS, CIP
Human Subjects Coordinator
UIUC Office for the Protection of Research Subjects
Suite 203, MC-419
528 E. Green
Champaign, IL 61820
Phone: 217-244-3939
Fax: 217-333-0405
Email: rbanks@illinois.edu

Appendix B

Recruitment Materials

Recruitment email

Hi! My name is Christine Spence and I am a doctoral student at the University of Illinois at Urbana-Champaign. I am conducting research for my dissertation on the experiences that families have had with early intervention. I would like to understand more about the outcomes of early intervention for families and how EI therapists helped to achieve those outcomes.

I was wondering if you would be able to share this information with families who currently participate in early intervention or who have recently discharged. I am attaching a flyer with information about the study as well as an email that you could forward to families. If families are interested, please have them contact me at cspace@illinois.edu, call 217-244-6742, or text 773-844-0980.

Thank you for consideration of this request,
Christine

If you are a parent of a child who currently receives or recently received early intervention services, I am inviting you to participate in a research study exploring outcomes and experiences of early intervention. You would provide some demographic information about your child and family, complete a survey regarding family outcomes, and participate in an interview. I anticipate that the total time commitment will be approximately 1-1.5 hours. You are eligible to participate if your child has received early intervention services for at least six months. They can still be participating in early intervention or discharged from early intervention services within the past six months. You will receive a \$25 gift card in appreciation for your time and input.

If you are interested in sharing your experiences and participating in this study, or if you have any questions, please contact me via email at cspace@illinois.edu, call 217-244-6742, or text 773-844-0980. We can schedule a time and location that is convenient for you. Thank you very much for considering this request.

Thanks,
Christine

Christine Spence, MM, MT-BC
Doctoral Candidate
Department of Special Education
University of Illinois at Urbana-Champaign
217-244-6742
cspace@illinois.edu

Has your child participated in early intervention?

I would like to understand more about the outcomes of early intervention for families and how EI therapists helped to achieve those outcomes.

I am inviting parents to complete a survey and participate in an interview describing your experiences in early intervention.

You are eligible to participate if you live in Cook or DuPage County and your child has received early intervention services for at least six months. They can still be participating in early intervention or discharged from early intervention services within the past six months.

The interview can be scheduled at a time and place that is convenient for you.

The total time commitment is approximately an hour to an hour and a half.

You will receive a \$25 gift card in appreciation for your time and input.

Please contact Christine Spence at cspence@illinois.edu or 217-244-6742 with questions or to schedule a time to meet for the interview.

Appendix C

Family Consent

UNIVERSITY OF ILLINOIS
AT URBANA-CHAMPAIGN

College of Education
Department of Special Education
288 Education Building
1310 South Sixth Street
Champaign, IL 61820-6990



Dear Families,

We are conducting a study on the outcomes of early intervention for children and families. For purposes of this study, we would like to invite you to participate by agreeing to complete a survey and participate in an interview, discussing your participation in early intervention.

The survey will be completed immediately prior to the interview and your total time commitment will be approximately 1-1½ hours. The survey will include demographic information, including zip code and early intervention services that your child receives, and questions regarding your outcomes as a participant in early intervention. The interview will be audio recorded. We will be combining the data from your survey responses and interviews and analyzing them as a group. Upon completion of the project, we will destroy all of the individual data collected from this study. Results of this study will be used for a research paper, journal articles, presentations to state early intervention professionals, and conference presentations. In any publication or public presentations related to this study, pseudonyms will be substituted for any identifying information.

The information discussed within the interview will remain confidential to the best of our abilities, in that identifying information, such as names, will be excluded from written products. After transcription and analysis the voice recording will be destroyed.

Your participation in this project is completely voluntary and your choice to participate or not will not impact your current or future participation in Early Intervention. We do not anticipate any risk to this study greater than normal life and we anticipate that this project will contribute to the improvement of services in the area of early intervention. After you complete the survey and interview, you will receive a \$25 Target gift card in appreciation for your participation in the research study. After the completion of the interview, I will be sending an email to you with an analysis of the themes generated from the interview. I will ask for you to review the document and provide feedback if you feel that the information accurately reflects the conversation. Upon completion of this review, you will receive a \$10 Target gift card in appreciation for your time in reviewing the document.

When this research is discussed or published, no one will know that you were in the study. However, laws and university rules might require us to disclose information about you. For example, if required by laws or University Policy, study information which identifies you and the consent form signed by you may be seen or copied by the following people or groups: a) The university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for [Protection of Research Subjects](#); and b) University and state auditors, and Departments of the university responsible for oversight of research.

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu

If you agree to participate in this study, please keep a copy of this consent form for your records. If you have any questions about this request, you may contact me at cspence@illinois.edu or (217) 244-6742 or you may contact my advisor, Dr. Rosa Milagros Santos at rsantos@illinois.edu or (217) 244-3558.

Thank you for your consideration of this request,

Christine Spence, MM
Doctoral Student, University of Illinois

Rosa Milagros Santos, PhD
Faculty, Department of Special Education
University of Illinois

Consent Form

I have read the above information and voluntarily agree to participate in this project as described above. I understand the purpose of the study and that I may withdraw my consent at anytime. If I check "Permission Not Granted" for either box below, then I understand that I will not participate in this study.

Please check one column per statement:

*Permission
Granted*

☐☐

*Permission
Not Granted*

☐☐

I consent to participating in this study, including completing a survey and participating in an interview.

I consent to being audiorecorded during the interview.

Printed Name: _____

Signature: _____ Date: _____

Address: _____

Phone Number: _____

Email address: _____

University of Illinois at Urbana-Champaign
Institutional Review Board

Approved: 6-13-17
IRB #: 12142

Appendix D

Study Measures

ID:

Family Experiences with Early Intervention Demographic Information

Birthdate of child:

Gender of child:

Zip code of child's primary residence:

What services or supports are listed on your child's IFSP? Check all that apply.	For each service marked, please indicate:	
	<i>How often are these services provided as written in the IFSP?</i>	<i>When these services are provided, who is usually present at the sessions? (for example, mom, dad, grandparent, child care provider):</i>
<input type="checkbox"/> Applied Behavior Analysis (BCBA)		
<input type="checkbox"/> Developmental Therapy (DT)		
<input type="checkbox"/> Developmental Therapy – Hearing (DT-H), Vision (DT-V), or Orientation & Mobility (DT-OM)		
<input type="checkbox"/> Nutrition		
<input type="checkbox"/> Occupational Therapy (OT)		
<input type="checkbox"/> Physical Therapy (PT)		
<input type="checkbox"/> Psychology		
<input type="checkbox"/> Social Work (SW)		
<input type="checkbox"/> Speech-Language Pathology (ST)		
<input type="checkbox"/> Other (please list):		

In what month and year did your child first begin receiving early intervention services?

Has your child been discharged from early intervention? If so, what is the date of discharge?

Racial or ethnic background of child:

- | | |
|--|---|
| <input type="checkbox"/> African American or Black | <input type="checkbox"/> Hispanic or Latino |
| <input type="checkbox"/> American Indian / Alaska Native | <input type="checkbox"/> Caucasian / White |
| <input type="checkbox"/> Asian or Pacific Islander | <input type="checkbox"/> Multiracial (please indicate): |
| <input type="checkbox"/> Other (please indicate): | |

Birthdate of caregiver:

Gender of caregiver:

Highest Educational Level of caregiver (check one):

- ☐ Some high school, but no diploma
- ☐ Graduated high school
- ☐ Some college or vocational courses, no certificate or diploma
- ☐ Associates degree
- ☐ Bachelors degree
- ☐ Masters degree
- ☐ Doctorate or other terminal degree (PhD, JD, MD, etc)

Marital status of caregiver (check one):

- | | |
|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Single | <input type="checkbox"/> Married |
| <input type="checkbox"/> Divorced | <input type="checkbox"/> Widowed |

Racial or ethnic background of caregiver:

- | | |
|--|---|
| <input type="checkbox"/> African American or Black | <input type="checkbox"/> Hispanic or Latino |
| <input type="checkbox"/> American Indian / Alaska Native | <input type="checkbox"/> Caucasian / White |
| <input type="checkbox"/> Asian or Pacific Islander | <input type="checkbox"/> Multiracial (please indicate): |
| <input type="checkbox"/> Other (please indicate): | |

Annual family income (check one):

- ☐ Under \$25,000
- ☐ \$25,001-\$50,000
- ☐ \$50,001-\$75,000
- ☐ \$75,001-\$100,000
- ☐ Over \$100,000

Primary language spoken in your home:

Please list other language(s) also spoken in your home.

**Have you participated in early intervention previously, with another child?
If so, what services did they receive?**

FAMILY OUTCOMES SURVEY

Revised Version

Section A: Family Outcomes

Instructions: Section A of the Family Outcomes Survey focuses on the ways in which you support your child's needs. For each statement below, please select which option best describes your family right now: not at all, a little, somewhat, almost, or completely.

	Not at all	A little	Somewhat	Almost	Completely
Outcome 1: Understanding your child's strengths, needs, and abilities					
1. We know the next steps for our child's growth and learning.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. We understand our child's strengths and abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. We understand our child's delays and/or needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. We are able to tell when our child is making progress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 2: Knowing your rights and advocating for your child					
5. We are able to find and use the services and programs available to us.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. We know our rights related to our child's special needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. We know who to contact and what to do when we have questions or concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. We know what options are available when our child leaves the program.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. We are comfortable asking for services & supports that our child and family need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 3: Helping your child develop and learn					
10. We are able to help our child get along with others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. We are able to help our child learn new skills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. We are able to help our child take care of his/her needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. We are able to work on our child's goals during everyday routines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 4: Having support systems					
14. We are comfortable talking to family and friends about our child's needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. We have friends or family members who listen and care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. We are able to talk with other families who have a child with similar needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. We have friends or family members we can rely on when we need help.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I am able to take care of my own needs and do things I enjoy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Outcome 5: Accessing the community					
19. Our child participates in social, recreational, or religious activities that we want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. We are able to do things we enjoy together as a family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Our medical and dental needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Our child care needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Our transportation needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Our food, clothing, and housing needs are met.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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FAMILY OUTCOMES SURVEY

Revised Version

Section B: Helpfulness of Early Intervention

Instructions: Section B of the Family Outcomes Survey focuses on the helpfulness of early intervention. For each question below, please select how helpful early intervention has been to you and your family over the past year: Not at all helpful, a little helpful, somewhat helpful, very helpful, or extremely helpful.

	Not at all helpful	A little helpful	Somewhat helpful	Very helpful	Extremely helpful
Knowing your rights					
How helpful has early intervention been in...					
1. giving you useful information about services and supports for you and your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. giving you useful information about your rights related to your child's special needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. giving you useful information about who to contact when you have questions or concerns?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. giving you useful information about available options when your child leaves the program?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. explaining your rights in ways that are easy for you to understand?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communicating your child's needs					
How helpful has early intervention been in...					
6. giving you useful information about your child's delays or needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. listening to you and respecting your choices?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. connecting you with other services or people who can help your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. talking with you about your child and family's strengths and needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. talking with you about what you think is important for your child and family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. developing a good relationship with you and your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping your child develop and learn					
How helpful has early intervention been in...					
12. giving you useful information about how to help your child get along with others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. giving you useful information about how to help your child learn new skills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. giving you useful information about how to help your child take care of his/her needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. identifying things you do that help your child learn and grow?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. sharing ideas on how to include your child in daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. working with you to know when your child is making progress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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Interview Protocol

Have participants sign consent, fill out demographic survey, and FOS-R.

Introduction

Thank you for meeting with me today. My name is Christine. I am currently a doctoral student at the University of Illinois-Urbana Champaign. For 11 years, I worked as an early intervention provider in the Chicago area. Now as a researcher, I am very interested in how early intervention supports families, what is working well, and how we can improve services.

Reason we are here

Today, I would like to talk with you about your experiences with early intervention. Please feel free to be open and honest with your experiences as this information will help us to better understand how early intervention can support families like yours. I want to know what is working and what is not working. I want to hear about strategies that your providers have used with you and your child, like what your speech therapist is showing you what to do to help your child learn to talk, or how your therapist is talking with you and coming up with ideas that you think you can do during the week.

Time and Procedure

Our conversation should last for about an hour. After we finish talking, I will ask you to review the survey you filled out and you will have the opportunity to change your response, if you choose. You do not need to change your responses, but you might find that you would answer it differently after we talk about them.

Recording and confidentiality

I will be recording the conversation today and notes will be shared with three other people who will help look at the information you share today. The information from this conversation and others that I am having will be combined and shared with others, including the Department of Human Services or other stakeholders in early intervention. Everything we talk about today will remain confidential to the best of my ability, in that all identifying information, such as your name or the name of your child, will not appear in writing.

I will destroy the recording after our conversation is transcribed. The information you share today will not be shared with your service coordinator or therapists, and this information will not directly impact your early intervention services.

Do you have any questions before we begin?

Scenarios

Please listen to and read along as I read the following scenarios. [Read scenarios]

Is there anything that is familiar to you? Is this similar to how you experience early intervention?
Is there anything that is described that you feel may have been helpful to you and your family but was not part of your experience?

Entry into the system

Can you tell me a little bit about how you and your family got involved with EI?

Probe: Did someone specific tell you about early intervention?

Probe: Did you mention a concern about your child's development to your pediatrician?

Probe: Did you know about early intervention prior to your referral?

Outcome 1: Understanding your child's strengths, needs, and abilities

Q1: How do you learn about your child's specific developmental needs and abilities?

Probe: How has early intervention helped you with that understanding?

Probe: If you feel that early intervention has not helped you in this way, can you tell me a little more about why not? Are there specific things or experiences that you wish you had that you did not?

Q2: Can you provide a specific example of a strategy that a provider (DT, OT, PT, ST, SW) or your service coordinator used that was really helpful?

Probe: How do you get information about child development? Do you rely on one person or do you talk to multiple people, such as your doctor, neighbor, family member, websites, etc.?

Outcome 3: Helping your child develop and learn

Q1: How do you feel that you are able to help your child learn new skills and work on those during daily routines, such as eating a meal or bathtime?

Probe: If this is a struggle, what additional supports, services, or resources do you feel would be helpful?

Q2: Can you provide a specific example of a strategy that a provider (DT, OT, PT, ST, SW) or your service coordinator used that was really helpful?

Outcome 4: Having support systems

Q1: Who do you feel comfortable talking with about your child's needs, including family members, child care providers, doctors, or other people your child spends time with?

Probe: Do you talk with other families who are in early intervention? Is that something you wish for?

Q2: Can you provide a specific example of a strategy that a provider (DT, OT, PT, ST, SW) or your service coordinator used that was really helpful in having those conversations?

Probe: Do you feel comfortable explaining what services and supports you need?

Outcome 5: Accessing the community

Q1: How has early intervention helped you and your family do things that you like to do in your community?

Probe: Are you and your child able to do the things that you would like, such as go to the park, library, grocery store, neighborhood block party, etc.?

Q2: Can you share an example of something that a therapist has taught you when you are out and about in the community?

Outcome 2: Knowing your rights and advocating for your child

Q1: Do you feel able to advocate for your child? If so, were there specific ideas or strategies that helped you?

Q2: How has early intervention helped you to understand your rights as a parent of a child in early intervention?

Probe: If you have started the transition process into school, do you feel that you know your rights? Do you feel comfortable talking about school and community options, such as preschool or park district program?

Q3: Did therapists, service coordinators, or parent liaisons do anything specific that you felt was really helpful in helping you advocate for your child?

Participation in EI system

Is there anything that you felt would have been useful to have in early intervention, but that you did not receive? This is not about a specific service, such as occupational therapy, physical therapy, or speech therapy for your child, but rather a support, strategy, connection, or something else that would have helped you to better support your child.

Are there any unique circumstances about your family that early intervention was a great support for or that you felt limited or hindered your participation in early intervention?

Please look at the Family Outcomes Survey that you filled out at the beginning of our time today. If you feel that any of your responses should change after our conversation, please fill in the circle for your new answer with the red pen.

Thank you for being here and talking with me today. I really appreciate the time you spent. I will be emailing you in several weeks with a summary of the conversation today. Please review it and make sure that I have captured the information you shared. Let me know if there are any changes that should be made. You will receive a \$25 gift certificate as a small token of my thanks for participating today and a \$10 gift certificate when you reply to the email and let me know of any corrections or changes.

Early Intervention Scenarios

Mara, the developmental therapist, knocks on the door to Kayla's house. Kayla's mother, Shari, answers the door and Kayla waves at Mara as she walks in the house. Mara asks Shari how the week has been and if anything new happened with Kayla since the last time Mara visited. Shari tells a story of a new word that Kayla started using while they were at the park. Mara then asks Shari if there was anything difficult that happened during the week or goals that they weren't able to work on. She asks Shari what she would like as the focus of their time together. Shari shares that Mara tends to have more challenging behaviors in the late afternoon, when Shari is preparing dinner and Mara's older brother has come home from school. Shari and Mara brainstorm several ideas of strategies that the family can try this week. Mara asks if they can schedule next week's visit at this time of the day so that she can observe what is happening and they can discuss which strategies worked and which ones did not work.

Sylvia, a speech pathologist, sees Jamie at his home. Usually Jamie's mother is present during the sessions; however, sometimes his father or another relative is at home. Sylvia and Jamie sit on the living room floor and play a variety of games that Jamie enjoys. Sylvia models specific words or sounds that she wants Jamie to use. At the end of the session, Sylvia talks with the adult who is present to review what happened during the hour and to give ideas for what they can do to support Jamie's language until she sees them next week.

Appendix E

Fidelity Checklist

Families' Outcomes & Experiences with Early Intervention Fidelity Checklist

Participants:

Interview #:

Individual Interview: (Use space to make notes. If no, indicate what happened instead.)

	Yes	No
1. Participant signed consent		
2. Participant completed demographic survey		
3. Participant completed FOS-R		
4. Facilitator read scenarios and gave families opportunity to respond		
5. Facilitator engaged caregiver in discussion of the following 5 outcomes:		
1. Understanding / learning about child's developmental needs and abilities		
2. Helping child develop and learn new skills		
3. Talk with family members / have support system		
4. Access community		
5. Understand rights		
6. Facilitator gave each participant the opportunity to fill out FOS-R after discussion		
7. Facilitator thanked participants and gave gift card / incentive at end		