Understanding experiences of families and their partnerships as they navigate early intervention, transition, and early childhood special education

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Understanding experiences of families and their partnerships as they navigate early intervention, transition, and early childhood special education

by

Aryn D. Kruse

A dissertation submitted to the graduate faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Major: Human Development and Family Studies

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ABSTRACT

Building effective partnerships with families is a recommended practice in early intervention and early childhood special education. These relationships have shown long-lasting, positive impacts on student achievement and lead to increased parent involvement (Knopf & Swick, 2007). The purpose of this critical ethnography was to understand how families experience partnerships in early intervention, during the transition from early intervention, and in early childhood special education. In a critical ethnography, researchers provide a thick description of a culture (in this study, the culture of parenting a child with a disability) and accounts for the social and political structures (such as power) that shape human behavior. A series of three interviews was used to socially construct an understanding of families’ experiences and to identify factors that contribute or damage partnerships in early childhood services. Family life course theory, ecological framework, and conflict theory were all used to position the study questions and findings. Key findings of this study include factors and experiences that play a role in the family partnership experiences and that both families and professionals play roles in the establishment and maintenance of these partnerships.
CHAPTER 1. GENERAL INTRODUCTION

Background and Context

“Our generation got our kids into the schools, your generation will make it quality.” I don’t think I’ll ever forget that statement. It was made to me by a mother of a child with cerebral palsy. I’m also a mother of a child with a disability, so where do our stories differ? Her son is an adult, and my child is only 6 years old. As a parent who advocated for her child in the 1970s, she’s a real-life example of a parent who has been traveling along with legislative history regarding special education services and civil rights. Her journey began prior to 1975, and special education began its journey on a national stage with the adoption of PL-94-142 soon thereafter. 

On November 29, 1975, Congress enacted the Education for All Handicapped Children Act (PL 94-142; Thirty Years of Progress, 2010). Prior to this law, children with disabilities did not have equal access to education; this law was intended to protect the rights of children with disabilities and ensure that parents can participate actively and equally in the decision making process about their child’s educational programming and services. In 1990 the law was renamed to what it is known by today, the Individuals with Disabilities Education Act (IDEA), and has gone through reauthorizations in 1997 (Turnbull & Turnbull, 2001) and 2004 (Building the Legacy, n.d.). The 1986 amendments to IDEA mandated preschool services for children with disabilities, under the provisions of Section619 of Part B, and the development of service systems for children with delays or disabilities or who are at risk for disabilities between birth and age 3 years (Part C; Bruder, 2010; Trohanis, 2008). Part C services are provided by early intervention systems; the 1986 amendments to IDEA
gave states the authority to decide which state agency would take the lead in providing these services (Bruder, 2010). Part C of the IDEA also recognized the need to enhance the capacity of families to meet their child’s needs (National Early Childhood Technical Assistance Center, n.d.). Part B early childhood special education services are provided by local school districts and are governed by the same regulations that govern special education services for school-aged children. The nature of Part B and Part C of the IDEA being overseen by different systems creates a transition for families and children, and federal legislation requires planning for this transition (Rosenkoetter et al., 2009).

Six main principles, outlined in the IDEA, provide a framework to guide special education services: zero reject, nondiscriminatory evaluation, free appropriate public education, least restrictive environment, due process, and parent participation (Turnbull & Turnbull, 2001). Parent participation refers to the roles of parents in the special education system. This principle allows parents to have full access to their student’s records, partner in decision making regarding their child’s Individualized Family Service Plan (IFSP) and Individualized Education Program (IEP), and participate on state and local advisory committees. This principle also sets the stage for programs and families to engage in collaboration and partnership. Dunst and Dempsey (2007) defined partnerships as a relationship in which parents and professionals work toward a common goal that is based on shared decision making, as well as a relationship based on respect and mutual trust.

In the Part C early intervention system, when a child reaches 2 years 3 months to 2 years 9 months, IFSP teams must begin discussing a transition out of Part C services. Upon exiting the Part C system, some children will be eligible for Part B services and enter the early childhood special education system. An inevitable component of this transition is the
transfer of parents’ partnerships from Part C providers to Part B providers. Families exiting Part C services leave partnerships built during the time of early intervention. After leaving early intervention, they begin school- or community-based services, and they must build and maintain new partnerships with new service providers. Families often experience a shift in their roles in this partnership because of a philosophical shift from the roles they play in family-centered Part C services to program-centered Part B services (Fox, Dunlap, & Cushing, 2002). In other words, roles change due to parents’ higher level of involvement in family-centered services, which often occur within the walls of their own home, versus them no longer having a major role in the education environment where direct services occur. This shift can lead to parents feeling abandoned by the early intervention system (Soodak & Erwin, 2000). The context in which the intervention occurs also shifts; often Part C interventions are provided within natural (home) settings and Part B services take place outside of the home, in classroom settings.

**Problem Statement**

Current researchers and authors have not adequately addressed the transition of the partnership between service providers and families from early intervention (Part C) to early childhood special education services (Part B). Some have stated that more focus should be given to the transition that takes place when a child approaches 3 years of age (Rosenkoetter et al., 2009). Literature on partnerships is robust in describing the roles of service providers in building partnerships with families in early intervention (e.g., Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dinnebeil, Hale, & Rule, 1999; Keen, 2007; Lea, 2006; Patterson, Webb, & Krudwig, 2009; Soodak & Erwin, 2000). Current literature on the roles of families in partnerships is sparse and provides little information regarding strategies to
enhance families’ capacities for establishing and maintaining partnerships with service providers.

**Statement of Purpose and Research Questions**

The purpose of this study was to understand the partnerships that surround families from early intervention to preschool, to understand the process of changing partnerships between families and professionals during times of transition, and to identify the needs of families in creating smoother transitions and partnerships. Understanding these partnerships at varying stages can help identify the supports and strategies needed as families transition from early intervention to early childhood special education. The following research questions were addressed:

1. What characteristics do families describe as contributing to an ideal partnership between parents and professionals in early childhood special education and early intervention programs?
2. What do families consider beneficial in building partnerships between families and professionals in early intervention and early childhood special education?
3. What do families experience when they partner with early invention systems and transition into partnerships with early childhood special education systems?
4. What do families identify as supports needed during the transition process to establish effective partnerships with early childhood special education providers?

**Research Approach**

A qualitative approach was used to address these questions. Philosophical assumptions that underpin qualitative research were reflected in this study. These assumptions include ontological, epistemological, axiological, and methodological
assumptions (Creswell, 2007). Ontological assumptions deal with the nature of reality (Creswell, 2007). Throughout this study, I assumed that reality was subjective and that each study participant interpreted her reality differently than did other participants. The ontological assumptions were reflected in this study through the use of open-ended interviews with participants and the use of participants’ quotes to support the underlying themes of the study’s findings.

An epistemological assumption of qualitative research is that knowledge is socially constructed between the researcher and the participant (Creswell, 2007); therefore, the distance between the researcher and the researched is lessened. This was reflected throughout the study through the use of face-to-face interviews between each participant and me. I also had multiple engagements with the participants as I sought to understand the meaning participants made of their experiences.

An axiological assumption within qualitative research is to recognize that values are embedded within research, the researcher, and the researched and that bias is inevitable (Creswell, 2007). This study addressed this assumption through the use of reflexive practices. In qualitative research, reflexivity is a continual self-awareness of the researcher’s own experiences, biases, and values and how they influence the meaning of new knowledge (Finlay, 2002). To address this assumption, I reflected on my own experiences, biases, and values and acknowledged how these were positioned within the study through the use of analytic memos.

Finally, the methodological assumptions of qualitative research are that the researched are studied within their own contexts and that inductive logic and an emergent design are used (Creswell, 2007). All of these assumptions were reflected within this study.
as I used a critical ethnographic approach and allowed for emergent design as the understanding of my topic was socially constructed between my participants and me as well as through reflection of how this understanding fit within the context of current literature and research.

**Methodology**

The qualitative methodology for this study was a critical ethnography. Ethnographic studies describe and interpret the culture of groups (Merriam & Associates, 2002). Ethnographies in education often study the culture of schools and the education system (Lichtman, 2006). This ethnography studied early intervention and early childhood special education systems with a focus on families within these systems. Ethnography was an appropriate methodology because it recognized the influence that culture—including social and political forces—have had on the researched.

More specifically, this study was a critical ethnography. Critical ethnographies attempt to diminish the “power” relationships between the researcher and the observed; researchers lose their “privileged status” by joining those being studied (Lichtman, 2006, p. 63). This is one reason I felt the critical ethnographic methodology was most appropriate in light of my research questions and who I am as a researcher. Like my participants, I also am a mother of a child with a disability, have navigated through the early intervention and special education systems, and identify myself as being a part of a subculture of parents who are raising a child with a disability.

The “critical” aspect of critical ethnography addresses power and issues of injustice (Madison, 2005). Critical ethnography “disrupts the status quo, and unsettles both neutrality and taken-for-granted assumptions by bringing to light underlying and obscure operations of
power and control . . . it moves from ‘what is’ to ‘what could be’” (Madison, 2005, p. 5). In this study, I examined the current literature about best practices in partnerships between service providers and parents and used a critical ethnographic lens to study what parent say they are experiencing with partnerships, specifically partnerships during transition out of early intervention. Using information from what parents say is beneficial, and what they need to become partners with service providers will help the field of early intervention and special education move from “what is” to “what could be” in partnerships. The need to examine parents’ perspectives in this study was further reinforced at a professional conference during a session that focused on a study in which parents were interviewed. A parent of a child with a disability mentioned as feedback to the study, “It is refreshing to hear that professionals are trying to hear the family’s viewpoint” (personal communication, October 16, 2010).

Dissertation Organization

This dissertation was organized in an alternative dissertation format. It is comprised of four chapters: a general introduction followed by two articles and concluding chapter. The first article addresses the topic of how families have characterized ideal partnerships from their early intervention and early childhood special education experiences. It includes a discussion of the roles of both parents and professionals in the process of building and maintaining partnerships. The second article addresses partnerships specifically during times of transition. It includes a discussion of family experiences as the parents partnered with the system, teams, and individual professionals.
References


CHAPTER 2. UNDERSTANDING HOW PARENTS DESCRIBE IDEAL PARTNERSHIPS AND THE ROLES EMBEDDED WITHIN:
A CRITICAL ETHNOGRAPHY

A paper prepared for submission to *Topics in Early Childhood Special Education*

Aryn Kruse, Carla Peterson, & Gayle Luze

Abstract

Although literature on parent and professional partnerships is expanding, little attention has been given to the voice of parents who have navigated early intervention (EI) and early childhood special education (ECSE) systems. The purpose of this critical ethnography was to expand the knowledge of the parent perspective of partnerships with early intervention and early childhood special education systems. This study explored how families describe ideal partnerships and the partnership building process in EI and ECSE.

A series of three open-ended interviews was used to collect data. Mothers described their family story, examples of partnership experiences, and what they identified as being the ideal partnership. Findings indicated that parents identified that both parents and professionals play a role in partnerships. Parents were able to define the professional role in more detail than their own role. Recommendations include increasing resources and support to parents to help them fulfill their roles in parent/professional partnerships. Conflict theory was used to guide the discussion of this study.

Introduction

Partnership, as defined by Merriam-Webster’s (n.d.) online dictionary, is:

the state of being a partner; a legal relation existing between two or more persons contractually associated as joint principals in a business; a relationship resembling a
legal partnership and usually involving close cooperation between parties having specified and joint rights and responsibilities.

In early intervention literature, partnership is defined as an alliance between parents and service providers (Dunst & Dempsey, 2007), involving trust, shared planning and decision making, and mutually agreed upon goals (Keen, 2007). Other authors have defined partnership as “mutually supportive interactions between families and professionals” (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005, p. 49). Fox, Dunlap, and Cushing (2002) described the role of parents in a partnership as an alliance between parents and professionals through which families bring in information about the child that cannot otherwise be known, such as contextual factors and knowledge about the child, and professionals contribute their own technical knowledge and resources. A partnership such as the one described by Fox et al. recognizes the contributions and wisdom of both families and service providers.

Partnerships between professionals and parents in early childhood special education are also legal relationships. Federal legislation mandates that the special education system involve parents in the Individualized Family Service Plan and Individualized Education Program (IEP) process (Turnbull & Turnbull, 2001) as well as the assessment and placement processes. Within the partnership literature, similar terms often are used interchangeably. These terms include parent participation (Soodak & Erwin, 2000), parent involvement (Huntsinger & Jose, 2009; Yamamoto, Holloway, & Suzuki, 2006), collaboration (Dinnebeil, Hale, & Rule, 1999; Lea, 2006; Osher & Osher, 2002), parent–school interaction (Roopnarine, Krishnakumar, Metindogan, & Evans, 2006), relationships (Brookes, Summers,
Dimensions of Partnership

Researchers have moved beyond the basic definition in describing partnerships. One way to describe partnerships is to understand the dimensions and characteristics that encompass partnerships. Using focus groups of families and individual interviews of service providers, six dimensions of partnerships have been identified: communication, commitment, equality, skills, trust, and respect (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

Communication in positive partnerships has been described as having both quantitative and qualitative components (Blue-Banning et al., 2004). Family members wanted professionals to be tactful but honest (Blue-Banning et al.). Other authors also have found communication as an important element in partnership. Researchers examining parent and child-care teacher interactions described communication as being the hallmark of professional–parent partnerships (McGrath, 2007). Soodak and Erwin (2000) also interviewed parents who wanted open and frequent communication. In addition, these parents described a school’s lack of consideration of family schedules and availability as a barrier to forming effective partnerships. Other authors have noted the importance of employing staff who were skilled communicators in order to support collaboration between the program and parents (Dinnebeil et al., 1999). Knopf and Swick (2007) encouraged professionals to make communication meaningful and supportive and to employ a variety of modes (face-to-face, electronic, etc.).
Commitment in partnerships is a dimension in which professionals see their work with families as being more than just a job (Blue-Banning et al., 2004). A powerful statement by a participant was that he or she experienced professionals that worked to meet the letter of the law rather than the spirit of the law (Blue-Banning et al.). In a study examining home visitor–mother relationships, researchers found that home visitors who were committed to being dependable, honest, and persistent were able to overcome any lack of trust that parents held (Brookes et al., 2006).

Equality is another component of partnerships (Blue-Banning et al., 2004). Blue-Banning et al. (2004) found that there was a general belief that parents were disadvantaged in partnerships because of system policies and practices. Professionals were described, in partnership literature, as having power over parents because of their knowledge of the system or the child’s educational experiences (McGrath, 2007). Equality can be established through the sharing of power between families and professionals, systems that foster empowerment, and systems that provide options for families (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). In order to address the imbalance of power within the current system, authors have described a need for the system to make a paradigm shift away from being provider-driven to being family-driven (Osher & Osher, 2002).

Skills, or professional competence, is another dimension of partnership (Blue-Banning et al., 2004). Family members made positive comments about providers who were skilled, confident, and able to keep up with changing technology (Blue-Banning et al). Furthermore, parents saw providers as being competent if the providers were able to acknowledge if they did not know particular information but were willing to find the answer. Other authors described skills that build partnerships including the provider’s ability to
individualize interventions and provide appropriate services; to show a willingness to continue to learn; and to set high expectations for him- or herself, the child, and the family (Turnbull et al., 2011).

Trust, the fifth dimension of partnership identified by Blue-Banning et al. (2004), was described in terms of reliability, safety, and discretion. Parents commented that providers should be trustworthy, fulfill promises, provide a safe environment for their child, and keep the family’s confidential information private. Trust was further described by parents through qualitative interviews as having confidence that professionals would follow through, respect their children, keep parents informed, and be supportive of family decisions and perspectives (Soodak & Erwin, 2000). Other authors described trust as the keystone in partnerships, the construct that connects all aspects of partnership (Turnbull et al., 2011).

Respect, the final dimension of partnership described by Blue-Banning et al. (2004) was described as recognizing and respecting the child as a person first, not the child’s diagnosis or disability. This description is consistent with the work of Soodak and Erwin (2000) who also identified actions of respect as being characterized by valuing and appreciating children as individuals. Other authors described respect in terms of listening and responding to the concerns of parents (Lea, 2006).

**Building Partnerships**

How do partnerships happen? Embedded in the partnership dimensions above were some ideas about how partnerships develop, but authors have noted even more. One critical component in helping parents become effective partners is to address the emotional needs of parents as well as the emotional needs of the service provider (Brotherson et al., 2010).
Relationships also seem to be strengthened when teachers project a positive attitude and are responsive and respectful and when parents trust the teacher (Knopf & Swick, 2007). Recognizing provider stereotypes of families is another way that service providers can help impact parent and family involvement (Knopf & Swick, 2007). Knopf and Swick (2007) encouraged teachers in early childhood settings to pursue meaningful relationships with all families and to listen and learn from parents as strategies to combat negative stereotypes.

Other authors have discussed contextual factors in fostering partnerships and collaboration with families (Dinnebeil et al., 1999). A survey of 1,134 parents and 226 service coordinators found that program climate and philosophy as well as having a choice of service delivery options, effective teams, policies that encourage collaboration, and quality personnel were all seen as characteristics that would foster collaboration. One hindrance identified was that larger community systems (such as funding sources and disagreements between agencies) affect early childhood programs. Many of these same contextual factors were echoed in a study of family support (Epley, Summers, & Turnbull, 2010), where researchers found that contextual factors, such as administrative vision and leadership, organizational climate, resources, and service provider practices, all play a role in family support in early intervention.

**Research Problem**

The literature defining parent–professional partnerships is growing. Authors have been working to define partnership and give practical strategies for professionals to build partnerships (e.g., Blue-Banning et al., 2004; Hanson & Lynch, 2004; McWilliams, 2010; Sileo & Prater, 2012; Turnbull et al., 2011). However, there is still the need to understand
partnerships from the perspective of parents who have experienced services in the early childhood special education and early intervention systems. Researchers have provided little voice to parent wisdom and experiences, giving the literature a school-centric view (Knopf & Swick, 2007). This current study attempted to enrich partnership literature by providing parental voice regarding best practices for partnerships. The questions guiding this study were: What characteristics do families describe as contributing to an ideal partnership between parents and professionals in early childhood special education and early intervention programs? What do families consider beneficial in building partnerships between families and professionals in early intervention and early childhood special education?

**Method**

**Methodology**

This study was conducted as a critical ethnography. Ethnographic studies describe and interpret the culture of groups (Merriam, 2010). Ethnographies in the field of education often study the culture of schools and the education system (Lichtman, 2006). This ethnography focused on families and professionals within the early intervention and early childhood special education systems. Ethnography was selected because it recognizes the influence culture, including social and political forces, has on the researched (Madison, 2005). Authors of critical ethnographies attempt highlight the imbalance of power in relationships.

**Background of the Researcher**

Critical ethnographies attempt to diminish “power” relationships between the researcher and the observed; researchers lose their “privileged status” by joining those being studied (Lichtman, 2006, p. 63). I naturally joined the participants in this study because I
shared with them the culture of raising a child with a disability. Like my participants, I also
had navigated the early intervention and early childhood special education systems. These
shared experiences were noted through autoethnographic reflections and analytic memos.

**Participants**

I used convenience sampling to recruit families for this study. The families in this
study met two specific criteria: (a) they were former recipients of early intervention (Part C)
services and (b) their child had received services through an early childhood special
education (Part B) program. Because I had life experience of raising a child with a disability,
participants meeting these two requirements emerged from these experiences. One
participant was familiar with me through a community-based support agency, one participant
was the daughter of a colleague and introduced to me because of having the shared
experiences as a parent, and the final participant was the daughter of a colleague who was
navigating the special education system at the same point in time as I was. Participants were
recruited through email communications. I emailed each participant individually, explained
my research, and explained how their experiences might help inform the research questions.
Each participant responded back through email and confirmed interest in participating.

Three mothers were interviewed as representatives of their family. All mothers were
residents of a Midwestern state and lived in suburban communities. Two of the parents lived
in a university city approximately 30 miles from a major metropolitan area, and one parent
lived in a small but fast-growing suburb of a major metropolitan area. Two mothers were
Caucasian and grew up in the Midwest, and one mother was a native of a South American
country, having moved here in young adulthood. Demographics of participants are
displayed on Table 1. Pseudonyms have been used to protect the confidentiality of the participants.

I also sought to have varying early learning needs of the children represented in the study. My assumption was that children with different diagnoses would have unique needs and add uniquely to the cumulative understanding of all three families. One parent spoke to the experiences of raising a child with severe developmental delays caused by a viral infection during pregnancy. The second parent spoke to the experiences of raising a child with developmental delays with no other specified diagnosis, and the third parent spoke of raising a child with a physical delay as well as mild social and emotional challenges.

Table 1.

**Demographics of Participants**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Ethnicity</th>
<th>Child’s diagnosis</th>
<th>Number in household</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naomi</td>
<td>Caucasian</td>
<td>Developmental delay</td>
<td>4</td>
<td>PT, OT, EI, SC, PSLP, ECSE</td>
</tr>
<tr>
<td>Mary</td>
<td>Caucasian</td>
<td>Developmental delay</td>
<td>3</td>
<td>PT, EI, SC, ECSE</td>
</tr>
<tr>
<td>Anna</td>
<td>South American</td>
<td>Intellectual disability</td>
<td>5</td>
<td>PT, OT, EI, SC, ECSE, PPT, POT, PR</td>
</tr>
</tbody>
</table>

*PT-physical therapy, OT-occupational therapy, EI-early intervention, SC, Service Coordination, ECSE-early childhood special education, PSLP-private speech therapy, PPT-private physical therapy, POT-private occupational therapy, PR-private respite*
Data Collection

Interviews. Each mother participated in a series of three interviews, as described by Seidman (2006; a conceptual model of the three-interview series is included in Appendix A). The three-interview format was chosen because critical ethnography requires prolonged engagement with participants to allow for the understanding of the context in which the participant’s experiences are embedded. The study was approved by the Institutional Review Board at Iowa State University (see Appendix B) and all participants signed an informed consent form prior to the first interview (see Appendix C).

The first interview was a “focused life history”; the interview focused on the family’s history from the time they realized their child had a disability until the child received early childhood special education services. The second interview was focused on “detailed experiences” and elicited details of the family’s history, specifically the details involving partnership and transition. The third interview focused on making meaning of the family’s experiences. This final interview elicited opinions, emotions, and advice regarding partnerships and transitions in early intervention and early childhood special education. The interview protocol for the study is included in Appendix D. The average time for each interview across all three participants and each phase in the series was 43 minutes.

Interview summary forms. At the conclusion of each interview, I immediately spent time in reflection about the interview by completing an interview summary form. The purpose of this form was to track any initial reflections from the interview or follow-up needs. A sample of this form is included in Appendix E.
Autoethnographic memos. I inserted autoethnographic observations (observations of my own experiences embedded within the culture of being a parent of a child with a disability) throughout the data collection and analysis process. This supported and brought greater understanding of the ethnographic context. The following is an example of an autoethnographic memo: "It seems that there are a lot of instances where I’ve found decisions being made for the convenience of the district and not what makes sense for families.” More examples of these types of memos are included in the third column in Appendix F.

Data Analysis

Data analysis was based on the analysis process and methods of Saldana (2009). I used two cycles of coding. For the first cycle, I used precodes, or initial codes. During this first cycle of coding, I combed through the data, noting first impressions as initial codes while simultaneously writing analytic and autoethnographic memos (see Appendix F). This process produced systematic autoethnographic memos to support researcher reflexivity. The process of writing these memos allowed me to pause and engage with the data beyond simply reading the transcriptions. First cycle coding also produced initial codebooks. The initial codes were words and phrases that came from the transcripts and were identified as being main points of information given by the participants. The initial code books were also created to allow me to see where codes across participants were similar or different and how codes across the stages of early intervention and early childhood special education were also similar and different (see Appendix G).

For the second-cycle of coding I employed two coding techniques. These techniques included in vivo coding with codes identified using the verbatim statements of participants.
These verbatim statements were used to maintain the contextual authenticity of the participants’ experiences. I also used focused coding whereby verbatim statements were summarized (see Appendix H). Initial codebooks, created in the first cycle of coding were used as a guide to focus the second-cycle coding process.

After employing first and second cycles of coding, I moved to grouping my in vivo and focused codes into categories. Categories were noted alongside the in vivo and focused codes in the second-cycle codebook. Categories were then listed in a table according to research question and phase of the early intervention/early childhood special education process. These categories were analyzed and then collapsed into themes (see Appendix I). The category to theme analysis involved looking at each individual category and deciding if it was conceptually similar to other categories. Those that were similar were collapsed into themes.

**Addressing Credibility**

The methods involved to address credibility in this study were consistent with methods described by Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005). These methods include researcher reflexivity, collaborative work, member checks, prolonged engagement with participants, and an audit trail.

**Research reflexivity.** Throughout the study, I disclosed any assumptions, beliefs, or biases. These were disclosed within researcher memos, analytic memos written during the coding process, and interview summary forms.

**Collaborative work.** Although I was the sole investigator for this study, I established a peer debriefing group of doctoral students who had successfully completed a
doctoral-level advanced qualitative research methods course. This group met periodically to discuss the data analysis process and emerging themes of the study.

**Prolonged engagement with participants.** Contextual factors are important in ethnographic research. I used Seidman’s (2006) three-interview series to allow for multiple engagements with participants in order to establish the ethnographic context for this study. Having multiple interviews allowed me to build rapport with participants and gave me an opportunity to check my understanding of the participant’s experiences frequently. Participants also were contacted to provide member checks during the data analysis process.

**Audit trail.** Detailed records of every aspect of this study were kept. I recorded the details of the context of each interview on interview recording forms. Analytic memos were kept throughout coding process to track researcher reflexivity, autoethnographic reflections, and decisions regarding research questions and establishing the codes, categories, and themes. Examples of analytic memos are included in the third column of Appendix F.

**Member checks.** Member checks were performed both within the interviews and during the data analysis process. The three interviews in the series were purposefully separated by 7 to 10 days in order to allow time to reflect on the content of the interviews so that I could check my understanding of the participant’s experiences at the next interview. Participants also were asked to engage in the member-checking process after data analysis. I emailed portions of the data analysis to participants, and participants e-mailed their feedback to me. Participants in this study all agreed with the study findings and did not request any changes.
Findings

Through this study, I sought out to answer the question: How do families characterize ideal partnerships in early intervention and early childhood special education systems? This paper seeks to extend beyond problem identification to problem solutions. Keeping this purpose in mind, parents were asked specifically to speak to how ideal partnerships are formed and identify the characteristics of ideal partnerships. In relating their responses, the names of the study participants have been changed to protect their confidentiality and grammar and sentence structure has not been changed in order to respect the individuality of each participant.

The main finding of this study was that parents identified that both professionals and parents play an important role in the formation of a strong partnership, with differing specific roles to bring to the partnership. The roles of professionals and parents that emerged from the data are displayed in Table 2. Table 2.

Roles of Professionals and Parents in Creating Ideal Partnerships

<table>
<thead>
<tr>
<th>Role of professionals</th>
<th>Role of parents</th>
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<tbody>
<tr>
<td>Communication</td>
<td>Communication</td>
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<tr>
<td>• Frequent communication</td>
<td>• Be prepared with information</td>
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<tr>
<td>• Communication is reciprocal</td>
<td>• Ask questions</td>
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<tr>
<td>• Allows members to voice concerns</td>
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<tr>
<td>• Being on the same page</td>
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<tr>
<td>Valuing parents as partners</td>
<td>Advocacy</td>
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<tr>
<td>• Respect</td>
<td>• Don’t be silent</td>
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<td>• Valuing input</td>
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<td>• Listening</td>
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<td>• Engaging Families</td>
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<td>Trust</td>
<td>Interpersonal skills</td>
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<td>• Reciprocal Trust</td>
<td>• Build a connection</td>
</tr>
<tr>
<td>• Following-through</td>
<td>• Be flexible &amp; open-minded</td>
</tr>
<tr>
<td>• Non-judgmental</td>
<td>• Be respectful</td>
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Role of the Professional

Parents shared the following characteristics when describing the ideal partnership between professionals and parents: communication, valuing parents as partners, and trust. Within each of these themes, categories of “what this looks like” emerged.

Communication. All families spoke of the importance of communication in an ideal partnership. In fact, this was a major theme of this study. The interviews revealed several stories of communication failures. These communication failures resulted in families feeling mad, frustrated, and confused. They centered on issues regarding service eligibility, relationships among IEP team members, and parent involvement. Participants described that the main characteristic of an ideal partnership is good communication and went on to portray the professional’s role in establishing communication. Categories of communication emerged during data analysis, including: frequent communication, reciprocal communication, allowing members to voice concerns, and in the words of a participant, “being on the same page.”

When asked to describe an ideal partnership, Naomi immediately stated,

I think having them there to listen and communicate . . . to develop kind of a trusting relationship where you can, you know, talk to them about your concerns with your child and your goals for them. . . . I think we should be a team and everybody be on the same page, and if we can’t be on the same page at least respect where each other’s at with it.

Mary stated that she would describe an ideal partnership as being like the one that she had with one service provider. She used the phrase “good communication” throughout her detailed example of her relationship with the service provider. She stated, “If you can’t
communicate or trust them, it’s hard to work with them.” She also spoke of the idea of reciprocal communication: “Good communication [is when] you’re both communicating with each other.” This statement also has implications for the role of the parent, which will be discussed later in this paper. In addition, Mary extended the definition of communication beyond talking and listening to acknowledgement. She stated, “Good communication . . . I don’t just mean talking to each other, I mean that they have to actually acknowledge what I’m saying, and help me feel like we have a confident answer in what we’re going to do about it.”

Anna also spoke to the importance of communication. She stated, “I think the best situation is when everybody is on the same page. Because that does not always happen.” She was asked to further describe how she thought team members get on the same page. She responded, “I think they need to listen to the parents. I think we are the persons who know our kids best.” She also spoke of the need for professionals to be on the same page not only with families but also with the other agencies with which families work. She spoke throughout the interviews about what she perceived as “jealousy” between agencies. Anna thought that agencies were not working together because they were being competitive with each other and did not value each other’s work. She mentioned that in order for agencies to begin to work together, “I think [working together] is a big thing and they need to change their attitude about that . . . work all together.”

Valuing parents as partners. Naomi shared many examples of how she was no longer a part of the intervention team when her son transitioned from early intervention to early childhood special education services. When asked what would have been ideal for
preschool, she made a statement that spoke to the need to partner with parents during planning and decision making:

I think they still need that communication piece. I think I felt like I got put on the back burner. I was just a part of his team that had to go to sign the paper. It didn’t really matter.

Naomi also spoke of the desire to partner during the intervention process:

. . . involving the parents a little more, just even giving them suggestions they could do at home, I mean, most parents are more than willing to work on this stuff with their kids at home if it would help them. But I guess, I never felt like I knew what I needed to do to help them.

Mary had stories throughout the three-interview series about how she did feel involved in the intervention and planning processes. She was taught different strategies to help with her son’s motor and social/emotional development that she was able to implement in her home. Mary also used the term “we” more than any other participant when reflecting on her teaming experiences, whereas other parents tended to use the term “they.” This signifies an underlying understanding of where they perceived their position on the intervention team. The parent that used the term “we” had many examples of being involved in team decisions and the intervention process. When reflecting about an eligibility decision that appeared to have been made unilaterally by one service provider in the early intervention system, Mary described how she felt it should have gone, saying,

At this point we might not need to do the IEP, we might do perfectly fine [at the childcare center], but I didn’t want just fate to be left up to that. I wanted it to be that
we were all seeing that he was doing great, or that we were all seeing that he needs help.

Anna also spoke to valuing parents as partners. Her quote, “I think we are the persons who know our kids best,” speaks to the reason why one should attend to the importance of valuing parents as partners. The term “working together” was the first term this participant used to describe the perfect relationship between parents and preschool staff.

**Trust.** Trust was the third theme that emerged as being the role of the provider. Trust was often referred to as a key indicator of an ideal partnership. Trust also was understood as two actions: building trustworthy relationships with parents and professionals trusting parents.

Naomi described situations that both built or broke a trustworthy relationship with her. She spoke of actions such as “listen” and “communicate” as ways to build a “trusting relationship.” Later, when asked why she had more trust in the early interventionist, she explained,

I think it was because I could talk to them and communicate with them, and because of the fact that I could sit down and watch everything that they did with him, and I knew what they were working on and how he responded to them. . . . I think that helped a lot.

Naomi also described how trust was lost in the preschool system: “My level with trust that we had before started to decrease because all of the sudden they kind of just made decisions on their own.”

Mary cited “trust” as one of the most “solid” indicators of an ideal partnership: “I would say good trust and communication are probably the most solid ones . . . because if you
can’t trust them it’s hard to work with them.” Many of the stories Mary told during all three interviews were centered on a relationship with a service coordinator who was not dependable in following through with what she had told the family she was going to do. She described how this professional’s follow-through behaviors impacted the building of trust:

“If you’re not going to do help me . . . it’s hard for me to trust you.” Mary also spoke about the necessity of allowing time for parents to build trust. In thinking of her early experiences, she stated, “I was still unsure because I was like, this is my baby, what’s wrong with him . . . I’m scared . . . I’m nervous . . . I don’t know who you are . . . I don’t trust you yet.” She described this process of trust building as “each time it was at first, ‘hey, I need to ask you the right questions and feel you out, make sure you are one person that I can trust.’”

Mary also spoke of having reciprocal trust, in other words, professionals also trusting parents. In reflection of one relationship, she fondly recollected, “She trusted me and listened to me as a parent and really complimented me on how much I knew about it [parenting] myself.” Later, she bluntly stated, “I’m not going to trust you if you can’t trust me a little bit too,” and “She has to trust that I know what I’m talking about, and what my child needs, or what my family needs to succeed.”

Finally, trust was built with parents through nonjudgmental behaviors. Mary described her thoughts on nonjudgmental behaviors:

I’d say, you know, just because the house might appear to be messy or something, or unorganized, doesn’t mean that the child is not safe and that it is not a good home. I mean, I admit there were a couple of times that the house was unorganized, and I was like, “Oh my gosh, I’m sorry,” and she was like, “That’s okay,” and there was one time when I was living with friends . . . [my roommates] were not cleaning up as well
as they should have . . . but she still knew that [my son] was still being taken care of.

. . . They didn’t pass judgment.

**Role of the Parent**

The mothers thought that they, as parents, also had a role in the creating and sustaining partnerships. These thoughts were gathered mainly in asking parents about the advice they had for other parents as they navigated the system. The advice given was centered on the actions of parents. The roles described included advocacy, communication, and interpersonal skills. Anna summarized the need for parents to be active in their roles, stating, “Those years are the most important for the child to improve, grow, and see changes. You can see change all of the time . . . but the preschool years, you can see more change . . . so it’s really important.”

**Advocacy.** The parents’ role in advocating for their child was noted. Mary stated, “You’re the main advocate for your child. At the preschool age [children] are not going to tell you very easily what their feelings are.” Anna stated, “I think you need to advocate for your child . . . advocate first . . . sometimes it’s hard. . . these kids, they can’t defend themselves” and “I think advocate is the best thing.” Participants urged parents to not “sit silent” when they have concerns. Anna stated, “If you have any doubt, concerns, don’t let them just be silent, bring them up.”

**Communication.** Parents also thought they had a role in communication, specifically in being prepared to give information about their child and asking questions. Anna had an experience when a specific team member was not informed about her child’s diagnosis and she had left the meeting feeling “shocked” about what had happened. In reflecting on the situation, the parent stated, “Going back . . . you know, [I’d] be more
prepared about that. Because it was a shock to me what happened in that meeting. I think I’d be more prepared to discuss or to advocate for that.” When asked in the interview to give advice, she quickly gave the advice: “Be prepared.” I asked her if she could elaborate, and her response was:

“Write your questions on paper... all of the concerns you have... be really prepared about that. Things that might not be important really are important... put everything on a paper and be prepared. Because when you are there, you might forget, and then later you might be like, why did I not say this or that?”

Anna also summarized her ideas on communication at the end of the interview, stating:

Don’t feel bad if you have to ask questions... Don’t think, “I’m not going to ask this because it’s not important,” because it might be important. And try to be in communication all of the time, don’t think you are bothering them.

Naomi also cited communication as a role of the parent, though she was unsure whose responsibility it was to initiate the interaction: “Communicate with [the team]. I don’t know though as it should be our [responsibility] to initiate it all, but maybe that’s what we need to do so we know where things are at.”

The need for asking questions came up in Mary’s interview. She stated, “Ask as many questions you feel is necessary until you get the answers.” Throughout the third interview, she specifically listed “good communication” as a reciprocal process between provider and parent. She also spoke to the idea that “good communication” is what builds trust between provider and parent.

**Interpersonal skills.** Anna spoke about the interpersonal skills that participants thought parents might need in order to participate in a partnership with early childhood
systems. She stated, “Try to work with the teacher and all of the group. Be flexible, but be open-minded to listen and respect the other opinions.”

**Discussion**

This study was undertaken to describe parents’ views about the roles of both professionals and parents in creating ideal partnerships. The data revealed that communication, valuing the parent as a partner, and being trustworthy as well as trusting parents were indicators of ideal partnerships from a parent’s perspective.

Parents shared their perspectives that communication should be frequent and reciprocal and that professions need to allow team members to voice concerns and attempt to achieve an overall goal of being on the same page as parents. Naomi judged her communication quality with ECSE providers by comparing it to her early interventionists, moving from a system in which she felt very involved, to one where she felt “left out.” Parents in other studies have identified this same phenomenon of having active involvement in early intervention to having indirect and distant communication with service providers in the preschool system (Podvey, Hinojosa, & Koenig, 2011). Although early intervention services were delivered in a home-visitation service-delivery model, Naomi’s comparison to the early childhood special education setting and resulting feelings can inform how to communicate with families, such as frequent reciprocal communication.

Naomi’s statements also speak to the need for frequent communication that is responsive to the information needs of parents. Being responsive to an individual family’s needs is a part of the paradigm shift when programs go from being provider-driven to family-driven (Osher & Osher, 2002). The findings of this study are consistent findings from another study in which parents described the need for frequent and open, as well as high
quality, communication (Blue-Banning et al., 2004). Another study described how communication between programs and families can diminish the imbalance of power in system/family relationships (McGrath, 2007). Programs can support teachers in fostering open communication with families by structuring their programs to allow for time for teachers to communicate with families. These supports could include dedicated “visiting” times for parents to come to the school and smaller class sizes to allow for teachers to meet the needs of multiple classroom priorities (including family involvement and engagement). Teachers can also reflect on their personal skills of being responsive to parent needs, such as their ability to respond to parent concerns in a timely manner, with effective information, and with empathic support.

The current study also revealed that parents saw that providers who communicated, through both giving information and acknowledging information, signaled that the providers were respecting them and their children. This finding was consistent with the findings of Blue-Banning et al. (2004), who also found parents identified that when they felt acknowledged, they also felt respected. An implication from this finding and the supporting literature is that there is still a need for helping providers understand communication strategies that will enhance partnerships between families and professionals. Professionals need explicit opportunities to develop and be coached in the mastery of these skills. Other researchers have pointed out that professionals partner best with families who are similar to themselves in values and beliefs (Brotherson et al., 2010). The chances of professionals always being matched with parents who are similar to them are not likely. Professionals need to engage in ongoing professional development to build and maintain interpersonal
partnership skills to ensure that they are competent in partnering with a variety of diverse families.

Service providers should seek ways to enhance both the quality and the quantity of communication to meet the needs of individual families. As Mary described in this study, communication plays a role in trust-building between provider and parent.

Another role of professionals is to value parents as partners. This role attends to the notion of equality between parents and the early childhood special education system. Participants in this study wanted to be engaged in both the decision-making and intervention aspects of their child’s services. Researchers have noted that, once parents leave the early intervention system, they are left feeling as if they are no longer key players in their child’s service provisions (Podvey et al., 2011). Other researchers have discussed equality in partnerships, pointing to the need for professionals to assist families in gaining the skills necessary to be equals in decision making as well as in fostering a sense of equity in both decision making and intervention implementation (Blue-Banning et al., 2004). The findings of this study and other studies could be extended in order to conceptualize where service providers are falling short in truly valuing parents as partners in special education service provision and what specific strategies correspond with engaging all parents as partners. In other words, future studies could identify the support and skills that professionals need to use to engage parents of varying needs and characteristics.

Another finding of this study was the importance of trust, both being trustworthy and trusting parents, in the partnership-building process. In this study, Mary spoke frequently across all three interviews about how following through on promises created or broke trust. Findings of other qualitative studies revealed that the relationship between families and
professionals was damaged if service providers did not follow through on promises and services (Brookes et al., 2006; Lea, 2006). The notion of professionals trusting parents has not been well researched. One researcher did examine this issue and described how misperceptions or a lack of respect toward adolescent mothers created a barrier for collaborative relationships (Lea, 2006). More can be explored about how trusting families affects parent–professional partnerships and the strategies that would be useful in the provider’s trust-building process.

Parents also spoke of their role in partnerships. They characterized their role as advocates, communicators, and using interpersonal skills. Parents found that one of their main roles was to be the primary advocate for their child, mostly because their child was unable to speak for or defend him- or herself. They also spoke of the need to be in communication with their teams, bringing up concerns and asking questions. Furthermore, one finding that emerged, which has not been brought to light very often in partnership literature, is the interpersonal skills that parents may need to have when participating in these partnerships. These skills include the ability to be flexible and open minded, as well as team-work skills when participating on the intervention team.

Although parents were able to speak to their own role, this study only began to scratch the surface regarding the roles of parents in the special education system. Questions arise when considering parents’ roles. Do parents know their role(s)? How do parents know their role? How do parents gain the skills needed to fulfill their role? Naomi mentioned that she was unsure if it was her role to be initiating communication with the service providers. I asked her, “How do you think parents know their role on those teams?” and she quickly and bluntly responded, “They wouldn’t.” Although there may be parent support groups or
advocacy groups to assist parents in learning and playing their roles, the infrastructure for assuring that all parents understand their roles and have the opportunity to enhance or grow the skills they need in order to fulfill those roles effectively is underfunded and underutilized by families in early childhood systems.

It is important to further study how parents can fulfill their roles on intervention teams. When parents do not know the depth of their roles, an imbalance of power is created between the family and the system because parents are not equipped to navigate the system or effectively advocate for their child.

Certain family theories can help articulate why this disparity of resources and knowledge for families in building and maintaining partnerships is important. Conflict theory suggests that those who have the most resources in a negotiation will be favored in the outcomes of negotiation (White & Klein, 2002). These resources include knowledge and skills. When considering this theory, the amount of resources available to service providers in fulfilling their role in partnerships far exceeds the amount of resources available to parents, creating a disadvantage for families and making them less likely to be favored in times of negotiation or when coming to agreement in decisions regarding their child. This concept is displayed in Figure 1. The resources put into preparing professionals and parents to function within these partnerships is not equal.

Family life course theory also can inform this study, as it describes the critical points along the time-line of a family. When considering a family that includes child with a disability, it makes good sense to enhance the capacity of families to be equipped to partner with professionals. Bruder (2010) summarized family-centered orientation and described the family as the constant in a child’s life and the primary unit for the delivery of services.
Limitations

There were only three participants in this study. Although they were able to give rich descriptions of their experiences, caution should be used when generalizing their experiences to a broader population. Additional research should include families from other geographic locations, demographic characteristics, and developmental needs of their children. In addition, including other researchers who may analyze data from differing theoretical orientations may be helpful.

Conclusion

This study explored how parents characterized and described ideal partnerships. Parents revealed that both professionals and parents have a role in building and maintaining partnerships. Further studies should explore the efficacy of partnership strategies that
professionals use, but they also should be designed to facilitate understanding how to help parents understand their roles on intervention teams and the skill-building process needed to assist them in fulfilling their roles. Early Interventionist should allow time to describe, coach, and encourage parents in their role on the intervention team. Staff in early childhood special education also should help families identify their roles and encourage parents to fulfill their roles. Staff in both systems should become aware of the state and local resources available to parents that can assist them in advocating for their child across their family’s life course.
References


CHAPTER 3. A CRITICAL ETHNOGRAPHIC STUDY OF PARENTS’ EXPERIENCES AS THEY NAVIGATE EARLY INTERVENTION, TRANSITION, AND EARLY CHILDHOOD SPECIAL EDUCATION

A paper prepared for submission to Journal of Early Intervention

Aryn Kruse, Carla Peterson, & Gayle Luze

Abstract

Many families with young children with disabilities who receive services through the provisions of the Individuals with Disabilities Education Improvement Act (IDEA) experience a transition out of early intervention services as the child reaches 3 years of age. Inherent in this transition is the loss of a relationship in one system and a gain of a relationship in the next. This critical ethnography was undertaken to understand the experiences of families as they partnered with early intervention and early childhood special education personnel and to identify the supports they need to establish effective partnerships through of the transition. Across time, the participants wove in and out of power disequilibrium and harmony in their partnerships, felt a sense of gratitude for the existence of the service system, and felt advocacy was their dominant role in the partnerships. Findings led to recommending that professionals be coached in using strategies that enhance partnerships, and prevent breakdowns during the transition process.
**Introduction**

One principle of the Individuals with Disabilities Education Improvement Act (IDEA) is parent participation (Turnbull & Turnbull, 2001). Parent participation refers to the roles parents assume in their children’s special education processes. This principle allows parents to have full access to student records, participate on state and local advisory committees, and be decision makers for their child’s Individualized Family Service Plan (IFSP) and Individualized Education Program (IEP). This principle sets the stage for programs and families to engage in collaboration and partnership.

The IDEA also calls for transition planning, initiated by the early childhood program, at least 90 days prior to the child’s third birthday (Kagan & Tarrant, 2010). An inevitable component of this transition is the transfer of partnerships among parents, Part C providers and Part B providers. The context in which the intervention occurs also shifts; often Part C interventions are provided within natural (home) settings and Part B services take place outside of the home, in classroom settings.

The partnerships that surround transition periods are important because a child’s adjustment to the transition can be seen as a product of the relationships involved in the child’s own ecological context (Pianta, Kraft-Sayre, Rimm-Kaufman, Gercke, & Higgins, 2001). Dunst and Dempsey (2007) defined a partnership as parents and professionals working in collaboration to pursue a common goal. This relationship is based on shared decision making, responsibility, mutual trust, and respect. Once a child reaches the age of 3 years, families exit Part C services, often leaving partnerships they had built during the time of early intervention. After leaving early intervention, they begin school-based services and must build and maintain new partnerships within a new system and often with new service
providers. Families frequently experience a shift in their roles in this partnership because of a “radical philosophical shift” from the roles they played in a family-centric Part C system to a school-centric Part B system (Fox, Dunlap, & Cushing, 2002). In other words, roles change from parents’ high level of involvement in family-centered services, which often occurs within the walls of their own home, to no longer having a major role in the environment where education services occur (often a school building). Examining how families experience partnerships across time is critical to allowing systems to be responsive to the family’s changing demands, needs, and expectations across the family life cycle (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005).

**Transitions**

Transitions within early intervention, which have been defined as a dynamic process of moving between programs or service delivery models (Bruder, 2010,) are based on relationships (Rosenkoetter et al., 2009) and involve both emotional components and procedural components (Hanson et al., 2000). One transition of particular importance is the transition families make from early intervention (EI) programs to early childhood special education programs (ECSE; Brandes, Ormsbee, & Haring, 2007; Rosenkoetter, Hains, & Dogaru, 2007; Rosenkoetter et al., 2009). The IDEA states that the IFSP addresses the transition at age 3 and requires the following steps: discussion with parents of future placements, procedures to help the child adjust to a new setting, and if the parents give consent, the transmission of information on the child between agencies (Bruder, 2010). This transition to school entry may involve parents tackling issues of school systems preparing to meet the needs of their child as well as realizing social issues their child may face, such as finding playmates (Seligman & Darling, 2007). Other authors have described new
expectations families face when moving from home and community programs to formal education settings, including understanding expectations for child behavior, the acceptable ways to communicate with the program, and standards for academic work (Rous, Hallam, McCormick, & Cox, 2010).

When transitions are implemented successfully, positive outcomes are experienced by both the child and the family. The National Early Childhood Transition Center has identified positive transition outcomes for children and families (Dogaru, Rosenkoetter, & Rous, 2009). The outcomes for children include “continuous growth and development…successful adaptation to the structure and the culture of the new environment… engagement in the new social and physical environment” (Dogaru et al., 2009, p. 11). Positive outcomes for families include “increased self-efficacy as parents,” “increased knowledge,” “adaptation to and meaningful participation in the new environment,” and “facilitation of their child’s development” (Dogaru et al., 2009, p. 11). However, when transitions are unsuccessful, children are at higher-risk for developing mental health and adjustment problems, have difficulty with their peers, and have an increased risk for academic failure (Rous & Hallam, 2006).

This transition from early intervention to early childhood special education preschool services is all too often a single event—a formal meeting that takes place at one point in time (Hanson et al., 2000). However, best practices encourage a process of long engagement and partnership with families (Malone & Gallagher, 2009). This process involves preparing the family to be partners and decision makers on intervention teams, and supporting this involvement has been linked to smoother transitions and outcomes (Rous & Hallam, 2006).
Transition in the Context of Partnership Practices

Transition researchers have not identified explicit transition practices that challenge or enhance family and professional partnerships. However, because some authors have begun to operationalize partnerships and others have worked to describe effective transition practices, it is possible to conceptualize how transition practices can enhance various dimensions of partnership. Blue-Banning, Summers, Frankland, Nelson, and Beegle (2004) have identified the following partnership dimensions: communication, commitment, equality, skills, trust, and respect. Transition literature shares explicit transition strategies that could be conceptualized as enhancing the partnership dimensions described by Blue-Banning et al.

Communication. Blue-Banning et al. (2004) purported two characteristics of communication: quality and quantity. Quality indicators include positive communication that is respectful of all members of a partnership; the quantity of communication meets the communicative needs among all members and is both efficient and effective. Communication has been cited as a key factor in successful transitions (Rosenkoetter & Schroeder, 2008). Transition strategies that may enhance communication include sharing information, including program options and information about the transition process itself (Rous, Myers, & Stricklin, 2007). Sharing information can be accomplished through written materials, such as handbooks for transition, that contain basic information (Rous et al., 2007, 2010); can include timelines, roles and responsibilities, and provisions for family participation (Fox et al., 2002); and should represent the language and culture of the family (Dockett & Perry, 2010). Systematic planning instruments have been developed to inform families of timelines, roles, and activities of the transition process (Brandes et al., 2007). Communication involves answering the family’s questions (Rosenkoetter & Schroeder,
but also should be viewed as an *exchange of information* between parents and professionals (Hanson et al., 2000).

Teams should consider the use of reciprocal communication, such as notebooks that travel between home and school, phone-calls, e-mails, and frequent conversations (Stoner, Angell, House, & Bock, 2007), rather than one-way communication strategies (Rosenkoetter et al., 2007). Furthermore, as one considers the multiple transitions families make across the family life course, teams may want to consider the use of comprehensive communication plans that follow children from year to year (Stoner et al., 2007). This plan could include a child’s likes and dislikes, strengths and challenges, and unique information about the child.

**Commitment.** Blue-Banning et al. (2004) described a committed professional as one who shows loyalty and dedication to the child and family. In practice, practitioners demonstrate commitment by being sensitive to the emotional needs of the family and being available and accessible to families outside of dedicated intervention times (Turnbull, Turnbull, Erwin, Soodak, & Shogran, 2011). Teachers who are responsive to the needs of families are able to create positive relationships with parents, and in turn, families are more likely to value their child’s education when strong relationships between providers and families exit (Knopf & Swick, 2007).

**Equality.** Blue-Banning et al. (2004) described an equal partnership as one in which members feel a sense of equity in various aspects of the intervention process—from decision making to intervention implementation. One transition strategy that is built into the early intervention/special education system through the IDEA is family participation during the IFSP and IEP processes (Lovett & Haring, 2003; Rous et al., 2007). Researchers have identified that parents who were uncomfortable with the transition process did not feel as
though they were able to fully participate in IEP meetings and believed they did not have any choices regarding preschool placements (Lovett & Haring, 2003). Throughout the decision-making process, parents should be regarded as equal partners (Brandes et al., 2007).

Equality involves the diminishing of a power relationship; in other words it eliminates a power imbalance between two parties. Conflict theory suggests that those who have the most resources will be favored in the outcomes of any negotiation (White & Klein, 2002). These resources include knowledge and skills. One author described this equity issue as it relates to transition by stating, “Successful transition plans provide families with knowledge and supports to obtain needed resources. Only when families are fully informed can they make decisions in partnership with other providers regarding future placement services” (McWilliams, 2010, p. 109). This knowledge could be transferred through workshops or other intentional training for parents who are going through the transition process (Rous et al., 2007). Service providers can help families understand the structure and philosophy of the special education system and help family develop advocacy skills (Rosenkoetter et al., 2007).

**Skills.** Blue-Banning et al. (2004) described the skills partnership dimension as members in the partnership perceiving that others on the team are competent, able to fulfill their roles, and carry out recommended practices. Transition process skills are related to both the emotional and procedural components of transition (Hanson et al., 2000). Service provider skills include the ability to understand parent anxiety and facilitate events to prepare the family (Lovett & Haring, 2003); share strategies with parents to help them foster positive relationships with new service providers (Rosenkoetter et al., 2007); help families locate, interpret, organize, and respond to information (Rosenkoetter et al., 2007); and help families formulate their questions and expectations (Lovett & Haring, 2003).
**Trust.** Blue-Banning et al. (2004) stated that trust occurs in a partnership when members “share a sense of assurance about the reliability or dependability of the character, ability, strength, or truth of the other members of the partnership” (p. 174). Families build trust through the transition process when programs and individuals are provided reliable and consistent information (Lovett & Haring, 2003). There are certain strategies that could assist in the trust-building process. One strategy cited in research as effective in transitioning is to have families visit programs prior to the start of school (Rous et al., 2007). This visit could be structured in a way that gradually exposes the family to the new environment, from neutral participation to full participation in the program (Lovett & Harring, 2003). Conversely, trust can be built by receiving program staff members conducting home-visits (Rous et al., 2007, 2010).

**Respect.** Through careful questioning of study participants, Blue-Banning and colleagues (2004) were able to define respect as when “the members of the partnership regard each other with esteem and demonstrate that esteem through actions and communications” (p. 174). During transitions, providers can show respect to families by listening to alternative points of view (Dockett & Perry, 2010) and being sensitive to the emotional state of parents (Lovett & Haring, 2003).

**Current State of Transitions**

Federal monitoring reports have revealed that the transition process is marked with problems and barriers (Malone & Gallagher, 2009); this is echoed in the findings of authors who have examined early childhood transitions (Podvey, Hinojosa, & Koenig, 2011). A qualitative study of 22 families who were followed through the transition process reported negative experiences such as feeling as though transition was an event rather than a process
(Hanson et al., 2000). Professionals involved in the study echoed this finding and saw the transition event as a formality. This same study reported that families felt anxious about moving from one service delivery system to another due to the shift in the service delivery model inherent in home-based versus school-based delivery systems. Another qualitative study of family perceptions of transition found that families who were not comfortable with the transition from early intervention to preschool services felt unprepared, anxious, and abandoned by the early intervention staff on whom they had been relying (Lovett & Haring, 2003). Families in this study reported that they had difficulties in communicating with service providers, did not understand the transition process, were not given choices about placements, and did not fully participate in IEP development because they did not understand the process.

**Barriers to Successful Transitions**

The current state of transitions shows that there are barriers in implementing best practices. Rous and colleagues (2010), in a survey of 2,434 preschool teachers, found that teachers believed that parents do not read school-to-home communications and some parents are not interested in school. These negative perceptions of family involvement contradict other studies in which families reported they wanted input on choices during the transition process (Hanson et al., 2000; Lovett & Haring, 2003); that communication between home and school was lacking (Stoner et al., 2007); and that they desired participation, noting that information exchange was crucial (Hanson et al., 2000). In addition, Stoner et al. (2007) stated that parents felt that education professionals lacked knowledge of transition strategies and were ill prepared.
Research Problem and Questions

Despite defining partnerships and transitions and the research work that has been done to understand best practices regarding these two concepts, little is known about how partnership practices transfer from early intervention systems to early childhood special education programs. Inherent in this transition is the loss of one relationship (with the early intervention system) and the development of another (the early childhood special education system). Very little is known about families’ experiences during this transition, despite a call for early intervention systems to equip parents to become effective partners with special service providers as children age (Blue-Banning et al., 2004). Furthermore, researchers generally have given little voice to parent wisdom and experiences, resulting in the research literature having a school-centric view (Knopf & Swick, 2007) in which understanding of relationships and systems are described from the point of view of the professionals within the system. The present study attempted to, give parental voice to identifying best practices for partnerships as they begin in early intervention and transfer into early childhood special education. The purpose of this study was (a) to understand the process of building and changing partnerships as families begin their experiences in early intervention (Part C) and transition into early childhood special education preschool programs (Part B), and (b) to identify the needs of families in creating smoother transitions. This study addressed the following questions:

1. What do families experience when they partner with early intervention systems and transition into partnerships with early childhood special education systems?

2. What do families identify as needs in the transition process to establish effective partnerships with early childhood special education providers?
Method

Methodology

This study was a critical ethnography. Ethnographic studies describe and interpret the culture of groups (Merriam & Associates, 2003). Ethnographies in education often study the culture of schools and the education system (Lichtman, 2006). This ethnography studied the early intervention and early childhood special education systems with a focus on families within these systems. Critical ethnography was selected because it recognizes the influence of culture, including social and political forces, on the researched.

Theoretical Perspective

Family life course theory and the ecological framework both informed this study and offered valuable theoretical perspectives. Family life course theory recognizes disability from a developmental perspective (Marshak, Seligman, & Prezant, 1999). It recognizes the delay of development of children with disabilities, the effect this delay has on the family’s life course, as well as how this delay in development is not aligned with traditional family timelines. This theoretical perspective is valuable to the current study because it supports the notion that, although services and policies offered through the education system change, the needs of a family may not change or disappear altogether. I liken this difference to the metaphor of a pinball machine. The services and supports of the education system are much like the framework of a pinball machine, and without a gentle transition, the family (the ball) is often forced into sudden and unanticipated directions.

The ecological framework purports that child and family behavior can be understood on several contextual-dependent levels (White & Klein, 2002). Brofenbrenner (as cited in White & Klein, 2002), a theorist who first articulated the framework, described systems
surrounding the individual: microsystem, mesosystem, exosystem, and macrosystem. Many researchers have drawn on the work of Brofenbrenner’s ecological framework when considering transition processes as a way of expressing how contexts and systems influence phenomena. Dockett and Perry (2010) described an ecological perspective of transition in which the child’s transition is understood within the child’s contexts and the connections within these contexts. The child’s adjustment during the transition process is a product of the systems and partnerships that surround the child (Pianta et al., 2001). This perspective aligns well with an ethnographic study because both highlight the influence that contextual factors have on the researched. It takes into account the effect that partnerships with individuals and the broader system have on the behavior and outcomes of the child and family.

**Background of the Researcher**

Critical ethnographers attempt to diminish “power” relationships between the researcher and the observed; researchers lose their “privileged status” by joining those being studied (Lichtman, 2006, p. 63). I had a natural place among the participants in this study because we all had the shared experience of raising a child with a disability. Like the participants in this study, I have navigated the early intervention, early childhood special education, and medical systems.

**Participants**

I used convenience sampling to recruit families that met two specific criteria: (a) they were former recipients of early intervention (Part C) services and (b) their child had received services through an early childhood special education (Part B) program. I recruited participants from a pool of families that I knew personally from my experiences raising a child with a disability. I had met each participant in the context of my role as a mother and
chose a convenience sample to facilitate conversations about sensitive topics with individuals with whom I had already begun building rapport. Three mothers were interviewed as representatives of their families. Two of the parents lived in a Midwestern university city approximately 30 miles from a major metropolitan area, and one parent lived in a small but fast-growing suburb of a major metropolitan area. Two mothers were Caucasian and grew up in the Midwest, and one mother was a native of a South American country, having moved as a young adult.

One participant was familiar with the author through a community-based support agency, one participant was the daughter of a colleague and introduced to the author because of having shared parenting experiences, and the final participant was the daughter of a colleague who was navigating the special education system at the same point in time as me.

I also sought to have three children with varying early learning needs represented in the study. My assumption was that each diagnosis would present a case of a child with unique needs and add uniquely to the cumulative understanding of all three families. One parent spoke to the experiences of raising a child with severe developmental delays caused by a viral infection during pregnancy. The second parent spoke to the experiences of raising a child with developmental delays with no other specified diagnosis, and the third parent spoke of raising a child with a physical delay as well as mild social and emotional challenges. Each parent is described in more detail in the Ethnographic Context section of this paper.

**Data Collection**

**Interviews.** Each family participated in a series of three interviews, as described by Seidman (2006; a conceptual model of the three-interview series is included in Appendix A).
The three-interview format was chosen because critical ethnography requires prolonged engagement with participants to allow understanding of the context in which the participant’s experiences are embedded. The study was approved by the Institutional Review Board at Iowa State University (see Appendix B) and all participants signed an informed consent form prior to the first interview (see Appendix C).

The first interview, a “focused life history”, focused on the family’s history from realizing their child had a disability until their child was involved in early childhood special education. The second interview was focused on “detailed experiences” and elicited details of the family’s history, specifically the details involving partnership and transition. The third interview focused on making meaning of the family’s experiences. This final interview elicited opinions, emotions, and advice regarding partnerships and transitions in early intervention and early childhood special education. The interview protocol for the study is included in Appendix D. The average interview time across all three participants and all three sessions was 43 minutes.

**Interview summary forms.** At the conclusion of each interview, I immediately spent time in reflection of the interview by completing an interview summary form. The purpose of this form was to track any initial reflections from the interview or follow-up needs. A sample of this form is included in Appendix E.

**Autoethnographic memos.** Because I did not seek to observe interactions between professionals and families to fully understand the depth of the meaning and emotion that comes with these experiences, I inserted autoethnographic observations throughout the data collection and analysis process. This supported and brought greater understanding of the ethnographic context. Qualitative researchers have commented on this practice by stating
that personal accounts give voice to those who, historically, have been silenced or marginalized (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). The following is an example of an autoethnographic memo: “This phrase resonates with me. I often felt like my son’s principal was much more concerned for what was easiest for the district over what was best for my child.”

**Data Analysis**

Data analysis, based on the analysis process and methods of Saldana (2009), involved two cycles of coding. For the first coding cycle, I used precodes, or initial codes. During the first cycle of coding I combed through the data, noting first impressions as initial codes, while simultaneously writing analytic and autoethnographic memos (see Appendix F). The autoethnographic memos support the researcher reflexivity process and allowed me to engage with data at a more reflective level. After the first cycle of coding, initial codebooks were created to allow me to see where codes across participants and across stages of early intervention/special education were similar or different (see Appendix G). These codebooks allowed me to see where I would need to go back into the data to recode different portions of the transcripts or identify experiences that were common and uncommon among participants.

For the second cycle of coding I employed two coding techniques. These techniques included in vivo coding with codes identified using the verbatim statements of participants. I used verbatim statements in order to maintain the contextual authenticity of my participants. I also used focused coding whereby verbatim statements were summarized (see Appendix H). This allowed for detailed experiences to be concisely conceptualized. Initial codebooks that were created in the first cycle of coding were used as a guide to focus the second-cycle coding process.
After employing first and second cycles of coding, I moved to creating categories from my in vivo and focused codes. Categories were created by analyzing codes and finding codes that were conceptually similar and fitting them into larger categories. Categories were noted alongside the in vivo and focused codes in the second-cycle codebook. Categories were then listed in a table according to research question and phase of the early intervention/early childhood special education process. These categories were analyzed and then collapsed into themes (see Appendix I). The process of creating themes involved analyzing the categories and understanding which categories were most conceptually similar as well as relevant to the research questions. It is also noteworthy that the article by Blue-Banning et al (2004) was a foundational piece in the literature review of this article and influenced the data analysis process in this study because it operationalized varying aspects of partnership.

**Addressing Credibility**

The methods involved to address credibility in this study were consistent with methods described by Brantlinger et al. (2005). These methods included researcher reflexivity, collaborative work, member checks, prolonged engagement with participants, and an audit trail.

**Research reflexivity.** Throughout the study, I disclosed any assumptions, beliefs, or biases as a researcher. These were disclosed within researcher memos, analytic memos during the coding process, and interview summary forms. One example of this action was when one participant experienced positive relationships and confidence in the receiving preschool program. I reflected on this experience, discovered that my coding was not thoroughly reflecting the positive experiences of participants, made note of this within an
analytic memo, and recoded transcripts to ensure that I was giving the participants’ experiences a comprehensive analysis.

**Collaborative work.** Although I was the sole investigator for this study, I established a peer debriefing group of doctoral students who had completed a doctoral-level advanced qualitative research methods course successfully. This group served as a sounding board during data analysis and aided in establishing codes, categories, and themes.

**Prolonged engagement with participants.** Contextual factors are important in ethnographic research. I used Seidman’s (2006) three-interview series to allow for multiple engagements with participants in order to establish the ethnographic context for this study. This allowed me to build rapport with participants over time as well as allow for natural and frequent checking of my understanding of their experiences. Participants also were contacted to provide member checks during the data analysis process. I e-mailed participants portions of the data analysis. All participants participated by e-mailing me back with their feedback. All of the participants agreed with the findings, and none of the participants requested any changes.

**Audit trail.** Detailed records of every aspect of this study were kept. I recorded the details of the context of each interview on interview recording forms. Analytic memos were kept throughout coding process to track researcher reflexivity, autoethnographic reflections, and decisions regarding research questions and establishing the codes, categories, and themes. Examples of analytic memos are included in the third column of Appendix F.

**Ethnographic Context**

**Introducing the Parents.** As stated earlier, three parents were interviewed for this study in a series of three interviews. Each family brought unique stories and experiences to
this study. Below are descriptions of each parent interviewed, followed by commonalities among participants. Commonalities were also found between the participants and the author’s autoethnographic memos. Participants names have been changed to the pseudonyms Samantha, Amber, and Rosa.

**Samantha.** Samantha was a Caucasian mother in her mid-20s. She had two children; her youngest was identified as having a need for early intervention and early childhood special education services. Samantha had a normal pregnancy, and her son’s diagnosis was not a sudden event; rather, it was a gradual process of understanding that there were signs of concern. Through the encouragement of family members who were familiar with the system, Samantha sought out screening through the local early intervention system. Her son was deemed eligible for early intervention, which would take place in Samantha’s home. Through a challenging journey of navigating the medical system, Samantha was told that her son had “developmental delays.” This news was not surprising to her because the delays are what brought on the concerns to begin with, and she was glad to have found pediatricians who understood her son’s needs and could be “on the same page” as her. The services that Samantha’s child qualified for included occupational therapy, physical therapy, and services related to cognitive goals from an early intervention teacher. At preschool entry, Samantha’s child was eligible for services from an early childhood special education teacher for academic goals as well as consultation from an occupational therapist. The child also qualified for private services in speech therapy.

**Amber.** Amber was a Caucasian mother in her mid-20s. Her son with a disability was her only child. Like Samantha, the knowledge of her son’s needs was a gradual process. Amber’s family first noticed his gross motor needs, and when they did not seem to improve,
she also called the early intervention system in for screening. Amber’s son was also found to be eligible for services, primarily through a physical therapist (PT). As Amber’s son grew older, it also became apparent that he would need some support in the area of social and emotional development. Amber’s son qualified for physical therapy, occupational therapy, and eventually some services regarding social and emotional development from the early intervention service coordinator. At preschool entry, Amber’s son did not receive services, but within the first year was identified as needing services for social and emotional development.

Rosa. Rosa grew up in South America and came to the United States in adulthood. She was a mother of three, and her middle child received early intervention and special education services. Unlike Amber and Samantha, Rosa’s journey began in pregnancy. A late-pregnancy ultrasound revealed that her baby was not growing well and that the baby would need to be delivered pre-term. After delivery, Rosa was informed that her baby’s future development would be significantly delayed because of a virus that she had contracted during her pregnancy. Early in infancy, Rosa’s child began receiving early intervention services at her home as well as private therapy services through a local agency. Early intervention services included occupational therapy, physical therapy, support from an early intervention teacher, and service coordination. She received similar services from private therapy, though it also included respite care services.

Common Culture

Although none of the participants knew each other, they, along with me, have shared experiences that could be identified as a common culture—the culture of raising a child with a disability. Commonalities were found throughout each interview and through a review of
analytic memos. These commonalities include being involved frequently with many professionals from a variety of agencies and developing relationships with these professionals that last over time. They also include being recipients of government-funded services and having to navigate these systems. All families frequently faced unknowns—unknowns regarding the trajectory of their child’s progress and health and unknowns about the process of the system. All families dealt with the experience of diagnostic labels placed on their children and felt a strong need for advocacy for their child in multiple systems (medical systems and educational systems).

**Findings**

The first research question, “what are the experiences of families as they partner with early intervention systems and eventually transition into a partnership with early childhood education systems,” recognized the importance of considering the family life course in context of both partnerships and transition. Families found themselves maneuvering in and out of power struggles between themselves and the early intervention/special education system. Times of both struggle and harmony were identified across time from early intervention and transition to early childhood special education services. Underlying these struggles were issues of power between the service system and the family. Periods of harmony could be attributed to experiences in which participants felt equity of their role within the system.

The findings are organized first by umbrella themes then themes are identified across time, from early intervention to early childhood special education services. Umbrella themes are dominating themes that were not bound by time. In other words, they are themes that
were identified across the stages of the early intervention, transition, and early childhood special education. Figure 1 presents a conceptual model of these findings.

![Conceptual model of the findings](image)

**Figure 1.** Conceptual model of the findings.

In the description of the findings, grammar and phrasing were not changed in the quotes unless it was to identify a pronoun or change confidential information. Samantha and Amber spoke English as their primary language. Rosa did not have English as her first-learned language; her wording was not changed in order to respect her individuality.

**Umbrella Theme: Power Disequilibrium versus Harmony**

Underlying the experiences of these families is equilibrium of power. Conflicts that arose during their experiences could be attributed to disequilibrium of power between themselves and the system, and times of harmony could be attributed to periods of a
perceived sense of equal power. Examples of quotes that support this umbrella theme are
displayed in Table 1.

Table 1.

*Examples of Power Disequilibrium versus Harmony by Participant*

<table>
<thead>
<tr>
<th>Power disequilibrium</th>
<th>Harmony</th>
</tr>
</thead>
<tbody>
<tr>
<td>Samantha</td>
<td></td>
</tr>
<tr>
<td>• “Speech is one area where we have fought and fought and it’s like they don’t want to even do it.”</td>
<td>“They were really good with working around my schedule.”</td>
</tr>
<tr>
<td>• “I wish I would have known more about the transition. . . . I think I was just kind of . . . letting them do it and I just kind of went along with it.”</td>
<td></td>
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<tr>
<td>• “My concerns weren’t really acknowledged.”</td>
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<tr>
<td>• “The IEP . . . I come to a meeting and they already have goals that they’ve set for him.”</td>
<td></td>
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<tr>
<td>• “My level of comfort with them has decreased [because of] the lack of feeling like I am really even a part of it anymore.”</td>
<td></td>
</tr>
<tr>
<td>• “I think I felt like I got put on the back-burner. I was no longer an essential part of his team. I was just a part of this team that had to go sign the papers.”</td>
<td></td>
</tr>
<tr>
<td>• “All of the sudden they kind of just made decisions on their own.”</td>
<td></td>
</tr>
<tr>
<td>• “There wasn’t really a whole lot of options, I was basically told [where he would be going].”</td>
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<tr>
<td>Amber</td>
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</table>
• “If you guys want to continue services with my son, then you’re going to stay here and give services to him or I will find somewhere else to go . . . and I’ll do it myself . . . and they were just like, no, no, you don’t need to do that.”

• “I don’t feel like I got enough information at that point. I don’t feel like I was let go very easy. I kind of feel like I was dropped.”

• “I feel like I was just left in the dark . . . and part of it was I probably just didn’t have the words or knowledge of where to ask of where to go from that.”

• “[The IEP team] were like, ‘she’s smart, that’s not good. She knows too much, we have to follow that.’”

• “She said, ‘That’s good, you’re the mother, that’s fine, I don’t blame you’.”

• “She would tell me I was doing a good job because she could see that he was improving.”

• “We always had a meeting, once a month . . . just to make sure that things were going okay. And I could call them anytime and go, ‘Hey, something isn’t right, can you come look? Or, I have a question on something.’”

• “I felt more like that with the preschool team . . . I felt like I knew where we were going, I knew what we were doing, that I could trust them, that they knew what they were doing with him.”

• “I felt like everyone was on the same page. Everyone knew where everyone wanted to be. And we were giving [my child] a chance to lead us where he needed to be.”

<table>
<thead>
<tr>
<th>Power disequilibrium</th>
<th>Harmony</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rosa</td>
<td></td>
</tr>
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</table>

- “It was a shock to me, what happened in that meeting [first IEP meeting]. Because I was surprised because I took a letter from our pediatrician [regarding child’s diagnosis] and she was like, [gasp] ‘he doesn’t know anything’. I don’t know if she thinks she knows more than the doctor. I think I would be more prepared to discuss or advocate for that.”

- “I think they listen more on what I really want for her . . . at least they were more open”

- “I think she understands my point of view and respects that.”

- “I have a pretty good relationship with the teacher, I can say what I think”.

Times of power disequilibrium were characterized by experiences in which parents did not feel they were a part of the intervention team. When reflecting on her role on her son’s preschool special education team, Samantha remarked, “I think I felt like I got put on the back burner. I was no longer an essential part of his team. I was just a part of this team that had to go sign the papers.” At other times, participants felt they did not have the knowledge to fulfill their expected role on the team. When considering an event that did not
have a perceived favorable outcome Amber said, “I feel like I was just left in the dark . . . and part of it was I probably just didn’t have the words or knowledge of where to ask or where to go from that.” And still, there were times when participants felt the information they did bring to the team was not recognized as valid. As Rosa was remembering a time when she needed to bring information to the team regarding her child’s diagnosis, she recalled,

It was a shock to me, what happened in that meeting. Because I was surprised because I took a letter from our pediatrician [regarding child’s diagnosis] and she was like, “[gasp] he doesn’t know anything.” I don’t know if she thinks she knows more than the doctor. I think I would be more prepared to discuss or advocate for that.

Each family’s story also described times of harmony as well. Harmonious times are when power between the family and the system appear to have balance. Samantha described times within the early intervention system when she felt engaged as a member, she was able to observe and participate in the intervention itself, as well as give input into the child’s IFSP. Amber shared experiences when she was made to feel like a valued member of the team. She articulated moments where service providers affirmed her role as a mother: “She would tell me I was doing a good job because she could see that he was improving” and “She said, ‘That’s good, you’re the mother, that’s fine, I don’t blame you.’” Perhaps the most harmonious relationship occurred with Rosa, who spoke highly of her relationship with the preschool teacher. Rosa described a situation when she and the teacher were not in agreement. When I asked why she didn’t think this situation damaged her relationship with the teacher, she stated, “I think she understands my point of view and respects that.” Later, after further questions and reflection, Rosa stated of the teacher, “I have a pretty good relationship with the teacher; I can say what I think.”
Umbrella Theme: Gratitude Despite Conflict

Even though each participant spoke of experiences that were both harmonious and challenging, each expressed gratitude toward the system, at both the individual service-provider level and the larger, systemic level. Amber reflected on her experiences with her child’s occupational therapist and the intervention she did with her child’s fine motor skills: “What she was doing for him was perfect. I don’t think he could write his name today if it weren’t for her.” Samantha, who probably spoke the most of her challenges in her partnerships with experiences, remarked on the gratitude she had for having the services available for her son by stating, “He’s had tons and tons of services and intervention, and people coming in and so I’m at least really glad that he had that . . . because I don’t know where he would have been without it.” She spoke further of her gratitude for systems that identify and intervene early when she remarked, “I just think the fact that it was caught early enough and things were done, it’s going to make it better for him in the long run.” Similarly, Rosa also spoke to the importance of early intervention systems: “Those years are the most important for the child to improve, grow, and see changes. You can see change all of the time . . . but the preschool years, you can see more change . . . so it’s really important.”

Umbrella Theme: Role Integrity

Throughout interviews with each mother, a theme that became apparent was the concept of “role integrity.” Ideas around role integrity surfaced for both parent and professional roles. As mothers described their family’s experiences while navigating from early intervention through preschool, they expressed how it was their mission, their role to be the primary advocate for their child. Many of the conversations that I had with Samantha centered around her mission to keep her son’s team from stalling, in other words, helping her
team realize the energy still needed to keep her son progressing. In one example, she described her experiences in this role by saying,

I understand he’s doing good, but I guess my focus at an IEP isn’t “Let’s talk about all of the advancements that we’ve done, let’s talk about what we need to do to keep him advancing.” . . . [It] felt like I was the only one saying that we had issues that we need to work on.

Samantha also stated, “I know he’s made an enormous amount of progress, but let’s not lose sight of other things” when speaking of her role as keeping the intervention team focused and centered on her son’s continued progress.

Rosa spoke to a mother’s mission primarily through being persistent and being an advocate. When asked about advice she might give to other parents going through transitions she spoke about being an advocate:

“I think you need to advocate for your child . . . advocate first. And if you don’t think he is the best teacher for him or her, then you need to say that. . . . Sometimes it’s hard [with the] system sometimes. . . . [Children] can’t defend themselves.”

Later she went on to say, “I think to advocate is the best thing, ask questions . . . because it might be important.” Rosa also stated that her role was to be persistent. She spoke at length about experiences she had with advocating for her team to keep high expectations for her child, specifically regarding her daughter’s ability to be mobile beyond the use of a wheelchair. When speaking of these experiences, Rosa described her persistence by simply stating, “I never want to give up.”

Amber was the most direct in describing her mission as a mother navigating the system. When reflecting on her overall experiences with her son’s services she stated, “I
stand up for my kid a lot. It’s not just being a mother, it’s not because I have to . . . I really
legitimately do . . . I put that kid first. . . . I think that’s what a mother is supposed to do.”
When asked about advice that she’d give to a parent facing a transition, she made it clear
what she believed to be the main role of a parent during the process when she stated, “Ask as
many questions you feel is necessary until you get the answers. You’re the main advocate
for your child right now.”

Participants also spoke of experiences with professionals fulfilling their roles. For
both Rosa and Samantha, the team, as a whole, remained silent about challenging issues.
When a staff member was challenging Rosa’s daughter’s participation, I asked Rosa what the
team’s response was to the staff member’s behavior. Rosa replied, “Nobody say anything.”
Samantha replied similarly in reflection to the team’s reactions to the school district’s
placement decision: “The others stayed quiet.”

Experiences in Early Intervention

The need for external support. Every family interviewed accessed resources and
supports beyond the Part C early intervention system. This support came from two different
categories: (a) informal support from friends and family and (b) formal support through
professionals (such as doctors and therapists) not employed by the Part C system.

Each family used the support of close friends or families during the early intervention
process, though the degree to which they depended on this support varied. Rosa identified a
close friend as her path through the “child find” process. Rosa was new to the United States
when first needing services and explained that her best friend, who also came to the United
States from her home country, was aware of the Part C system and referred her to the
resource. Amber and Samantha both had stories of knowing family members who actually
worked, at some point, in the Part C system. Both Amber and Samantha had support from family when navigating early intervention. When describing a challenging experience in accessing services for her child, Samantha stated, “We were told that until he was 3 they wouldn’t give services. However . . . my [family member] went to them and said that he could legally get these services.” I asked Amber if her family member was helping her advocate, and she responded, “Yes, because I didn’t know the laws and stuff.” Samantha described several instances when a family member supported her. When initially trying to decide where to go for help, Samantha explained,

    We had a discussion, and my [family member] said, “Let me ask my friends at work because this might be something early intervention can help you with” . . . so we got hooked up with that. She gave me the number to call and helped me do the initial process.

Throughout all three of their interviews, both Amber and Samantha described times when they needed extra support from family members while working with the system.

    Participants also needed the support from professionals not employed by the Part C early intervention system because of eligibility and the need for a more aggressive service delivery model. The majority of this support came from services in the medical field that provide services under a medical model rather than an educational model. These models are different in the way that they determine eligibility for and delivery of services and the manner in which they consult with families. The support utilized by all three participants included support from pediatricians or other pediatric specialists for diagnostic services. Each family spoke in detail and at length of the diagnostic path of their child and the need for these specialists in order to understand the needs of their children. Beyond pediatric
specialist support for families, all three participants spoke of specialists that provided direct services outside of the Part C system. The reasons for the decision to go beyond the Part C system varied. Rosa spoke of many services, such as occupational therapy, physical therapy, speech therapy, that she accessed. She was very clear in her reasoning behind this decision. She stated on a couple of occasions that the Part C system was “not aggressive as they have to be.” Rosa wanted services that were more direct and frequent rather than consultative. She described many of the Part C services as “watching.” She described the services by saying:

At the beginning they were watching and saying how she was doing . . . but the services were more watch and give me ideas on what to work in the first two years was like that. I think the difference is that in private therapy the PT works with the kids, in early intervention, it’s like the PT gives you ideas to work with your kid. I’m not a PT. I can do things, but it is not the same like what the PT is able to do with her.

Rosa also recognized that not all parents had access to the more “aggressive” therapies to which she was referring. She mentioned,

“I think [private therapists] are really good help for a lot of parents, and there are a lot of parents who don’t have insurance and they can’t afford private therapy and things like that. But I think [early intervention] needs to be more aggressive . . . to try that the kid gets his best potential.

The longevity of these partnerships with professionals outside of the Part C system could be attributed to feeling more comfortable with the medical model (as Rosa felt). Furthermore, Amber described interactions with outside professionals with whom she had
long relationships as being ones where she felt the professionals were “on board” with what
the family was also “seeing” in her son. She spoke fondly of her long relationship with a
pediatric neuro-specialist:

I just love it because I can just call her, even for the speech stuff, if we need prior
authorization or to say, “He needs this evaluation.” . . . I just love how much she
listens. She takes your concerns . . . if you’re concerned she listens to your concerns.
She might say, “We’ll watch it,” but she won’t say that it’s not a big deal. We’ve
brought him in time after time and she says that she is amazed with his progress, she
says, “Honestly from the first time you brought him in, I didn’t think we’d be here
right now.” You know, it’s nice to have a doctor that saw it through my eyes as well.

Amber dug deeper into the concept that parents do have a choice with what agency or
individual provider delivers services. She stated, “I’m not going to waste my time with
having them come see my family. And I feel kind of bad saying it in that way, but I think
I’ve had enough people helping my family that I can pick and choose which ones are the
most beneficial.”

**Misaligned visions.** This theme describes how participants perceived the vision the
early intervention system had for their child was not the same as the vision their family had
for their child. Rosa mentioned in all three interviews her “fight” with the PT regarding
appropriate mobility equipment for her daughter. Rosa explained that her PT urged her at
“every meeting” to buy a wheel chair. The PT’s vision of the child using and learning the
mobility device was not in alignment with what Rosa was visioning for both her family and
her daughter. She was not ready to “give up” on her vision for her daughter to walk, and it
did not fit in with her family’s lifestyle. Rosa explained,
At every meeting that I have with her it’s like, “Do you want to buy the wheelchair,” and I say, “No” . . . I don’t want to change my van, and go to my country with a wheelchair, it is so complicated. . . . It’s not like we want her all of the time in a wheelchair.

Throughout the interviews it was evident that the vision of the PT and Rosa were not aligned, and it began in early intervention and lasted through the preschool years. Clearly this misalignment put stress on Rosa’s relationship with the PT. Rosa commented on her relationship by saying,

It’s not a relationship because I can’t say anything that I like [about her] like a person. We don’t have the same points of view with [my daughter]. She want to put [my daughter] in a wheelchair, and I say, “No way.”

Samantha also spoke of her experiences of a misaligned vision during early intervention. As mentioned earlier in the “mother’s mission” theme, Samantha had many experiences in which she felt she had to keep her team focused on her child’s continued progress toward her family’s vision, closing the gap between him and his peers. Samantha stated,

I know he’s getting better, but I know he’s not going to be . . . I hate to say “normal,” but he’s always going to have issues. I know that, I’m okay with that, so don’t sugar coat it for me. Tell me how it is. Yes, I saw the progress he was making, but compared to kids his age . . . we were nowhere close to that.

This mismatch in vision began in early intervention, but it extended into preschool as well. Samantha commented on her first IEP experiences by stating,
I guess maybe that’s just me and where I want to see his IEP . . . he’s at point B, but the rest of the kids are at F, so what are we going to do to get him moving up. I know he’s making progress, I see that . . . but what are we going to do to get him as close to the progress as his peers are making . . . what are we going to do for that? I felt like I was the only one saying that we had issues that we need to work on.

**Parent engagement.** Although parents spoke of being involved to different degrees throughout their child’s early childhood experience, parent engagement in the early intervention process was described more comprehensively. Even though it wasn’t Rosa’s preferred model of service delivery, she did state that early intervention gave her ideas in what she could be doing with her daughter at home as a part of the intervention process. Amber recalled specific strategies that her PT taught her to do “between visits”: “[It involved] massage, taking your finger from the bottom of his ear all the way down to his shoulder, massaging that one muscle up and down . . . I had to do that twice a day for 30 minutes.”

Amber talked about other intervention strategies with which she was involved, including creating and reading social stories to help her child learn social/emotional skills. Samantha spoke of her involvement in the early intervention process: “I was able to sit there and see what they were working on . . . what his progress was . . . then I would be able to work on the stuff, the same types of things that they were doing with him when they weren’t around.” Samantha also spoke of her involvement in the IFSP process: “I thought I had more input in the IFSP meetings . . . They would say, ‘Say what would you like to see us working on? What would you like to see him able to do?’” Later in the interview Samantha spoke of how she had input in the direction of the goals with the IFSP process. She also spoke of her
role during intervention: “Every time they left, they gave me something new to work on with him or a suggestion of what I could do to help him out.”

Experiences with Transition

Experiencing conflict. All three participants experienced conflict to some degree during the transition process. The types of conflict varied among participants, and it involved conflict with both the overall system (teams, policies, process, etc.) and with individual team members. The most dominant conflict was centered around eligibility and placement. During all three interviews, Amber spoke in detail about an eligibility determination issue in relation to transition planning out of early intervention. Simply put, in Amber’s words, her family was “dropped” during the transition process, and no eligibility determinations were made regarding her son’s next early childhood experiences. Throughout the interviews with Amber, the storyline became clear: transition was experienced as a moment in time, and the family’s early intervention experience came to a premature halt, despite examples that Amber gave of possible continued support for her child’s social/emotional development and family goals related to “parenting is overwhelming.”

Her introduction to the details of her transition began with a statement describing her relationship with one of the family’s service providers: “I think I did have a really good relationship with her until he was about . . . 2½ . . . then I kind of lost [the relationship]; I don’t think I had a very good transition.” Amber made many statements throughout the interviews regarding this drop. She stated, “As far as I know, we were supposed to schedule another meeting . . . and figure out where to go next . . . but that was it, that was the last I heard from her”. She went on to say, “Yeah, it was like . . . where do I go now? You can’t
help me anymore because he’s 3, but who’s there?” When asked more on what that
transition experience felt like, Amber replied,

I was still kind of left hanging, like I don’t know where we’re supposed to go next
now. I don’t feel like I got enough information. . . . I don’t feel like I was let go very
easy. . . . I felt like I was just left in the dark. He’s 3, we’re done. And part of it was
I probably just didn’t have the words or knowledge of where to ask of where to go
from that.

Several months later, Amber was able to again navigate the system and have her son
evaluated for preschool special education services. Her son did qualify for early childhood
special education preschool services, where conflict arose again regarding placement
decisions. The following is how Amber described her story:

The thing was, they wanted to pull [my son] out of [his preschool] to attend [the
school district preschool] for half day in a specific program, and I said, “No, I don’t
want to take him out of his preschool at all, I want to keep him where he’s at.” So
then they were like, “Okay, we’ll take him out for an hour for [the teacher] to meet
with him.” I was like, “Well, no, this is silly. . . . he’d have to be bussed over to [the
school district preschool] for an hour and then come back to [his preschool]. And I
thought, “Wow, what’s up with that? What about the least restrictive environment?”
Like, if he was a third grader, they wouldn’t pull him out of his school to take him to
another school for an hour . . . and they didn’t like that. They were like, “Wow, she’s
smart. That’s not good. She knows too much. We have to follow that.”

Similarly, Samantha faced a conflict in placement, but the district did not change the
placement determination. Samantha explained that, despite her son’s enrollment in a
childcare setting that also served as a district-run preschool and employed a licensed teacher, her son had to be bussed out of the family’s community to a neighboring town that was still considered within the boundaries of the school district. In reflection on this conflict experience, Samantha recalled:

I would have liked for him to be able to do it at his home daycare to where he wouldn’t have to go to a different school. . . . I still had to pay full price for daycare. So, yeah, he was only there half the time and we still had to pay because they don’t do part time and they had to keep the spot for him. And it’s really hard to see that in the morning they do preschool stuff there, and all of his friends have pictures up . . . and he doesn’t. All of his friends have a birthday party, and he doesn’t. His friends have a concert at the end of the year. He didn’t. Because he missed that preschool piece. . . . He doesn’t seem to be bothered by it, but it bothers me. Because those are the kids that he invites to his birthday party. Those are the kids he plays with. Those are the kids on his baseball team here in town. And yet, he wasn’t with them for those [preschool] experiences.

Although Rosa did not describe many options for her daughter’s placement, she appeared to be conflicted by the lack of options. Rosa had little worries during her daughter’s transition but did describe conflict between herself and a member of the receiving school staff. In fact, she introduced this conflict to me by stating,

My big tough and bad things at [the school district preschool] was like with [a staff member]. Because of what [my daughter] was born with [a rare virus contracted during pregnancy], she was like misunderstood because of [the virus], that she could
be contagious and things like that, and that was a big fight. . . . It was kind of a panic with the nurse.

Rosa attempted to resolve the conflict by involving her pediatrician. Her pediatrician wrote a note educating the new IEP team of the virus and how it did not create any health risks to the program. Rosa reflected on this experience and said,

And what upset me more was that our pediatrician wrote a note explaining everything about [the virus], that is it is the same risk as any other kid as [my daughter]. Most people have it [already], they never screen [in pregnancy] because most people have it. I remember the meeting, and she was like [makes a wave with her hand as if she was pushing the note away], “This is not like this,” like she knows more than the doctor. But, you know, I don’t like her.

In a later interview, Rosa described her reaction to this meeting: “I finished crying when I came back. Yeah. I felt so bad about that.” And in later reflection, Rosa stated, “She made my life miserable at the beginning.”

Underlying the conflicts related in Rosa’s and Samantha’s stories are the reactions to these conflicts by the broader IEP team. For both Rosa and Samantha, the team, as a whole, remained silent about the issues. Rosa described the team’s reaction to the staff member as, “Nobody say anything.” Samantha replied similarly in reflection to the team’s reactions to the school district’s placement decision: “The others stayed quiet.” And she spoke specifically of the receiving special education teacher’s reaction to the district’s placement decisions: “Her support wasn’t to keep him where he was; her support was, “Don’t worry.” . . . I think she had her school’s best interest in mind, whereas I had [my son’s] best interest.
Supporting factors. Each participant was able to identify factors that aided or supported the transition process. These factors can be grouped into two subcategories: formal support and informal support. The formal support that aided transition included familiarizing the family with the receiving program’s environment and preparing the family for the first IEP meeting. The informal support in this study was characterized by actions taken by parents to either leverage services or navigate the system.

Samantha and Rosa both talked about formal supports in the transition process that were initiated by the early intervention system. Samantha described a summer-program at the receiving school designed to help children acclimate to the school building and also work on their IFSP goals. Samantha also described a home visit by the receiving school that was designed for the child to get to know his new teacher. She described the visit:

I think they [the teacher and child] just read a book, [he] kind of got used to her and knew who she was, and she went over the goals of the class . . . the routines . . . they asked family questions too . . . I think to make him feel comfortable [for] that transition when he came to school, at least there is a friendly face he remembered. . . . I liked it.

Rosa also described a strategy used intentionally by the early intervention system. The early intervention team intentionally prepared Rosa during a home visit for her first IEP team meeting. Rosa stated,

They gave me the ideas and they told me how it was going to be and everything. . . . I remember that . . . I didn’t have an idea what the IEP was for paperwork, but they told me about what they do there and everything.
All three participants spoke of informal support—support that was not intentional or planned by the sending or receiving programs. All three participants identified a friend or family member who was knowledgeable or working within the system who supported them during the transition process. As described earlier, both Amber and Samantha had family members who were knowledgeable of the system and could help them navigate the transition. Samantha also described experiences of a transportation conflict during the transition process that was solved due to her husband’s relationship with the receiving school’s superintendent. Rosa considered the receiving school’s preschool teacher a “friend,” which aided in her confidence about the new environment.

Another informal strategy included the accumulation of experiences in the receiving program setting. Rosa had the benefit of being familiar with the preschool program because of her past experiences. She spoke about her confidence in the receiving preschool program, despite the conflict with the staff member who was misinformed about her daughter’s diagnosis. When asked why, Rosa explained that the preschool her daughter was going to was also the preschool that her older son had attended. She stated that she was familiar with the school, and identified the teacher as her “friend” because of her experiences with her older son.

An additional informal strategy used to navigate the transition process could be characterized as a “threat.” Two participants described experiences in which the receiving school district was not compromising, and eventually the parents had to threaten to remove their child from services if the district was not willing to compromise. Samantha’s experience involved a complex transportation issue. She stated,
I think that’s when I finally said, “This is a mess. We either get something figured out or he’s just going to go to daycare and we are going to drop services. . . . This is stupid.” And so, I think once I finally said that, that’s when things finally were made to happen.

Amber described a similar situation involving a placement decision:

“If you guys want to continue services with my son, then you’re going to stay here and give services to him or I will find somewhere else to go . . . and I’ll do it myself,” and they were just like, “No, No, you don’t need to do that.”

Going through a range of emotions. Finally, the transition process was marked by families experiencing a range of emotions. Amber’s experience was characterized by confusion; she stated, “I was feeling really confused.” In reflection of the drop in services during transition, she stated, “I kind of felt like, where’d she go, what are we supposed to do?” and “I was still kind of left hanging like I don’t know where we’re supposed to go next.”

After the transition drop, Amber’s child was able to eventually qualify for preschool special education services. After her son began receiving preschool services, Amber also experienced feelings of trust with her new providers. She stated, “I felt like I knew where we were going, I knew what we were doing, that I could trust them, that they knew what they were doing with them.” She went on to explain that these feelings of trust stemmed from her past experiences and perception of competence of specific early intervention staff.

Samantha’s emotions ranged from frustration with system conflicts (transportation and placement decisions) and worry for her child’s acclimation to the new setting and new friends to trust with the preschool teacher but mistrust with the related service providers.
When asked further about her mistrust in preschool-related service providers, she said, “My level of trust . . . started to decrease because all of the sudden they kind of just made decisions on their own. I felt like I was no longer a part of that.”

Overall, Rosa had a positive experience with transition, but she still experienced a range of emotions. Rosa experienced feeling “miserable” and “mad” with the conflict involving a staff member’s misunderstanding of the virus that caused her daughter’s disability. But overall, she was confident in the receiving preschool, stating,

I think it was that I feel confident because I knew the place she was going to. I knew the teacher, I knew how things work there, it’s like a familiar place for me. I think that was the best thing.

Later, she continued with a description of why she was confident: “I know the teacher, I know the room, I know how things go. It’s like I was trusting the person that my kid is going to be with . . . that is so important.”

Experiences with Early Childhood Special Education

Changing roles. Samantha spoke in great detail in her interviews regarding her changing role on the team once her son began receiving preschool special education services. When considering her involvement on the IEP process, she stated, “I don’t feel like I have anything to do with it whatsoever, I feel like the goals are something they’ve set for themselves and we’re really not a part of it.” Samantha described a decrease in comfort with the preschool team, and she attributed this decrease in comfort to “just the disconnect, the lack of feeling like I am really even a part of it anymore.” She went on to describe these experiences, as she stated,
I think I felt like I got put on the back burner. I was no longer an essential part of his team. I was just a part of his team that had to go to sign the papers. It didn’t really matter. . . . The only reason I’m here is because you guys need me to be here for your piece of it.

**Communication.** Families in this study experienced communication differently. However, because it was a theme throughout all three interviews, it would be difficult to deny its influence on the early childhood experience, whether it is positive or negative.

When reflecting about communication with the early childhood special education providers, Samantha described her thoughts:

I feel like the level of communication is a lot less with an IEP . . . every so often I’ll get the progress reports, but those are just plots on a graph that don’t really tell me a whole lot of what he is necessarily doing.

Later, when asked what advice she would have for both parents and professionals during the transition process, Samantha listed and described “communication” several times. Rosa described more positive communication experiences with the preschool. She had the opportunity to talk daily with the preschool teacher when she transported her child to the school. She also said that she would be completely comfortable in e-mailing and calling the teacher regarding any issue. When asked about advice to parents and professionals, both Rosa and Amber spoke of the need for reciprocal and ongoing communication between families and professionals.

**Building trust.** Participants also talked about the trust-building process with preschool staff. Rosa was very trusting of the receiving preschool program. Rosa also described experiences that built this trust, which included an accumulation of positive
experiences starting with her older son, that eventually made the preschool setting a familiar and trustworthy environment. Although Samantha experienced a decrease in trust with the service providers on her child’s preschool IEP team, she was able to build trust with her child’s classroom teacher. She explained that this trust occurred through a relationship-building process: “I felt like I had more trust in her because we had more of a relationship.” Amber characterized the trust-building process as an accumulation of events that largely involved staff following-through on actions and observing staff competence with both the family and the child. Amber also spoke of the need for staff to trust the family in the trust-building process (reciprocal trust). She stated,

I’m not going to trust you if you can’t trust me a little bit too. . . . My child is really important to me, and I want the people who are taking care of him to be on the same page with me.
Discussion

Discussion and Implications of Umbrella Themes

Power disequilibrium versus harmony. At the center of the conflict that was described by all three participants across all three interviews is the concept of power disequilibrium, in other words a lack of equality in the partnerships between the system and the family. In times of conflict, some families were left out of the decision-making process and were not invited to engage with the intervention team. Conversely, times of harmony were characterized by experiences when the family members felt they were involved and included in decisions and intervention. Current literature states that families should be given the opportunity to be decision makers and should be offered alternative choices (Lovett & Haring, 2003) and that parents should be regarded as equal partners (Brandes et al., 2007; Dinnebeil, Hale, & Rule, 1999). The Council for Exceptional Children’s Division of Early Childhood (DEC) has recommended that families and professionals engage in shared responsibility and collaboration (Sandall, Hemmeter, Smith, & McLean, 2005). Systems, and service providers within these systems, should seek strategies beyond simply allowing for parent participation and should engage families in equal partnerships through involving them in decision-making processes and helping them see their role in intervention. Using terms described by Soodak and Erwin (2000), teams should reflect on whether their policies and practices are engaging families as “valued members or tolerated participants” (p. 29) of the intervention team. Teams can show parents they are valued by showing a commitment to including their child in the school community, fostering a school climate that encourages partnership, and working to maintain these connections over time (Soodak & Erwin, 2000). Systems can begin to diminish the power inequities between the system and families when
they recognize a paradigm shift from provider-directed to family-directed services and systems (Osher & Osher, 2002).

Gratitude despite conflict. An important theme to recognize is that, despite having times of conflict and conflict that caused a great deal of negative emotion in some participants, participants still expressed gratitude and positive affect toward the system and service providers. Some families questioned where their children would be today in terms of progress had they not been involved in early childhood intervention and early childhood special education. Although some literature has been written specifically to help professionals work with what they’ve coined as “challenging parents” (Gorman, 2004), perhaps the system would benefit from finding the common ground between parents and service providers, that the system was intended to help children make progress, and that it is possible to find the strengths in the system and individuals that surround the child. To foster this change, systems should consider ways to involve parents as true stakeholders in the system and at varying levels. Parents should have opportunities to not only be recipients of services, but also to be involved in leadership. It is noted in DEC recommended practices that both families and professionals are involved in policy, procedures, and systems change (Sandall et al., 2005)

Role integrity. Each mother in this study saw that varying levels of advocacy for her child was one of her primary roles. This is in alignment with how some current literature also describes the role of parents. Osher and Osher (2002) suggested that it is the job of the family to provide care and support, unconditionally, for all members of the family. Implications for this perspective include respecting the broader role parents have advocating for their children across the family life course. Parents should be afforded this respect
because they engage with their children in more settings than do educators and have the perspective of the whole child in mind (Sileo & Prater, 2012).

**Experiences with Transition and Partnership Across Time**

This study made a special focus on each phase of the early childhood intervention and special education system because each phase can have implications for transition practices and the partnerships embedded within each phase. Understanding early intervention experiences can help the field identify all that is involved when young children and their families transition and what supports and considerations may need to be made based on the accumulation of experiences that occur during the early intervention phase. Addressing the transition phase specifically can help in the gathering of implications for how this process can be improved or reinforced and the necessary partnership elements that can be improved or reinforced during the transition process. Finally, examining the early childhood special education phase of the early childhood experience can help identify the “what’s to come,” which would be useful in helping families understand how to prepare for a new setting.

During the early intervention phase, participants in this study experienced the need for varying levels and types of support as well as a misalignment of their family vision with the vision and actions of the system; they also were engaged and involved in the early intervention process. The fact that parents sought out the support of family and friends speaks to the need to continue helping families make social connections to navigate the system. Two participants already had personal connections to help them navigate the system; one participant did not. This finding supports the need for programs such as “Parent to Parent” support programs to help families who do not already have personal support in the
community of “similar others” to help families as they journey through the system (Ainbinder et al., 1998).

Another important finding of this study was the existence of misaligned visions between what the family was envisioning for their child and what the system was envisioning and how the system was responding. This finding was consistent with another study in which the degree to which families perceived that professionals shared their family’s vision for the child impacted their partnerships with staff (Soodak & Erwin, 2000). In other words, families who perceived that professionals did not share their vision had a difficult time establishing and maintaining partnerships with staff. It is essential to the overall partnership between parents and the system that systems recognize that a family is involved with their child for the entirety of that family’s life course; in contrast, educational programs and classrooms are involved with the child for a very short time. According to family life course theorists, policymakers need to consider families as being involved in a dynamic process across life stages, not limit policies to any one stage (White & Klein, 2002). Implications for this finding include the need for teams to engage in discussion around the family vision. Team members need to be given the resources (such as time and training) to have these discussions. These vision statements can help families and professionals collaboratively develop priorities for the child’s IFSP and IEP (Turnbull et al., 2011). However, these vision statements and processes do need to be developed through a collaborative process, as shared values and beliefs strengthen parent–professional partnerships (Soodak & Erwin, 2000). Collaborative processes occur when all members of the team have opportunities to give input and feedback, teams are open minded in hearing the input of all members, and members are able to trust and respect the roles of each member of the team.
Participants in this study found themselves involved in both decision making and intervention during the early intervention phase. Service providers should continue seeking ways to maximize parent involvement during early intervention. Parent involvement in early childhood has been shown to influence later academic achievement and even IQ (Huntsinger & Jose, 2009). Furthermore, this study found that, although parents felt involved in early intervention, they did not all have that opportunity to be involved in preschool special education services. In fact, one mother felt very strongly that she was “left out” of the process, almost entirely. This has implications for transition in that system leaders can help preschool special education teachers understand the level of, and opportunity for, engagement families have had during early intervention and can then critically evaluate ways to continue to engage families as they move through the system.

Families experienced conflict and a range of emotions during transition. However, families did have accesses to support (both formal and informal) while navigating the system. Families described conflict that involved system policies and practices (such as transportation and placement decisions) as well as conflicts with personnel they felt lacked needed competence. Researchers have expressed that finding solutions for transition challenges extend beyond the practices of service providers to a need for a systemic look at transition practices and policies (Malone & Gallagher, 2009). The examples that families vividly described during their transition point to a need for researchers and leaders to look critically and systemically at transition policies and practices and ask questions of the system, such as:

- Are policies put in place for the convenience of the system, or are policies supportive of the development of both the child and the family?
Does the system allow for children to be in an environment that allows for both child progress and inclusion into the child’s home community or setting that they would be attending if not receiving special education services? Is the proportion of options available to families of children with and without special needs equitable?

Are the personnel that employed in the system capable of supporting families as they leave intervention, providing them with resources and options regardless of Part B eligibility? Does staff in receiving programs have the skills and information needed to provide support to the children and families entering their program?

The importance of transition practices is highlighted in both current literature and theory. Family life course theory recognizes transitions as being critical junctures in a family’s life course (White & Klein, 2002), and outcomes of positive transitions in early childhood have been recognized (Dogaru et al., 2009).

Understanding how families experience preschool special education services has implications for transition in that it helps in understand the setting to which professionals in special education will be “sending” families. Although it is important to identify components of the early childhood special education system that need to be improved, families will also need to have the skills to navigate the system and advocate for their child. In this current study, some families found that their role in intervention and decision making changed once their child began preschool services, all families varied in the way they experienced communication practices but all families valued communication, and families found themselves engaged in a trust-building process as they acclimated themselves and their child to a new environment.
One parent found herself less engaged in the preschool system than she was in the early intervention system. She felt that her only role on the preschool team was to simply provide her signature for necessary paperwork. Soodak and Erwin (2000) described a similar finding: Parents felt they were invited to a meeting at a single point in time (the IEP meeting) to approve predetermined decisions. This finding also is consistent with the findings of another qualitative study in which parents felt they no longer held an integral role in their child’s education and had been moved from feeling like an “insider” in the early intervention system to an “outsider” in the preschool special education system (Podvey et al., 2011).

Early intervention and early childhood special education staff should consider ways to invite and encourage parent involvement in their programs. Parent involvement has been associated with enhanced social function and lower behavior problems in children (Nokali, Bachman, & Votruba-Drzal, 2010), higher levels of achievement (Huntsinger & Jose, 2009), and stronger preliteracy skills in preschool (Arnold, Zeljo, Doctoroff, & Oritz, 2008).

**Limitations**

Although appropriate for an ethnographic examination, this study involved only three participants representing three families and did not involve a father’s perspective. This study also was limited in its geographical location, as all participants resided within a 40-mile radius of a major midwestern metropolitan area. Future studies should explore the experiences of families across a variety of geographical locations. Finally, the study’s findings were analyzed primarily by the principal investigator. Although the principal investigator did employ validation strategies that included peer debriefing and member checking, future research on this topic would benefit from the analysis of a team of diverse researchers.
Conclusion

Family–professional partnerships are important in facilitating smooth transitions (Rosenkoetter & Schroeder, 2008). The purpose of this study was to understand the experiences and partnerships that surround the transition process, including the experiences before and after transition. Although strengths exist in the system, much improvement is needed to strengthen the transition process and the partnerships embedded within that process. Future studies should extend this work in order to pinpoint the transition strategies that directly enhance partnerships between families and the system.
References


Center for Early Development and Learning’s kindergarten transition intervention.


CHAPTER 4. GENERAL DISCUSSION

Parent participation is one of the key principals of the Individuals with Disabilities Education Act (IDEA) and sets the stage for parent/professional collaboration and partnership. The IDEA also requires that the Individualized Family Service Plan (IFSP) team (made up of the family and professionals surrounding the child) engage in transition planning before the age of 3 years. Inherent in this transition is the transfer of partnerships from one system to the next (early intervention to early childhood special education). Family life course theorists recognize that transition times are fragile and critical junctures in a family’s life span (White & Klein, 2002). These transitions are fragile points that can have a positive or negative impact on the partnerships between families, the personnel in the system, and the system as a whole. In this study, I examined how parents characterized ideal partnerships; what parents thought was beneficial in establishing partnerships; what their partnership experiences were during early intervention, transition, and early childhood special education; and what parents identified as needs for the transition process.

Using Seidman’s (2006) three-interview series, I interviewed three mothers who represented three families. Study results were divided into two separate articles. The first article, entitled “Understanding How Parents Describe Ideal Partnerships and the Roles Embedded Within: A Critical Ethnography,” addressed the following research questions: How do families characterize ideal partnerships? What do families consider beneficial in building partnerships between families and professionals?

From the series of interview, I found that families identified that both professionals and parents have a role in building and maintaining partnerships. Participants identified the
need for professionals to engage in ongoing communication, value parents as presenters, and trust that parents are the expert on their child. Participants also identified that parents also play an important role in effective communication, advocacy, and have adequate interpersonal skills when partnering with professionals.

The second article, entitled “A Critical Ethnographic Study of Parents’ Experiences as They Navigate Early Intervention, Transition, and Early Childhood Special Education,” addressed the following research questions: What did families experience when they partnered with early intervention systems and transitioned into partnerships with early childhood special education systems? What do families identify as needs in the transition process to establish effective partnerships with early childhood special education providers?

From the series of interviews, I found three “umbrella” themes that were characterized across early intervention, transition, and early childhood special education. These themes included power disequilibrium versus harmony, gratitude despite conflict, and a mother’s mission. I used the power disequilibrium versus harmony theme to describe moments when either the system or families had knowledge, resources, or system policies that would give them an advantage or power over the other. The gratitude despite conflict theme was used to describe the phenomena that, despite situations or issues that caused conflict between the system and parents, parents were still grateful for the existence of the system and the opportunities it gave their child. Finally, the phenomena that participants saw their role as an advocate for their child above all other roles was described using the mother’s mission theme. Themes were found across the stages of early childhood (early intervention, transition, and early childhood special education).
Based on the findings of both studies, I recommend that personnel in the early intervention and early childhood special education engage in professional development to gain the necessary skills needed to build and maintain partnerships and to ensure smooth transitions for families. I also recommend that resources and supports increase for families in order for them to fulfill their roles on the IFSP team. Partnerships in early childhood are important because they set the trajectory for the partnerships families will engage in throughout the family’s life course. Parent involvement over time is important to the success of the educational system, as parent involvement has been linked to greater academic achievement (Galindo & Sheldon, 2011; McDonnal, Cavenaugh, & Giesen, 2012). Similarly, successful transition practices also have been linked to positive child outcomes (Dogaru, Rosenkoetter, & Rous, 2009).
References


APPENDIX A. SEIDMAN’S (2006) INTERVIEW SERIES

Focused Life History

Participants are asked to tell as much as possible about themselves in light of the topic of the study.

The Details of the Experience

Participants concentrate on the concrete details of the lived experiences of the topic. Don't ask for opinions, ask for details. This detailed reconstruction helps put experiences into context.

Reflection on Meaning

Participants are asked to reflect on the meaning of their experiences, focusing on intellectual and emotional connections of the experience. Explores past events/details to help clarify experiences and meaning in the present. Not productive unless the other two interviews have occurred.
APPENDIX B. INSTITUTIONAL REVIEW BOARD APPROVAL

1 Iowa State University
OF SCIENCE AND TECHNOLOGY

Date: 4/22/2011
To: Aryn Kruse
70 LeBaron
CC: Dr. Gayle Luze
51B LeBaron Hall
Dr. Carla Peterson
E262 Lagomarcino Hall

From: Office for Responsible Research

Title: Understanding Partnership Transitions from Early Intervention to Preschool Special Education

IRB Num: 11-099

Approval Date: 4/20/2011
Continuing Review Date: 4/19/2012
Submission Type: New
Review Type: Expedited

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

- Obtain IRB approval prior to implementing any changes to the study by submitting the "Continuing Review and/or Modification" form.

- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.

- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/irb/forms/ or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
APPENDIX C. INFORMED CONSENT

CONSENT FORM FOR: UNDERSTANDING PARTNERSHIP TRANSITIONS FROM EARLY INTERVENTION TO PRESCHOOL SPECIAL EDUCATION

This form describes a research project. It has information to help you decide whether or not you wish to participate. Research studies include only people who choose to take part—your participation is completely voluntary. Please discuss any questions you have about the study or about this form with the project staff before deciding to participate.

Who is conducting this study?

This study is being conducted by Aryn Kruse, a doctoral student in the Human Development and Family Studies program at Iowa State University. Aryn is conducting this study for her dissertation as a part of her requirements to complete the Ph.D. program.

Why am I invited to participate in this study?

You are being asked to take part in this study because you are a parent who has had a child receive services through early intervention and has since transitioned to receiving special education services at a local preschool. You should not participate if you are under the age of 18 and/or are not a parent of a young child who has made this transition.

What is the purpose of this study?

The purpose of this study is to understand the experiences parents have had with transitioning children and families from early intervention services to preschool special education services.

What will I be asked to do?

If you agree to participate, you will be asked to participate in interviews describing your transition experiences. You will be asked to participate in three interviews, each lasting approximately 90 minutes.

You will be asked to describe your family’s story in raising a child receiving services in early intervention and preschool special education. You will be asked to identify strengths and challenges of transitioning your family between systems.

Audio tapes will be used during the interview process and will then be transcribed into Word documents. Audio tapes will be deleted at the completion of the study.

You will be asked to meet with the researcher three times during the interview process, with approximately 4-9 days between interviews. You will also be asked to review portions of the findings after data analysis as a means to check to see if the researcher has analyzed your contributions accurately. Feedback given to the researcher from you during this process may be in the form of email, telephone conversation, or a face-to-face meeting.
Your participation will last for approximately 4-5 weeks. You will participate in three separate interviews, approximately 90 minutes in length each, with 4-9 days lapsing between interviews.

What are the possible risks and benefits of my participation?

Risks—The possible risks related to your participation in this research are feeling uncomfortable answering sensitive questions about your experiences with your family. You may decline from answering any question during the interview process or choose to withdraw from the study.

Benefits—You may not receive any direct benefit from taking part in this study other than the opportunity to voice your experiences regarding your transition experiences from early intervention to preschool special education. We hope that this research will benefit society by adding to a body of knowledge that helps identify the strengths and challenges of our early intervention and preschool special education systems by sharing your experiences.

How will the information I provide be used?

The information you provide will be used for the following purposes: To identify themes among all interviews to present as findings for the researcher’s dissertation. Other research team members who will have access to this information include 2-3 doctoral students who will check the researcher’s interpretation of the data for accuracy and clarity; members of the researcher’s doctoral committee who are faculty at Iowa State University who will be involved in the research design, analyzing, and evaluating process; and a doctoral student who will be checking the accuracy of the transcriptions from audio files to Word files.

What measures will be taken to ensure the confidentiality of the data or to protect my privacy?

Records identifying participants will be kept confidential to the extent allowed by applicable laws and regulations. Records will not be made publicly available. However, federal government regulatory agencies, auditing departments of Iowa State University, and the ISU Institutional Review Board (a committee that reviews and approves research studies with human subjects) may inspect and/or copy your records for quality assurance and analysis. These records may contain private information.

To ensure confidentiality to the extent allowed by law, the following measures will be taken: Audio files will be transcribed into Word files and then deleted at the completion of the study. All audio and word files will be kept and maintained on a password protected computer. Word files will not contain any identifiers (names of individuals, names of schools, names of cities/towns, etc.) in the text. The findings reported in the study will not contain any identifying information of the participants (name, place of employment, resident city, etc.).

If the results are published, your identity will remain confidential.

Will I incur any costs from participating or will I be compensated?

You will not have any costs from participating in this study.
You will be given a $30 gift card for participating in the three-interview series. Gift cards will be received regardless of completing the entire study and will be compensated at time of study completion or study withdrawal.

What are my rights as a human research participant?
Participating in this study is completely voluntary. You may choose not to take part in the study or to stop participating at any time, for any reason, without penalty or negative consequences. You can skip any questions that you do not wish to answer.

Whom can I call if I have questions or problems?
You are encouraged to ask questions at any time during this study.

- For further information about the study contact Aryn Kruse at 515-231-7604 or aryn@iastate.edu. Supervising faculty are Dr. Carla Peterson (294-7804 or carlapet@iastate.edu) and Dr. Gayle Luze (294-4045 or gluze@iastate.edu).
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, (515) 294-3115, Office for Responsible Research, 1138 Pearson Hall, Iowa State University, Ames, Iowa 50011.

Consent and Authorization Provisions
Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the written informed consent prior to your participation in the study.

Participant’s Name (printed) ____________________________________________

(Participant’s Signature) __________________________ (Date) __________

Witness __________________________ (Date) __________

Office for Responsible Research
Revised 06/14/10
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APPENDIX D. INTERVIEW PROTOCOLS

Qualitative Interview Discussion Starters: Parent Interview 1 (of 3)

**I’d like to hear about your family:**

- Who is in your family?
- What are their ages? Birth order?
- How do individuals in your family spend their time? (Work, school, etc.)
- How do you spend time together as a family? (Hobbies, daily routines, etc.)

**I’d like to hear more about the experiences you’ve had with your child:**

- Describe your child’s needs or diagnosis
  - When did you find out your child had unique needs?
  - How did you come to know about early intervention services?
- Describe your child’s early intervention services
  - What type of services were received?
  - Where did services occur?
  - What was a typical early intervention session like?
- Describe your child’s preschool services
  - What is their classroom like?
  - How does your child get to and from school?
  - What services do they get while they are school?
  - What does their schedule consist of?
Qualitative Interview Discussion Starters: Parent Interview 2 (of 3)

I’d like to focus this second interview more on the time of transition your family made from early intervention services to services at preschool.

- Thinking back when you were getting early intervention services, when did you and the early intervention service providers begin to discuss what would happen once your child turned 3?
- What were the options presented to you?
- What considerations did you have when thinking of your options?
- How did you decide on the option?
- What sort of questions did you have?
- Who addressed these questions?
- What sort of planning/preparation did you and your IFSP team engage in prior to the transition?
- What was your initial IEP meeting like? What roles were present? What were the major discussion topics?
- When did you first meet your child’s new teacher and service providers? Can you describe those first interactions for me?
- How much time passed between the initial IEP meeting and when your child began receiving services?
- How did your child travel to and from school?
- How often were you in contact with your child’s new teacher and service providers? What were the main purposes for contact?
- Did you remain in contact with your child’s early intervention service providers? If so, how often? For what purpose?
Qualitative Interview Discussion Starters: Parent Interview 3 (of 3)

I’d like to focus this interview again on transition and I’d like to hear some of your feelings on the transition, what went well, what you were concerned about, suggestions you’d have for service providers, early intervention systems, school systems, and advice you’d give to parents who are facing a time of transition.

What were you feeling prior to your child’s transition?

- What were your concerns?
- What were your hopes?
- How did you feel about transitioning from your early intervention service providers to having new providers?
- What was challenging?
- What made approaching the transition time easier?
- How were your questions addressed? How satisfied were you with the manner in which your questions were addressed?

What were you feeling during the first IEP meeting?

- How did you feel about the process of your child’s initial IEP meeting?
- How did you feel meeting new individuals that would be working with you and your family?
- Did you meet them prior to the IEP meeting? If so, what was that like?

What were you feeling on your child’s first day of preschool services?

- What were your concerns for your child’s first day?
- What were your hopes for your child’s first day?
- Were you able to meet with your child’s teacher after his first day? Describe that experience.
- If not, when were you able to meet or be in contact? What information did you learn?

What were your feelings during and after transitioning from working with early intervention service providers to preschool service providers?

- What was concerning about the transition of this partnership?
- What did you hope for?
- What do you feel went well?
- What do you wish were different?
- How comfortable were you with your early intervention service providers toward the end of early intervention services?
o Were you able to achieve this same level of comfort with your preschool service providers?

o What was the relationship building process like? How long did it take?

What is the ideal partnership between parents and early intervention service providers like?

What is the ideal partnership between parents and preschool service providers like?

Ideally, how would this change in who you are partnering with occur? (i.e. the process)

Was your experience ideal? If so, what were the contributing factors that made it ideal? If not, what would have made it ideal?

What advice would you give parents who are about to make this same transition?
APPENDIX E. SAMPLE INTERVIEW SUMMARY SHEET

<table>
<thead>
<tr>
<th>Interview Summary Sheet</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Date:</strong> August</td>
</tr>
<tr>
<td><strong>Time:</strong> 5:00 p.m.</td>
</tr>
</tbody>
</table>
| **Description of Setting:**  
  We met inside the participant’s home, in her living room. Her husband and children were there. She also had a large dog that came in and out of the room. Her children and husband came in and out of the living room throughout the process. |
| **Description of Interview Process:**  
  First of the three interviews from Seidman’s Interview Series. |
| **Key concepts shared in interview:**  
  Participant was very detailed in her story of her child’s disability.  
  Parent was very frustrated while navigating both the medical and educational world. She really wants to work with people who are on the same page as her. |
| **Novel concepts/content:**  
  I’m amazed at the vivid details that she used in the interview. I feel like these memories are “keener” than if you were raising a child with typical development. |
| **Questions to ask during follow-up interviews:**  
  In addition to interview protocol, clarify the providers that were the same on the preschool team. Also, describe to her what research describes as a partnership (dimensions) and ask if she can identify with those dimensions. |
| **Reflection on interview process:**  
  Interview process is going well. I’m amazed how at ease these parents are with me, I think they can identify with me because we’ve both been through the “system”. I have a lot of anger towards some situations, I am trying to remain neutral in my interviews, but it’s tough to hear that we’ve had the same frustrations. |
APPENDIX F. SAMPLES OF FIRST CYCLE CODING AND ANALYTIC MEMOS

Participant One — 1

Participant 1 Interview 1

I: To start off this interview, I'd really like to hear more about your family, so, who is in your family? #00:00:15-0#

P: In our immediate family, there is, me and my husband, and then we have two boys, um, John and Jeff, ages, 9 and 5. #00:00:33-2#

I: And, so, how do you, spend time together as a family? #00:00:40-1#

P: We do, usually it's the boys' sports, or my husband is a wrestling coach so we do lots of wrestling, husband is a big Hawkeye fan so we do lots of stuff there, we do grilling out, we do, umm, bike riding, swimming, we do that all of the time. That type of stuff. #00:01:03-0#

I: So, what sort of sports are your boys involved with? #00:01:08-7#

P: Baseball, football, and wrestling? #00:01:12-9#

I: Do both boys do that? Do you have some sort of Parks department? #00:01:16-5#

P: Yep, over in Martinville they have stuff for the younger ones, and John only does you know, Bam-Bam baseball and then he'll do wrestling camp, sometimes you get to go because when your dad's the wrestling coach sometimes you get special treatment. #00:01:37-3#

I: Yeah! Well, that's neat, it sounds like you guys have a lot of shared interests that you do together. Umm, what about, what's your typical routine like during the school year? #00:01:49-4#

P: Um, most days, you know they go to school, we come home, and then it’s usually, we work on homework or whatever while I'm cooking supper and then one of them has a practice, usually it's Jeff has to go to practice, and then come home, and then they pretty much will read, watch T.V., head to bed, and start it all over again the next day. #00:02:15-1#

I: Do you feel like it's a pretty consistent routine during the school year? #00:02:20-4#
Participant One

P: Yeah, sometimes it will get thrown off, like sometimes we'll go to like a wrestling meet that might go later. Like during state wrestling we'll go down to the meets, sometimes we'll have late nights there, nothing consistent like that...usually on occasion. #00:02:40-3#

I: Okay, well, I'd like to hear more about your experiences with John. Can you describe what his needs are? #00:02:50-2#

P: Yeah, he's been diagnosed with...with just "Developmental Delays" is what they've just given him. #00:02:59-1#

I: And who's "they"? #00:02:59-1#

P: His doctor, umm... #00:03:03-7#

I: Like his pediatrician? #00:03:06-8#

P: Yeah, his pediatrician. Yeah, we saw lots of...they weren't really sure when he was born what the issue was. He was like stuck in the...the ATR position, had a really curved spine, you'd put him on his tummy and he'd flip right to his back because he was so curved....and just...tight. #00:03:34-3#

I: So, you knew from birth that something was different... #00:03:38-9#

P: Yeah, for about a month, at about six weeks...cuz I was saying "he shouldn't be rolling over yet" #00:03:45-7#
I mentioned it to my parents, who them being OTs and PTs, but they were like, "Yeah, we've noticed it too." They wanted to just wait and see where things were going, but that's when I decided to go ahead and have him evaluated by the COOPERATING AGENCY and see if he could get services and #00:04:07-6#

I: And you knew about the COOPERATING AGENCY because of your parents? #00:04:13-6#

P: Because of my mom, yeah. The COOPERATING AGENCY came out, the physical therapist came out and was like "yeah, there are some issues", he actually came
out...once a week for about an hour...and in the meantime, he also got...he had an occupational therapist that came...his hands were stuck in fists so we'd work on hand stuff and getting...he had little splints to help get his thumbs out, just little things like that. He had had...he was breast fed and was not gaining a whole lot of weight, but what they figured out was that he had an inefficient suck, we went and saw a speech pathologist that did all of the feeding issues, he had an inefficient suck, and I was going to nursing school at the time so during the day he would go to daycare, at the daycare he would only drink about 8 oz the whole day because about after an ounce or two ounces, his jaw would just...you could hear...milk would just drip out the side and he couldn't make that seal. Whereas breastfeeding was easier, he didn't have to suck, which is odd because with most people it is the opposite. However, I did have good milk production to where I think it just came, and he didn't have to do a whole lot...so... 

I: So, you were evaluated and he was eligible for PT and OT right away? 

P: Yes, and the home intervention teacher. The OT...as he got older we started working on foods and stuff, he was also very...like the bottle had to be...the milk had to be a specific temperature. It basically had to be the same temp as what I was giving him. If it was too cold he wouldn't take it, if it were too hot, he wouldn't take it. And as he got older there was a lot of textural issues as he was going into feeding and foods, and so we worked a lot on getting his tongue to move, and the neck brush, those types of things to get his tongue to go. We also found out, we were working with, I don't remember which person was there, but we had noticed, they thought he might have a "field cut", we were working on following objects, he never made eye contact, like when I was feeding, he didn't do, he never looked at me, we were trying to see if his eyes were okay, he'd follow to about here, and then he'd get to about here (participant pointing at her field of vision), and his eyes would stop...like the whole object would disappear into his peripheral vision there...We actually had a sight person come out too and look. And, he, there were objects placed and he could see them on his right side, but not on his left side.
Participant One →4

P: Ummm #00:07:33-1#

I: And what did they say about that? #00:07:35-7#

P: That has actually gotten better, over time. He went to the low vision clinic and they basically...when he was 1 he went there and they said that he was seeing like an infant, for some reason his vision wasn't coming. But, over time, he's seeing okay. He's kind of always had that, uh, that, where things just aren't there....they should be there, but they're not. And his hearing was exactly the same where we were worried to where he wasn't hearing anything because there would be loud noises and there was nothing. Umm, took him in to the sound booth and they did all of their testing, and once again, it was...his ear drums should be working, right, but when a thing would go he would show no sign of hearing the beep, but his ear drum was moving like it was okay. That again...we got tubes put in, they thought maybe there was just something with the pressurization. We got tubes put in and that's gotten better too. It's kind of just.... #00:08:57-9#

(Interruption in interview, participant tending to dog) #00:09:04-2#

I: So, he had tubes put in to help for hearing, and that has come... #00:09:33-7#

P: That has come back to you know, where he is doing good. Umm, he had the quiver chin we called it, where his chin...it was probably at least 6 to 8 weeks before it would go away. So they thought maybe it was something neurological, so they had an MRI done #00:09:56-0#

I: And all of this was happening.... #00:09:59-9#

P: Before he was a year. We got it done in Des Moines. Iowa City had all of the stuff there, but we did it here in Des Moines. Everything came out normal. Not really sure... Not really sure what or why. #00:10:16-2#

I: Yeah, I know that feeling. #00:10:24-0#

P: Yeah. And that was all up until he was one. He also wasn't talking. He wasn't really babbling much, we had to
Participant One — 5

actually work with him to move his tongue and to even make noises. And for about 18 months we really fought and fought for speech. And he didn't get his speech evaluation done by our normal speech therapist, someone, some head in the speech department in the COOPERATING AGENCY came. #00:10:57-3#

I: So, when you say "fought and fought", what do you mean by that? What was that like? #00:10:57-3#

#00:10:57-3#

Umm, we were told that until he was three they wouldn't give services. However, having my mom who....she went to them and said that he could legally get these services and up until 18 months it makes no difference but from 18 months on if you can get these kids speech it makes a lot of difference down the road. #00:11:25-7#

I: She was helping you advocate... #00:11:23-2# #00:11:28-8#

P: Yes, because I didn't know the laws and stuff. Speech has been the one area where we have fought and fought and it's like they don't want.... #00:11:42-1#

I: Is that still an issue? #00:11:45-1#

P: Yes, very much so. And now...he's started talking, he's doing better, in the speech arena. However, we found out...he got dropped from speech here just recently....ummm...so, I took him to a private gal that evaluated him and what we found out, um, was he, when he was given a board and when he was given a board with pictures and he could point to the picture to answer the pictures he could point to the correct picture to answer her questions. However, when she would ask him, her thing was, let's talk about our pets. Do you have a pet? And he just kind of sat there....and eventually, she said, "well, let me tell you, I have a dog, can you tell me about your pets?" And he said, "me...have a dog?" You know, like a question. He's kind of like, it came to the point where we came to realize that if he has to come up with stuff on his own he is not processing like he's supposed to, if he's given options, he does okay, but he's not....even here he's not one to ever make a decision on his own. He can't...you know, he can't....if you ask him a question like, "What do you want for breakfast?" It's "What's Jeff (his
I: And this is a private speech person? #00:13:28-6#

P: And based on a report, insurance approved it… and it's kind of frustrating… but… #00:13:37-0#

I: Yeah, I understand. #00:13:39-5# So, back to the ages of 1 to 3… he had PT, OT, a home interventionist, and then a speech person came in at 18 months? #00:13:54-3#

P: And actually about a year the PT person stopped. #00:14:01-1#

I: And that was a good thing? #00:14:03-5#

P: Yeah, actually, he had met all of his gross motor skills and he had to be taught everything. We taught him how to get on his hands and knees, we taught him how to sit… once he was about 12 months he was pulling himself up, and we taught him how to do it. That's when our PT said, "he just needs to be taught these things, once he's taught them he can do it". And eventually he started walking on his own, we noticed that he had one leg that turned in a little bit more… but that, once again, we didn't know if maybe there was a CP even though his MRI was fine, what was going on there… he still had a lot of the arm tightness so we didn't know too if it was… who knows. #00:14:46-2#

I: Okay, so, the PT stopped after about a year, at age 1. Still the OT then? #00:14:54-0#

P: Yes, still the OT. #00:14:56-7#

I: and she still worked with feeding? #00:15:00-7#

P: Yep, we worked a lot with feeding. He still was only eating certain things and this time his weight started to decline. He's always been smaller, but it was getting to where his line… he wasn't making a whole lot of growth and he was actually diagnosed with "failure to thrive", and they told me that it was my option, but I actually breastfed him until he was about 2, because they said if you don't and his weight keeps declining, we'll have to do a feeding tube. #00:15:35-0#
Participant One — 7

I: Okay. #00:15:40-6#

P: And we tried, he was ornery, we tried even supplements to put into the milk but if it changed the taste, or even the texture, he would have nothing to do with it. #00:15:50-3#

I: He could really notice those minor changes and that was bothersome to him. #00:15:53-4#

P: Yep, and so found out he loved peanut butter. And I swear he ate peanut butter... umm, what did he call it... "peanut butter on a 'poon" #00:16:10-1#

I: Cute #00:16:13-2#

P: And he would walk around with his peanut butter on a spoon and I swear we went through jars and jars of peanut butter. #00:16:14-9#

I: Well, that's nice that it has a nice fat content! #00:16:14-9#

P: Exactly, I know, the kid...yes. And so he did finally plump up a little bit, but it was one of those that, then he started walking and he was thinning out... but it was... #00:16:29-9# And even now... I think the lowest he ever got was the 3rd percent for weight... actually, no, because he wasn't on the chart for a long time. He kind of made his own chart, now we've actually gotten back up on the chart. I think 5 percent for weight. No, 5 percent for height, 15 for weight... but before... yeah, he's made progress. #00:16:53-2#

I: Do you, I don't mean to jump ahead, but do you still see sensitivity to foods and textures? #00:17:02-7#

P: Yes, I do, I'll be honest, he's a follower, it depends on whose around and whose eating what. Umm, even macaroni and cheese, it depends on the texture. Sometimes he'll eat it, sometimes he won't. Like if he's in a group with people he'll do it, but if it's just me and him he won't. He's very much, "what are the other kids doing and that's what I'm going to do" #00:17:36-3#

I: That makes sense from what you said before about visual things, he's taking these visual cues. #00:17:53-6# Umm,
Participant One — 8

so, toward the end you mentioned that he was going to
daycare during the day. So, did you work directly with Early
Intervention staff or did they work with the daycare, or both?
#00:18:15-6#

P: Because of my schedule with nursing, I would usually
have an afternoon off, I'd usually have some time. And
usually I'd have Wednesday afternoons off, or I'd only have
classes like...I'd have a big day of class, which would
usually be my Monday and Wednesday class...and so they'd
usually come then. And they were really good with working
around my schedule. They were good with that. #00:18:52-
7#

I: So, closer to age 3, what were his services like? Did he
still have OT? #00:19:01-3#

P: I think...I think...3 he did have OT still. I think it was in
his transition time that they went ahead and said they would
go ahead and keep her on as a consult. And she came to
see him sometimes. Actually, no she was there at preschool
when he was three, because he started the preschool in
Martinville, and yep, she was there because we were still
working on feeding....we were still working on feeding stuff
because he had such a limited, limited amount of foods that
he would eat. #00:19:45-3#

I: So, who would you say of that Early Intervention team
was the most consistent person from the start of services up
until the point of transition. Who did you see the most? Who
was there the entire time I guess? #00:20:05-9#

P: The early intervention....she was a psychologist, but she
was the home intervention. She's still in the preschool now.
#00:20:18-0#

I: As his teacher? #00:20:20-4#

P: No, she's on the team still. I don't know if she just has all
of those kids? Well, I'm trying to think...yeah, she was there
with him. His speech therapist is the same as well, the one
he's always had. And then, the OT, umm, kept him on
probably until this year now that I think about it...at least
three and half, maybe four. I think she changed jobs too, it
was just one of those where I said, you know what, we can
do this at home. Instead of bringing in another person....he's
the type that gets overwhelmed...he's the type that is kind of shy...you know, I just figured one less person if we can do stuff at home...if they noticed something I said we could definitely bring in another person. At that point most of his goals were academic anyway...physically he was doing okay. #00:21:35-4#

I: So, who would you say was your go-to person, who did you feel most comfortable with? Or did you have the same level of comfort with everybody? #00:21:47-4#

P: It was kind of the same level of comfort. I don't know if I every really felt, you know, comfortable with them. I never...I guess that was, I had a hard time with them always, "oh he's doing so great...look at all of this progress", and I'm going "yes, he's making little bits of progress but we have all of these issues that we haven't even touched." And that was kind of hard for me, too, with...because I went through that with doctors, I went through that with his biological dad...you know, to where I don't need to hear how good he is doing, I see how good he is doing, I see where he came from but we still have all of this other...stuff to work on... You know, so that's what was hard for me, is, is...yes, he was making progress, I know he is, I mean, I know he's made an enormous amount of progress, but let's not lose sight of the other things? #00:22:52-1#

I: Yeah, I totally get that. I think I was told once by our PT...she was trying to make me feel better about the situation and she said, "well, she's not the worst case" And I hated that because he's my case, and he's mine to worry about. #00:23:12-3#

P: Yeah, see, and I talked to my mom about that too. She said they are so used to parents that need that praise, that need that, need that...need their kids getting better. I know he's getting better, but I know he's not going to be...I hate to say "normal", but he's always going to have issues. I know that, I'm okay with that, so don't...sugar coat it for me. Tell me how it is...tell me, you know. Yes, I saw the progress he was making, but compared to kids his age....we were nowhere close to that. And so that's where my frustrations came, is...you know, yes, he himself is making great progress, but...it's not #00:24:01-7#

I: Yeah, Yeah #00:24:04-3#
P: I don't know. I guess that was my frustrations with them sometimes. #00:24:15-6#

I: Yeah, I understand. So, transition happened and so he went to preschool. Did he almost go to preschool for three years then? When is his birthday? #00:24:31-6#

P: Yes, he turned 5 in June. He went to preschool in Martinville for 3 year olds, and it was pretty much for Early Intervention stuff. #00:24:47-7#

I: So, is everyone in his classroom on an IEP? #00:24:53-9#

P: Most. It was kind of integrated. Some kids didn't, but for the most part a lot of them did. #00:25:02-5#

I: So, that must have started in the August after his birthday? #00:25:10-7#

P: Yes. He did that for 3 year and 4 year, and next year he will do optional kindergarten. Next year he will get one on one special ed services. They've kind of found with him that he is still needing that one on one time. They've tried him in a group and he's just not...he can't focus, so he needs the one on one. And, you know, where...he's starting to get frustrated with stuff because he's starting to realize that he's not where his peers are. School has been kind of tough this year just getting him to go. And he doesn't like it. I tried to talk to his teacher about it...I was like "do you know what's going on" and she said you can just tell that he's frustrated. Kids are done with their project and he needs help, he doesn't know where to go with it...so...hopefully next year, hopefully with that one on one, that it will help build up his confidence again. The problem is that with the preschool they weren't able to have that...that special ed one on one time. #00:26:23-8#

I: So when you say one on one, do you mean that an adult will be in the classroom with him, or do you mean that he will be pulled out more? #00:26:31-5#

P: He will be pulled out for more time. #00:26:32-1# #00:26:33-0#
Participant One —11

I: So, what is his IEP... what are his current areas on his IEP? #00:26:41-4#

P: Umm, I know... oh goodness, #00:26:45-5#
   #00:26:46-1#

I: Does he still see OT? #00:26:49-5#

P: No, no. They’ve actually gotten rid of all of his services except... it’s all academic. #00:26:58-8#

I: So, math.... #00:27:01-8#

P: Yes, he does have math #00:27:04-5#

I: And reading? #00:27:06-7#

P: Yes, and reading, both of those areas. #00:27:11-5#

I: And how do you feel about that, is that a good spot for him, how do you feel about that? #00:27:11-5#

P: Yeah, I think those are both areas that he really needs. And now that he has speech from an outside place.... umm... I wasn’t real happy with that one, but.... #00:27:27-3#

I: Has the preschool teacher and team... have they seen the reports from the outside place? #00:27:36-3#

P: No, because that was done this summer. So, I figure this fall when we meet, we will go ahead and share that with... well, I figure... like I asked the speech therapist, give me the tools that I can give his teacher to help him. So, I thought about these picture boxes... he gets very side tracked very easy if there is too much noise going on he will just shut down or he’ll you know, be unfocused, and even those... what am I supposed to be doing, am I doing it... you know, should I ask a question. You know, those simple things to help keep him on task... to help him visually see what he needs to do. So.... #00:28:20-7#

I: Okay. So, was his schedule last year during the school year... did he go all day? #00:28:33-6#

P: There was four days a week half days, and then he’d go to the daycare in the half days. #00:28:44-4#
Participant One — 12

I: And did he ride the bus to the daycare in the afternoon? #00:28:46-5#

P: Yes, he rode the bus. #00:28:46-5#

I: And did he like it? #00:28:46-5#

P: Oh yeah, he loved it. He thinks he's so cool riding that bus with all of the big kids. #00:28:50-4#

I: And so then, this next year he'll still be on an IEP and he'll go to optional kindergarten for half days every day? #00:29:05-0# #00:29:06-9#

P: Yes. #00:29:08-8#

I: And have you met that teacher? #00:29:08-8#

P: No. Not yet. #00:29:08-8#

I: And will that still be in Martinville? #00:29:08-8#

P: Yes, still in Martinville. #00:29:06-4# #00:29:09-7#

I: Same building? #00:29:12-5#

P: Yes, he's been there...this will be his third year. #00:29:18-1#

I: Does Jeff go to the same school? #00:29:23-6#

P: No, he goes to school here, which is where John will go the next year. The following year he will come here in Hilldale. #00:29:30-7#

I: It's tough being a June baby, it's nice that you have that option. #00:29:36-8#

P: Yes, that is so nice to have that option. #00:29:40-1#

I: Did your oldest go too? #00:29:44-3#

P: Yes, he went to optional too. He was a June baby too. You see it's funny, now for him, he will start third grade this
year and he has been bumped into fourth grade math. #00:29:56-9#

I: A range. #00:29:56-9#

P: Yes, a range. I know (laughs). #00:29:58-1#

I: Yeah, I understand. #00:30:01-4# Okay, let's see...so, this whole time that you've been working through your pediatrician...when did they start saying that it was a developmental delay? #00:31:15-8#

P: After I went to the third doctor. Because the first doctor said I don't do a whole lot with...he was a family doctor...he was like "well, he looks okay", and I was like "no, he doesn't look okay. Kids aren't stuck in this position. His spine shouldn't look like this, his chin shouldn't be quivering all of the time. I went to another pediatrician in Manchester and he told me the same thing. He said that some kids just prefer one side. You know his head was turned this way, his head was flattening. You know, I'm goin', this isn't normal. And he told me the same thing, not a big deal, we'll just keep an eye on him. I was like no. So, probably...there is a doctor at Blank who specializes in special needs. #00:31:14-1#

I: So, were you referred then? #00:31:15-8#

P: Nope, I just kept goin'. I just kept goin'. Umm, I think, I think it was one that my mom has had family go too. She took a look at him, I told him everything that had been going on. At this time, he had already had the early intervention going on. I said, he's seeing a physical therapist, he's seeing an occupational therapist, I just want a doctor that is on board with what is going on. And she, you know, just looked at me and said, "you know, I see it. you're right. There is something going on. She was like, your next step is referring you to everyone you already have for him. She was like, you're on your way. You're where you need to be with him. We're going to keep watching him and see. #00:32:09-4#

I: So, does she still follow him? #00:32:13-2#

P: Yep, she still follows him. Now we just see her once year. It's one of those...I just love it because I can just call
Participant One — 14

her, even for the speech stuff, if we need a prior authorization... just to say, "yeah he should get this evaluation"... she is very much so... I just love how much she listens. She takes your concerns... if you're concerned she listens to your concerns. She might say "we'll watch it" but she won't say that it's not a big deal. We've brought him in time after time and she says that she is amazed with his progress, she says, "honestly from the first time you brought him in, I didn't think we'd be here right now". You know. It's nice to have a doctor that saw it through my eyes as well. And that's... just made me... even the nurse was like, "You're his parent, if you think there's something wrong, there probably is. Like, trust your instincts as a parent."

I: Well, that's nice to hear that from someone. #00:33:25-8#

P: Yes, it is. Finally, after all of that, it was nice to hear.

I: So, who would you say, you mentioned your support wasn't from your Early Intervention team, who would you say is your support... for as a mom... for dealing with thinking of these issues? #00:33:44-9#

P: It was my mom. #00:33:47-1#

I: How is your friendship group, your friends, were you able to depend on them for things? #00:33:55-0#

P: Not really. And in all honesty, at that time... I was young still, with two kids, going to school full time. One kid getting services all of the time, and I was always working on therapy with him... I didn't... no. I didn't really have a group of friends. I mean, I'd have a friend or two that I'd go out and do stuff with, but there was really never any support with that. #00:34:25-8#

I: I found when I was, especially initially, it was tough for me, in my friendship group when they had typically developing children and they were doing comparison's of our children, I didn't want to be in those conversations. #00:34:49-3#

P: I know, and that's the thing for me, when I look at him and all of the growth that he's made... every so often you see
Participant One ---15

him with kids his own age and it hits you again... #00:35:03-2#

I: That's a tough feeling. #00:35:03-2#

P: It is. #00:35:03-2#

I: Because you want to be so proud and happy but, inevitably there's something whispering in your ear, "yeah, but look it..." #00:35:14-2#

P: Yeah. It's not like you don't accept them for who they are, but at the same time you see... I don't want to say "where they should be", but you see... #00:35:23-6#

I: where the world #00:35:23-6#

P: Yeah, where the world thinks they should be. #00:35:23-6# And that's when it's difficult. And it's gotten better as he's gotten older. Especially when he was younger....... I mean, he's had tons and tons of services and intervention, and people coming in and so I'm at least I'm really glad he had that...because, I don't know where he would have been without it. #00:35:51-4#

I: Did they typically come all together, or did they come separately? #00:35:57-4#

P: It would all usually be separate... except the home intervention and speech would come together. #00:36:09-7#

I: So, that was a pretty busy time for you then. Did you like that model, having them all separate? Or.... do you kind of wish they could have come together more often? #00:36:19-0#

P: Sometimes they would come together, the thing is, it would almost be too overwhelming for John. Umm, and then it was hard to, because Jeff would want to be involved with it, and that got to be difficult too.... so he would be trying to get attention, if it was just one or two people there we could usually include Jeff there with some activity to help brother out, and he thought that was so fun to do therapy with brother. #00:36:53-9#
Participant One ---16

I: Yeah, we always called it Noah's school. We had it varied with the way they came as well, and like you said, it could get overwhelming because usually I'd have somebody talking in my ear, I was trying to watch was going with them...It was a little chaotic...but like you said...I was glad, in hindsight, I was very glad I had that help there. #00:37:25-7#

P: I just look at people now, especially with me being in the school. Like, kindergartners, some of them...I've talked to their teachers...you know, I just think the fact that it was caught early enough and things were done, it's going to make it better for him in the long run." #00:37:52-4#

I: Yeah, for sure. #00:37:55-5#

P: Yeah, I think...noticing there is something there, instead of someone noticing down the road, saying "hey by the way". #00:38:07-9#

I: Well, I think....is there anything major you think I've missed out. I know we get to meet again next week, so I will be able to think more. But do you think there is anything I've missed asking about? #00:38:24-4#

P: I don't think so. #00:38:27-6#

I: So, then next time we meet...next time we'll focus specifically on the transition from Early Intervention into preschool and hear sort of about what happened before transition, during, and after transition time. Does that sound okay? #00:38:58-9#

P: That sounds good! #00:39:02-2#

Participant 1 Interview 2

I: So, thinking back into Early Intervention and when they first started thinking about transition, do you remember about the time when you first started discussing with your team what that transition would like? #00:00:29-3#

P: yes, it was probably about 3 months before he turned 3, I believe. It might have been a little bit before, but I know that we started talking about it early because we had another eval coming up and we were going to try and get his, ummm,
## APPENDIX G. SAMPLE OF INITIAL CODE BOOKS

### Participant Two—Pre-Coding Summary (Initial Codes)

<table>
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<th>Context—</th>
<th>Social support(parent groups)</th>
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<td>Services as an active choice</td>
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<td>Family Background</td>
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<td>Affirmation to parent when child makes progress</td>
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| Early Intervention—                   |                                                                                                  |
| Parent involvement in therapy         |                                                                                                  |
| Discontinued private services         |                                                                                                  |
| A mother’s mission                    |                                                                                                  |
| Multiple child needs addressed        |                                                                                                  |
| Searching for Diagnosis               |                                                                                                  |
| Building & Breaking Trust             |                                                                                                  |
| Parent Dismisses Services             |                                                                                                  |
| Extended family support/involvement   |                                                                                                  |
| View of progress                      |                                                                                                  |
| Parent worries/concerns               |                                                                                                  |
| Family needs                          |                                                                                                  |
| Parenting is overwhelming             |                                                                                                  |
| Organizational needs                  |                                                                                                  |

### Transition—

**Being Dropped**
- Still needed social goal at age 2
- Stopped hearing from SC before age 3
- No transition to community services

**Family support**
- Lapse in services
- Qualified for PreK
- The Fight
- Placement Location
- Threats

**Preschool**
- Lapse in services from EI
- Qualified for PreK services around 3 1/2
APPENDIX H. SAMPLES OF SECOND CYCLE CODING & CATEGORIES

Participant One — 1

Interview 1

I: To start off this interview, I'd really like to hear more about your family, so, who is in your family? #00:00:15-0#

P: In our immediate family, there is me and my husband, and then we have two boys, um, John and Jeff, ages 9 and 5. #00:00:33-2#

I: And, so, how do you, spend time together as a family? #00:00:40-1#

P: We do, usually it's the boys' sports, or my husband is a wrestling coach so we do lots of wrestling, husband is a big Hawkeye fan so we do lots of stuff there, we do grilling out, we do, umm, bike riding, swimming, we do that all of the time. That type of stuff. #00:01:03-0#

I: So, what sort of sports are your boys involved with? #00:01:08-7#

P: Baseball, football, and wrestling? #00:01:12-8#

I: Do both boys do that? Do you have some sort of Parks department? #00:01:16-5#

P: Yep, over in Martinville they have stuff for the younger ones, and John only does you know, Bam-Bam baseball and then he'll do wrestling camp, sometimes you get to go because when your dad's the wrestling coach sometimes you get special treatment. #00:01:37-3#

I: Yeah! Well, that's neat, it sounds like you guys have a lot of shared interests that you do together. Umm, what about, what's your typical routine like during the school year? #00:01:49-4#

P: Um, most days, you know they go to school, we come home, and then it's usually, we work on homework or whatever while I'm cooking supper and then one of them has a practice, usually it's Jeff has to go to practice, and then come home, and then they pretty much will read, watch T.V., head to bed, and start it all over again the next day. #00:02:15-1#

I: Do you feel like it's a pretty consistent routine during the school year? #00:02:20-4#
P: Yeah, sometimes it will get thrown off, like sometimes we'll go to like a wrestling meet that might go later. Like during state wrestling we'll go down to the meets, sometimes we'll have late nights there, nothing consistent like that...usually on occasion. #00:02:40-3#

I: Okay, well, I'd like to hear more about your experiences with John. Can you describe what his needs are? #00:02:50-2#

P: Yeah, he's been diagnosed with...with just "Developmental Delays" is what they've just given him. #00:02:59-1#

I: And who's "they"? #00:02:59-1#

P: His doctor, umm... #00:03:03-7#

I: Like his pediatrician? #00:03:06-8#

P: Yeah, his pediatrician. Yeah, we saw lots of...they weren't really sure when he was born what the issue was. He was like stuck in the...the ATR position, had a really curved spine, you'd put him on his tummy and he'd flip right to his back because he was so curved....and just...tight. #00:03:34-3#

I: So, you knew from birth that something was different... #00:03:38-9#

P: Yeah, for about a month, at about six weeks...cuz I was saying "he shouldn't be rolling over yet" #00:03:45-7#

I mentioned it to my parents, who them being OTs and PTs, but they were like, "Yeah, we've noticed it too." They wanted to just wait and see where things were going, but that's when I decided to go ahead and have him evaluated by the COOPERATING AGENCY and see if he could get services and #00:04:07-6#

I: And you knew about the COOPERATING AGENCY because of your parents? #00:04:13-6#

P: Because of my mom, yeah. The COOPERATING AGENCY came out, the physical therapist came out and was like "yeah, there are some issues", he actually came
out... once a week for about an hour... and in the meantime, he also got... he had an occupational therapist that came... his hands were stuck in fists so we'd work on hand stuff and getting... he had little splints to help get his thumbs out, just little things like that. He has had... he was breast fed and was not gaining a whole lot of weight, but what they figured out was that he had an inefficient suck, we went and saw a speech pathologist that did all of the feeding issues, he had an inefficient suck, and I was going to nursing school at the time so during the day he would go to daycare, at the daycare he would only drink about 8 oz the whole day because about after an ounce or two ounces, his jaw would just... you could hear... milk would just drip out the side and he couldn't make that seal. Whereas breastfeeding was easier, he didn't have to suck, which is odd because with most people it is the opposite. However, I did have good milk production to where I think it just came, and he didn't have to do a whole lot... so.... #00:05:48-1# #00:05:51-4#

I: So, you were evaluated and he was eligible for PT and OT right away? #00:05:59-5#

P: Yes, and the home intervention teacher. The OT... as he got older we started working on foods and stuff, he was also very... like the bottle had to be... the milk had to be a specific temperature. It basically had to be the same temp as what I was giving him. If it was too cold he wouldn't take it, if it were too hot, he wouldn't take it. And as he got older there was a lot of textural issues as he was going into feeding and foods, and so we worked a lot on getting his tongue to move, and the neck brush, those types of things to get his tongue to go. We also found out, we were working with, I don't remember which person was there, but we had noticed, they thought he might have a "field cut", we were working on following objects, he never made eye contact; like when I was feeding, he didn't do, he never looked at me, we were trying to see if his eyes were okay, he'd follow to about here, and then he'd get to about here (participant pointing at her field of vision), and his eyes would stop... like the whole object would disappear into his peripheral vision there. We actually had a sight person come out too and look. And, he, there were objects placed and he could see them on his right side, but not on his left side. #00:07:33-1#
Participant One

I: Okay. #00:07:33-1#

P: Ummm #00:07:33-1#

I: And what did they say about that? #00:07:35-7#

P: That has actually gotten better, over time. He went to the low vision clinic and they basically...when he was 1 he went there and they said that he was seeing like an infant, for some reason his vision wasn't coming. But, overtime, he's seeing okay. He's kind of always had that, uh, that, where things just aren't there....they should be there, but they're not. And his hearing was exactly the same where we were worried to where he wasn't hearing anything because there would be loud noises and there was nothing. Umm, took him in to the sound booth and they did all of their testing, and once again, it was...his ear drums should be working, right, but when a thing would go he would show no sign of hearing the beep, but his ear drum was moving like it was okay. That again...we got tubes put in, they thought maybe there was just something with the pressurization. We got tubes put in and that's gotten better too. It's kind of just.... #00:08:57-9#

(Interruption in interview, participant tending to dog)
#00:09:04-2#

I: So, he had tubes put in to help for hearing, and that has come. #00:09:33-7#

P: That has come back to you know, where he is doing good. Umm, he had the quiver chin we called it, where his chin...it was probably at least 6 to 8 weeks before it would go away. So they thought maybe it was something neurological, so they had an MRI done #00:09:56-0#

I: And all of this was happening... #00:09:59-9#

P: 'Before he was a year. We got it done in Des Moines. Iowa City had all of the stuff there, but we did it here in Des Moines. Everything came out normal. Not really sure... Not really sure what or why. #00:10:18-2#

I: Yeah, I know that feeling. #00:10:24-0#
P. Yeah. And that was all up until he was one. He also wasn’t talking. He wasn’t really babbling much, we had to actually work with him to move his tongue and to even make noises. And for about 18 months we really fought and fought for speech. And he didn’t get his speech evaluation done by our normal speech therapist, someone, some head in the speech department in the COOPERATING AGENCY came. #00:10:57-3#

I: So, when you say “fought and fought”, what do you mean by that? What was that like? #00:10:57-3#

#00:10:57-3#

Umm, we were told that until he was three they wouldn’t give services. However, having my mom who….she went to them and said that he could legally get these services and up until 18 months it makes no difference but from 18 months on if you can get these kids speech it makes a lot of difference down the road. #00:11:25-7#

I: She was helping you advocate… #00:11:23-2# #00:11:28-8#

P: Yes, because I didn’t know the laws and stuff. Speech has been the one area where we have fought and fought and fought and it’s like they don’t want…. #00:11:42-1#

I: Is that still an issue? #00:11:45-1#

P: Yes, very much so. And now…he’s started talking, he’s doing better, in the speech arena. However, we found out…he got dropped from speech here just recently….umm…so, I took him to a private gal that evaluated him and what we found out, um, was he, when he was given a board and when he was given a board with pictures and he could point to the picture to answer the pictures he could point to the correct picture to answer her questions. However, when she would ask him, her thing was, let’s talk about our pets. Do you have a pet? And he just kind of sat there….and eventually, she said, “well, let me tell you, I have a dog, can you tell me about your pets?” And he said, “me….have a dog?” You know, like a question. He’s kind of like, it came to the point where we came to realize that if he has to come up with stuff on his own he is not processing like he’s supposed to, if he’s given options, he does okay, but he’s not….even here he’s not one to ever
make a decision on his own. He can't...you know, he
can't...if you ask him a question like, "What do you want for
breakfast?" It's "What's Jeff (his brother) having?" So,
that's what the speech therapist is working on now.
#00:13:23-8#

I: And this is a private speech person? #00:13:28-6#

P: And based on a report, insurance approved it....and it's
kind of frustrating....but... #00:13:37-0#

I: Yeah. I understand. #00:13:39-5# So, back to the ages
of 1 to 3...he had PT, OT, a home interventionist, and then
a speech person came in at 18 months? #00:13:54-3#

P: And actually about a year the PT person stopped.
#00:14:01-1#

I: And that was a good thing? #00:14:03-5#

P: Yeah, actually, he had met all of his gross motor skills
and he had to be taught everything. We taught him how to
get on his hands and knees, we taught him how to
sit...once he was about 12 months he was pulling himself
up, and we taught him how to do it. That's when our PT
said, "he just needs to be taught these things, once he's
taught them he can do it". And eventually he started
walking on his own, we noticed that he had one leg that
turned a little bit more...but that, once again, we didn't
know if maybe there was a CP even though his MRI was
fine, what was going on there....he still had a lot of the arm
tightness so we didn't know too if it was...who knows.
#00:14:46-2#

I: Okay, so, the PT stopped after about a year, at age 1.
Still the OT then? #00:14:54-0#

P: Yes, still the OT. #00:14:56-7#

I: and she still worked with feeding? #00:15:00-7#

P: Yep, we worked a lot with feeding. He still was only
eating certain things and this time his weight started to
decline. He's always been smaller, but it was getting to
where his line....he wasn't making a whole lot of growth and
he was actually diagnosed with "failure to thrive", and they
APPENDIX I. CATEGORIES TO THEMES PROCESS

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### Early Intervention
- **RQ1**
  - Fighting for Services
  - Support by Family & Friends
  - Knowledge is Power
  - Going Elsewhere
  - Frustration
  - Flexible scheduling
  - Misaligned Vision
  - Parent Engagement
  - Sales in the process
  - Affirming parent
  - Staff seeing worker as parent
  - Ample time for communication
  - Lack of SC skills
  - Lack of SC follow-through
  - Dissatisfied with service delivery model
  - SC Helpful

### Transition
- **RQ1**
  - Meetings vs. Process
  - Lack of options
  - Child-level prep
  - Placement disagreements
  - Questions addressed by person parent trusted most
  - Lack of engaging the parent
  - Parent vs. home visit
  - Conflict w/ transportation
  - Filling
  - Power through who you know
  - In the best interest of the district
  - Threats to gain services
  - The Silent Team
  - Frustration
  - Not knowing what to expect
  - Power of the familiar
  - Anxiety for child
  - Being Dropped
  - Delay in PreK Services
  - No discussion of PreK eligibility in
  - Confusion
  - On my own
  - Confident in receiving teacher
  - Power of the familiar
  - Conflict Nurse
  - Involved in decisions
  - Preparing parents for IEP

### Preschool
- **RQ1**
  - Frequent Notes Home
  - Going Elsewhere
  - Frequent progress reports
  - Disagreement on progress
  - Trust building related to staff
  - Lack of engaging parent
  - Communication breakdown
  - Frustration
  - Misaligned vision
  - Power through what you know
  - Respect
  - Parent felt disconnected
  - Relationships are Repairable
  - Parents wanting to implement interventions from school to home
  - Monthly meetings
  - Feeling rushed in communications
  - Trust in PreK team
  - Positive Communication
  - Teacher as Friend
  - Disagreement in need for Private agency
  - Power of the familiar

---

### Comment [AK1]: Themes
- Knowledge is Power
- Support by Family & Friends
- Going Elsewhere
- Dissatisfied with Service delivery model
- Misaligned Vision
- Parent Engagement
- Being in the process

### Comment [AK2]:

#### Themes:
- Role of the parent changer
  - Lack of engaging parent
  - Feeling disconnected
  - Parents want to implement interventions from school to home
- Communication
  - When it breaks down
  - When it remains strong
- Trust
  - Building Trust
  - Power of the familiar

### Comment [AK3]:

#### Themes:
- Content
  - Placement disagreement
  - "Fight"
  - Frustration
  - The silent team
  - Staff not prepared for child (stress/conflict)

#### Transition Aids:
- Power through who you know
- Threats to gain services
- Power in the familiar
- Preparing Parents for Final IEP

#### Underlying Emotions
- Frustration
- Confusion
- Anxiety for the Child
- Negative-case: Confidence
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<td>Many professionals involved with family</td>
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<td>Vivid memories</td>
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<td>All working together as a team</td>
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<th>Comment [AK2]:</th>
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<tr>
<td>Themes:</td>
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<td>Communication</td>
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<td>Systemic Commitment towards Child &amp; Family</td>
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<tr>
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<th>Comment [AK3]:</th>
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<tr>
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