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A Study of Family Centered Help Giving Practices in Early Intervention

Christian Grygas Coogle
A STUDY OF FAMILY CENTERED HELP GIVING PRACTICES IN EARLY INTERVENTION

By

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ABSTRACT

The purpose of this qualitative study is to investigate the early intervention experiences of mothers who have a young child at risk for an autism spectrum disorder (ASD). More specifically, the goal was to explore the family centered help giving practices mothers identify and how these practices affect their early intervention experiences. Five mothers who have a child under the age of 3 years identified as being at risk for an ASD and their service providers participated. Data were collected through observations, interviews, and document analyses. Results of the qualitative analysis suggest 1) asset based attitudes and interpersonal skills of practitioners and provisions for family choice and collaboration lead to positive experiences of mothers who have a young child at risk for ASD; 2) asset based attitudes lead to family progress and competence; 3) effective partnerships between families and providers are developed through provider attributes and communication techniques; and 4) satisfaction with early intervention services results from practitioner responsiveness to help families access resources and facilitate child development. Implications of the results for future research, service provision, and personnel preparation are discussed.
CHAPTER ONE

INTRODUCTION

According to the Data Accountability Center (IDEA Part C Child Count, 2010), in the fall of 2009, 353,028 infants and toddlers in the United States received early intervention services in accordance with the reauthorization of the Individuals with Disabilities Education Act of 2004 (IDEA; US Department of Education, 2004). Early intervention services have been a part of IDEA since 1986 when Congress established the early intervention program in recognition of "an urgent and substantial need" to enhance the development of infants and toddlers with disabilities; decrease educational expenses by minimizing the need for special education through early intervention; diminish the likelihood of institutionalization; expand independent living; and enhance the capacity of families to meet their child's needs (US Department of Education, 2004).

Research indicates early intervention facilitates positive outcomes by enhancing the environment in which the child lives (Talay-Ongan, 2001). The Center on the Developing Child at Harvard University (2011) describes scientific evidence which reveals children are especially receptive to intervention early in life as this is when rapid development of the brain occurs. The environment critically affects how young children progress. Enriching experiences have positive outcomes on development while high stress environments can lead to delays in development (Barlow, Parsons, & Stewart-Brown, 2005; Webb, Monk, & Nelson, 2001).

During the crucial first three years of life, early intervention produces long lasting benefits; the earlier the intervention, the more sustainable the results (Gwynne, Blick, & Duffy, 2009). Early intervention impacts developmental domains including cognitive, communication, adaptive, psychosocial, physical, and self-help. Early intervention influences the quality of life by preventing additional developmental delays from manifesting and diminishes current delays in development (Barnett, 1995; Guralnick, 1997; Talay-Ongan, 2001; Yoshikawa, 1995). In addition to affecting the child, early intervention impacts the family. Intervention early in life supports the family and enhances interactions among family members (Dunst, Hamby, Trivette, Raab, & Bruder, 2000).

While researchers have proven the necessity of early intervention, these services go beyond serving the child in isolation. Researchers recognize that families should be at the core
of intervention. Early intervention should evolve around the family opposed to the child or service provider (Talay-Ongan, 2001). Because early intervention is crucial for the child and family, it is vital to understand key elements that make up effective intervention. One fundamental element is family centered services.

**Family Centered Practices Defined**

Family centered services have been a descriptor of intervention since the 1960s (Bruder, 2000). In 1986, the Individuals with Disabilities Education Act (IDEA) was reauthorized and added Part C services, serving infants and toddlers with disabilities and providing direct services and support for families and children. During the 1980s, the early intervention community adopted the principles of family centeredness. By the 1990s, family centered, early intervention focused on three principles: family strengths, family choice, and collaboration among professionals and families.

Allen and Petr (1996) reviewed the literature across social sciences and defined family-centered services by identifying five key components. These five components include family as the unit of attention, family choice, family strengths, family professional relationships, and individualized family services. The family as the unit of attention is exemplified by considering individual family needs (Epley, Summers, & Turnbull, 2010). Family choice is allowing the family to make decisions regarding the services they are receiving. Additionally, recognizing family strengths is critical in order to empower families. The fourth element of family centeredness is the family professional relationship that encompasses the partnership between the family and the professional. The final element is individualizing family services by matching the provided services to the unique needs of the family. After examining the literature, Epley, Summers, and Turnbull (2010) noted that these indicators are evidence-based practices.

Furthermore, a comprehensive description of family centered early intervention is apparent in the professional literature (Farrell, 2009). Key components include treating families with dignity and respect (Dunst, 2002; Dunst, et al., 2000; Hemmeter, et al., 2005; Turnbull, Turbiville, & Turnbull, 2000); providing individual services in order to address the unique needs of families (McWilliam, Tocci & Harbin, 1998; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005; Trivette & Dunst, 2005); focusing on the strengths of families (Dunst, Hamby, & Brookfield, 2007; Jung & McWilliam, 2005; Neisworth & Bagnato, 2000; Park & Turnbull, 2003; Trivette & Dunst, 2005); considering family expertise, involvement, and decision making.
(Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Crais, Roy & Free, 2006; Hemmeter et al., 2005; Park & Turnbull, 2003; Summers, Hoffman, Marquis, Turnbull & Poston, 2005; Trivette & Dunst, 2005; Turnbull et al., 2005; Turnbull et al., 2007); utilizing effective communication (Dunst et al., 2007; Jung & McWilliam, 2005; McWilliam et al., 1998; McWilliam, Young, & Harville, 1996; Neisworth & Bagnato, 2000); and implementing services in the natural environments and routines (Bailey et al., 1998; Dunst, 2007; Jung & McWilliam, 2005).

Problem Statement

Although numerous recommendations have been made regarding family centered practices, family experiences and perceptions of these practices have been inadequately investigated. Researchers have explored family early intervention experiences by using diverse methodologies, but these studies do not sufficiently address the experiences of families who have children at risk having an autism spectrum disorder, and how these families perceive the services they are receiving. Even more limited is research regarding families who have a child at risk for autism spectrum disorder and their experiences with and perceptions of family centered practice.

Research Questions

The goal of this research is to expand what is known about family perceptions of early intervention experiences. Specifically, the purpose of this study is to gain a better understanding of the perceptions of mothers who have an infant or toddler who is at risk for an autism spectrum disorder regarding family centered, help giving experiences described by Trivette and Dunst (1998). The goal of this study is to inform early intervention practice and personnel preparation. The questions this study answers are:

1. In what way does the attitude of the practitioner affect mothers of children at risk for an autism spectrum disorder and their early intervention experiences with early intervention?
2. What types of practitioner interpersonal skills do mothers of children at risk for an autism spectrum disorder report as most effective in developing a partnership with the service provider(s)?
3. In what ways do mothers of children at risk for an autism spectrum disorder report the family being involved as choice makers?
4. In what ways do mothers of children at risk for an autism spectrum disorder report practitioner responsiveness impacts family early intervention experiences?
Significance of the Study

Because early intervention improves developmental outcomes and lays the foundation for academic success and positive family relationships, it is crucial to learn more about family experiences and perceptions of early intervention as it relates to a fundamental practice, family centered services. Understanding family experiences and perceptions of the services they receive has the potential to contribute to personnel preparation and early intervention practice.

Of special significance to this research are families who have young children at risk for an autism spectrum disorder. Because children are more frequently diagnosed with an autism spectrum disorder and are receiving these diagnoses younger in age than ever before, these families are more frequently receiving early intervention services (Henderson, 2009).

In order to enhance the capacity of early intervention programs to effectively collaborate with families, this research has the potential to contribute to the early intervention field by learning from mothers’ experiences with and perceptions of early intervention services. This research leads to a deeper understanding of the practices taking place, an increased understanding of mothers’ perceptions of early intervention services, and enhanced provider awareness of those aspects of services that mothers identify as most effective.

Theoretical Perspective

Bowen’s Family Systems Theory provides a theoretical framework for family centered practice. Within this theory, the strengths and needs of all family members are considered. Pang (2010) explains how Turnbull and Turnbull (2001) elaborated on this theory by describing the basic behaviors families demonstrate that should be key considerations in the services families receive (see Table 1). These include family characteristics, family functions, family interactions, and the family life cycle. Family characteristics include aspects to the family such as siblings, temperament, and disability. Family functions are family resources, the culture of the family, and family level of resilience. Family interactions are factors that promote or inhibit family functioning. Finally, the family life cycle consists of transitions and stages in life. The family systems theory has provided cause for an amplified focus on families as it highlights the impact the family has on the developing child.
The Family Systems Theory is the theoretical foundation of family centered practice. The contributions of this theory have influenced intervention practice since the family directly affects the developing child (Bruder, 2010). Additionally, the Family Systems Theory identifies the various aspects/systems of a family that impact the child including characteristics, interactions, functions, and life cycles. The Family Systems of each family are unique. Therefore, services should be based on the family as a whole. By considering family characteristics, interactions, functions, and life cycles, one realizes each family is a unique, complex system that must be understood to ensure early intervention services are family centered.

**Conceptual Framework**

The framework designed by Trivette and Dunst (1998) was used in this study. Trivette and Dunst (1998) reported that the ways in which intervention is provided to the family is as important as the intervention provided (see Table 2). The model includes family centered practices. Trivette and Dunst (1998) define two categories of family centered practices. These are relational and participatory practices. Together these form family help giving practices.

**Relational practices** are the behaviors associated with effective interaction such as compassion, effective listening, communication, and the practitioner’s ability to identify family strengths and sensitivity toward family beliefs and values. Relational practices are clustered into the groups of interpersonal skills and asset based attitudes. **Participatory practices** are those that actively involve family members. Practices such as decision-making, obtaining resources and supports, and flexibility are all components within participatory practices. Participatory practices are grouped into the categories of family choice and action and practitioner responsiveness. Participatory practices are more important than relational practices in improving parenting capabilities; however, both are essential to delivering effective intervention (Dunst et al., 2007).

Trivette and Dunst created a checklist to determine the extent to which practitioners use relational and participatory family centered help giving practices. This framework was used in
this study to explore family experiences and perceptions of early intervention as they relate to family help giving practices defined by Trivette and Dunst (1998).

Table 2

*Family Centered Help Giving Practices (Trivette and Dunst, 1998)*

<table>
<thead>
<tr>
<th>Relational Practice</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpersonal Skills</td>
<td>• Communicate clear and complete information in a manner that matches the family style and level of understanding</td>
</tr>
<tr>
<td></td>
<td>• Interact with the family in a warm, caring, and empathetic manner</td>
</tr>
<tr>
<td></td>
<td>• Treat the family with dignity and respect and without judgment.</td>
</tr>
<tr>
<td>Asset Based Attitudes</td>
<td>• Communicate to and about the family in a positive way</td>
</tr>
<tr>
<td></td>
<td>• Honor and respect the family’s personal and cultural beliefs and values.</td>
</tr>
<tr>
<td></td>
<td>• Focus on individual and family strengths and values</td>
</tr>
<tr>
<td></td>
<td>• Acknowledge the family’s ability to achieve desired outcomes</td>
</tr>
<tr>
<td>Participatory Practice</td>
<td>• Work in partnership with parents/family members to identify and address family-identified desires.</td>
</tr>
<tr>
<td></td>
<td>• Encourage and assist the family to make decisions about and evaluate the resources best suited for achieving desired outcomes.</td>
</tr>
<tr>
<td></td>
<td>• Seek and promote ongoing parent/family input and active participation regarding desired outcomes</td>
</tr>
<tr>
<td></td>
<td>• Provide family participatory opportunities to learn and develop new skills.</td>
</tr>
<tr>
<td>Practitioner Responsiveness</td>
<td>• Assist the family to consider solutions for desired outcomes that include a broad range of family and community supports and resources.</td>
</tr>
<tr>
<td></td>
<td>• Support and respect family member’s decisions.</td>
</tr>
<tr>
<td></td>
<td>• Work with the family in a flexible and individualized manner.</td>
</tr>
<tr>
<td></td>
<td>• Offer help that is responsive and matches the family’s interests and priorities.</td>
</tr>
<tr>
<td></td>
<td>• Assist the family to take a positive, planned approach to achieving desired outcomes.</td>
</tr>
</tbody>
</table>

**Definition of Terms**

The following terms and definitions are provided to assist the reader in understanding the perspective from which the researcher has developed this study. Unless otherwise noted, the researcher has formed the definitions.

- **Family centered early intervention services:** In the context of this research, family centered early intervention services are those practices centered on the family. This research focused on the family help giving practices defined by Trivette and Dunst (1998).

- **At risk for an Autism Spectrum Disorder (ASD):** The definition of an autism spectrum disorder is a range of neurodevelopmental disorders that affect multiple developmental domains that may include social relatedness and reciprocity, nonverbal and verbal communication, and cognitive and adaptive functioning (Rodger, 2008). A child is at risk for an ASD when they begin to show a lack of reciprocity, nonverbal and verbal communication, and/or cognitive and adaptive functioning.
• **Early intervention services:** In this research early intervention services refers to a variety of intervention services provided to children ages birth to three.

• **Young children:** For the purpose of this research, young children are those who are age birth to 3 years old, encompassing infants and toddlers.

• **Professional:** For this context, professionals include early interventionists such as infant toddler developmental specialists, speech language pathologists, physical therapists, and occupational therapists. The terms service provider, provider, early intervention provider, intervention provider, and early interventionist are used interchangeably in this paper and refer to the professional providing early intervention services.

**Limitations, Delimitations, and Assumptions**

This study has the following limitations, delimitations, and assumptions:

1. The study was limited to participants who receive services in one local agency – Children’s Corner.

2. The study was limited to children aged birth to three who currently receive early intervention services.

3. It was assumed all information provided by the mother is true and provided to the best of her ability.

**Summary**

It is critical to continue learning about family experiences with and perceptions of early intervention services (Trivette & Dunst, 2004). Most research regarding family early intervention experiences has focused on specific intervention programs or aspects of early intervention and included children with diverse disabilities in the same study. To understand how early intervention providers can best collaborate with families, it is essential to learn more about family experiences with and perceptions of early intervention services, particularly their experiences and perceptions of family centered services. It is important to learn more about families who have young children at risk for an ASD, as these children are more frequently receiving services than ever before. Therefore, the purpose of this study is to explore how the attitude of the practitioner affect mothers’ early intervention experiences, how practitioner interpersonal skills help to develop a partnership with mothers, how mothers are involved as choice makers, and how practitioner responsiveness impacts mothers’ early intervention
experiences with early intervention. Mothers of children birth to 3 years who are at risk for an autism spectrum disorder participate.
CHAPTER TWO
LITERATURE REVIEW

The purpose of this study was to learn about perceptions mothers of young children at risk for ASD have regarding early intervention services. This chapter is a review of existing family centered models and the literature as they relate to the study. This chapter includes a discussion of (a) family centered models, (b) reported family experiences with early intervention, (c) participants who have been included in family experience research, (d) methodologies and measures used to research family experiences, and (e) family experiences measured. This review encompasses published research from 1993 to 2011.

Family Centered Models

Table 3 presents information regarding the family centered models reviewed. The models come from a variety of disciplines including health, criminal justice, welfare, and educational frameworks. This review is not exhaustive, but provides evidence of the importance of family-centeredness as its approach is supported in a diversity of disciplines.

Health Models

In addition to educational focused family centered models, others come from health services. Health care models were developed to support families who have children with health care needs. These family centered models are the Wisconsin Model, Brief Negotiation Approach, Personalized Pediatric Coordinated Services, and REACH.

The Wisconsin Model was developed to guide practitioners when they deliver genetic counseling to families who have an infant who tests positive for cystic fibrosis (Tluczek et al., 2011). The purpose of this model is to decrease family stress, facilitate parent understanding, increase the family’s ability to use the information they receive regarding genetics, and to enhance the family’s experience with genetic counseling. The strategies of this model include creating a comfortable environment, addressing both the emotional and information needs of the family, and developing a plan.

Another model developed for healthcare services is the Brief Negotiation Approach (Tyler & Horner, 2008). This model is for families who are in need of healthcare supports. The purpose of this model is to promote health. The strategies include being client centered, establishing a partnership with the client, developing understanding between current behavior
and health goals, exploring feelings regarding the new behaviors, prompting self-motivating
statements, refraining from unwanted advice, and supporting self-efficacy. Practical approaches
include collaborative agenda setting, allowing the clients to make decisions and select goals,
sharing information, and exploring family interests, confidence levels, and readiness to change.

Personalized Pediatric Coordinated Services (1996) is designed for families who have
children with chronic health care needs. The goal of this model is to provide family centered,
community based, and coordinated services for families. Personalized Pediatric Coordinated
Services includes three strategies. These are family centered services coordination, specialized
respite care, and community development.

Rural Efforts to Assist Children at Home (Freedman, Pierce, & Reiss, 1987; REACH)
was developed to support families at home who have children with health care needs. The goal
of REACH is to provide an effective case management model for families. The strategies in this
model include coordinating services for families, providing training to the family, and supporting
families.

**Criminal Justice Models**

Criminal justice intervention models that focus on the family have been created. The
Bradley Fire Safe Families Model is designed for families who have children who are considered
fire starters (Baretto, Boekamp, Armstrong, & Gillen, 2004). The purpose of this model is to
decrease risks associated with repeat fire starting offenders. Family centered interventionists
utilizing this model should use existing resources, develop skill based procedures that treat fire
competence as a part of a broader repertoire of emotional coping strategies developing in the
contest of the parent-child relationship, administer intervention in a family centered format,
develop a fire specific intervention, make note of all protocols, ensure the program is accessible,
and enhance existing behavior health treatment services.

**Welfare Models**

Welfare models are those designed to support the family who are personally involved in a
type of family crisis. These include the Crisis Intervention Model, FAMILIES, the Family
Treatment Model, and the Two Generation Program.

The Crisis Intervention Model emphasizes the importance of immediate intervention, as
families are most susceptible to change within 24 hours of a crisis (Nelson, Landsman, &
Deutelbaum, 1990). This model also focuses on behavior modification that supports families.
The specific strategies included are an efficient response to referral, in home services, behavioral support using psycho-educational techniques, and support services.

A similar model is FAMILIES that is designed for out of home adolescents. It was created to provide an alternative to out of home placements. This model provides in home services, focuses on the subsystems of the family (i.e., family relationships), and provides a wide range of interventions.

Another related model is the Family Treatment Model also referred to as Intensive Family Services. This was developed with the goal of supporting families to meet their needs in a more functional way. The strategies within this model include looking at the family as a whole, going through different phases of intervention including assessment, treatment, and termination; and using a variety of therapies.

The Two Generation Program is another model that is family focused (Hosley, 2000). The purpose of this program is to attack poverty from multiple angles and improve family conditions by providing the parents specific training such as job training or adult education. Additionally these programs typically encompass services to enhance parenting skills, alleviate depression, improve self-esteem, and increase family involvement.

**Educational Models**

Educational models focus on aspects of child development. These include Family Support Groups, Two Generation Program, and 21st Century Schools. Additional models include Touch point, Double ABCX, True Directions, CREFT, Interdisciplinary Practice in the Community, LIFT, Family Focused Intervention, and Family Oriented Models.

The purpose of Family Support Groups model is to alleviate family stress, promote family abilities to nurture their child, and locate resources to strengthen the family (Hosley, 2000). Family support groups typically serve children less than three years of age through home or center visits. Specific aspects of the family support model include developing partnerships with families, empowering families, being cultural competent, and building on parent strengths.

An additional educational model is the 21st Century School Program (Hosley, 2000). The purpose of this model is to provide high quality care to children birth to 12. There are three outreach goals including locating day care providers in the district, a resource and referral system to help with community supports such as health care, and a home based family support program.
The Touch Point Model was developed for families with young children (Tyler & Horner, 2008). The goal is to promote physical, social, emotional, and cognitive outcomes in young children by partnering with families. This framework includes valuing the relationship among team members, using comprehensible language, focusing on the parent child relationship, valuing disorganization by looking for opportunities to facilitate goal achievement, recognizing the beliefs and biases of interventionists, and being willing to communicate about issues beyond the traditional role of the interventionists. This model also includes assumptions regarding the family and intervention provider. Assumptions are that the parent is the expert who has strengths, wants to do the right thing with their child, has something to share at every developmental state, and has ambivalent feelings. In addition, the model recognizes that parenting is a process. Assumptions about interventionists are that each interventionist is the expert within the area of his or her practice setting, wants to be competent, and needs to reflect on their contribution to parent-provider relationships.

The Double ABCX Model is an educational model that is designed for families who have young children receiving early intervention (Xu, 2008). The purpose of this model is to develop meaningful goals by using a family centered approach. This model identifies four aspects to consider. These include family concerns, family resources, and family priorities, along with strategies to support families reach their desired outcomes.

The True Directions Model is designed for families who have children with an Individualized Education Plan (Chambers & Childre, 2005). The goal of this model is to ensure person centered planning takes place during meetings. This goal is met by using family, child, and professional forms. The family form prompts the family to identify resources, dreams, and goals for their child. The child form prompts the child to indicate his or her preferences. The professional form is a guide that helps the professional take the information from the family and child form to ensure person centered planning.

Another education model is the CREFT Model, designed for young children receiving intervention (Vangalder, 1997). The goal of CREFT is to enhance the caregiver’s ability to promote child development. The strategies within this model include training the caregiver to be the agent of change by learning skills from the professional and applying the newly learned skills in role play practice sessions.
The Interdisciplinary Practice in the Community Model is designed for families who have children with special needs (Prelock, Beatson, Contompasis, & Bishop, 1999). The purpose is to provide family centered interdisciplinary community based assessment and support. The strategies are delivered during the intake process where assessment is conducted in the community. Another strategy is to provide information and resources for the family through an interdisciplinary report and follow-up meeting.

Project LIFT (Sampson, 1988) is designed to provide rural families of children with special needs family focused, home based intervention. The strategies include working with families in their specific community to develop the IFSP, identifying resources, providing home based intervention, and utilizing a transdisciplinary approach.

The Family Focused Intervention Model was developed for families who have children with disabilities (Bailey, 1986). The purpose was to ensure families receive individualized services. The strategies include assessing family needs, determining family goals, implementing services based on the family, and evaluating effectiveness of the services provided.

**Summary**

The models reviewed are within the disciplines of health care, welfare, criminal justice, and education. Although these models come from different contexts, they conceptualize and utilize similar practices to ensure interventions are family centered. Common elements within these models include a focus on the family as a whole in order to meet family needs and goals. The models recognize the uniqueness of each family and the role the family has in intervention. As such, family centered services as those that recognize the family as the constant in the child's life, facilitate collaboration, share information with parents regarding their children's care and development, implement practices that are comprehensive, recognize family strengths, respect different ways of coping, understand and incorporate the developmental needs of families into the delivery systems, encourage and facilitate parent-to-parent support, and assure that the design of delivery systems is flexible, accessible, and responsive to family needs (Shelton, Jeppson, & Johnson, 1989). In addition, family centered services have been described as those that enhance a sense of community, utilize a collaborative approach involving the family, protect family integrity, strengthen family functioning by allowing family members to choose their level of decision making, and provide practical services (Bailey, Buyssee, Edmondson, & Smith, 1992; Dunst, Trivette, & Hamby, 1991; Lee, 1993).
### Table 3

**Family Centered Service Models**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Population</th>
<th>Purpose</th>
<th>Components</th>
</tr>
</thead>
</table>
| Baretto, Boekamp, Armstrong, & Gillen, 2004 | Bradley Fire safe Families          | Juvenile Fire starters                   | Decrease the risks associated with repeat fire starting | • Use existing resources  
• Develop skill based procedures that treat fire competence as a part of broader repertoire of emotional coping strategies developing in the contest of the parent-child relationship  
• Administered in a family centered format  
• The assessment should be fire specific  
• All protocols should be written in a manual  
• Program should be accessible  
• Should be designed to enhance existing behavior health treatment services |
| Bailey, 1986             | Family Focused Intervention          | Families with young children who have disabilities | The purpose is to individualize family services       | • Assess family needs  
• Determine family goals  
• Implement services that focus on the family  
• Evaluate effectiveness                                                                                                                                  |
| Bailey, Buyssee, Edmondson, & Smith, 1992 | Family Oriented Services          | Families who are receiving early intervention | Ensure that families are receiving family oriented services | • Children and families are inextricably intertwined. Intervention with support to families almost invariably influences children.  
• An intervention that involves and supports families is likely to be more powerful than one that focuses exclusively on the child  
• Family members should be able to choose their level of decision making and service delivery  
• Professionals should attend to family priorities for goals and services                                                                 |
| Chambers & Childre, 2005 | True Directions Model                | Families who have an individualized education plan | Implement person centered planning in IEP meetings   | • Utilize family, student, and team forms  
• Family forms identify life connections, dreams, and goals. Life connections are people involved with the child and their role. Dreams are the dreams the family has for their child. Goals are the short-term measures to meet the dreams.  
• Student forms include a who I am section where they indicate their friends, what they like to do, and what they would like to learn and be when the grow up. Preferences are the people they like to spend time with, what they like to do, what makes them happy, mad, sad, or afraid. They also discuss their favorite thing about themselves and what they are good at.  
• The team form prompts the clinician to consider life connections or the relationships which the family identifies. It also prompts the clinician to identify target skills in the natural environment, a present level of performance, and prompts team members to share information for their experiences regarding what supports child learning, consider family and child dreams and goals, and where, who and when the services will take place  
• These forms are used as the foundation for the IEP meeting to ensure person centered planning is the approach used, and that a person centered plan is put into action. |
<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Population</th>
<th>Purpose</th>
<th>Components</th>
</tr>
</thead>
</table>
| Dunst, Johnson, Trivette, & Hamby, 1991      | Family Oriented Services                   | Families who are receiving early intervention   | Ensure that families are receiving family oriented services            | • Enhancing a sense of community  
• Mobilizing resources and supports  
• Shared responsibility and collaboration  
• Protecting family integrity  
• Strengthening family functioning  
• Providing proactive human service practices |
| Freedman, Pierce, & Reiss, 1987              | Rural Efforts to Assist Children at Home   | For families with children who have health care needs | Case management model for children with health care needs             | • Coordinating health, social service, and educational needs of young children and their families  
• Provide families training to take the role of primary case manager  
• Support families                                                                                                                                                                                                                   |
| Lee, 1993                                    | Family Oriented Services                   | Families who are receiving early intervention   | Ensure that families are receiving family oriented services            | • Include families at program and systems levels in decision making, planning, assessment, and service delivery  
• Develop services for the whole family and not just the child  
• Guide goals and services by families' priorities  
• Offer choices and respect families' decisions regarding their level of Participation                                                                                                                                               |
| Nelson, Landsman, & Deutelbaum, 1990         | Crisis Intervention Model                  | Families at risk for having children removed from their home | Based upon crisis intervention theory, this model provides intervention within 24 hours of crisis per the crisis intervention theory; this is when families are most susceptible to change. Social learning theory is a foundation of this model as it emphasizes the importance of behavior modification. | • Efficient response to referral  
• In home services  
• Psycho-educational theory  
• Support services (i.e., transportation)                                                                                                                                                                                                 |
| Nelson, Landsman, & Deutelbaum, 1990         | Home Based Model (FAMILIES)                | Out of home adolescents                          | Designed to provide an alternative to the out of home placement of adolescents. | • In home services  
• Attention to the subsystems within the family (i.e., relationships)  
• Wide range of interventions                                                                                                                                                                                                 |
| Nelson, Landsman, & Deutelbaum, 1990         | Family Treatment Model (Intensive Family Services) | Support families when a child is about to be removed from a home | Based on Family Systems Theory, the goal is to support families meeting their needs in a functional way | • Family as a whole  
• Phases include assessment, treatment, and termination  
• Variety of therapies                                                                                                                                                                                                                   |
| Sampson, 1988                                | Project LIFT                               | Children with special needs who live in rural communities | Designed to provide family focused, home-based intervention           | • Development of the IFSP  
• Coordination to support families identifying and obtaining resources  
• Home based intervention  
• Transdisciplinary approach                                                                                                                                                                                                 |
| Tluczek, Zaleski, Stachowi-Hietpas, Modaff, Adamski, Nelson, Reiser, Ghat & Josephson, 2011 | The Wisconsin Model                      | Genetic counseling for cystic fibrosis newborn screening | Designed to minimize parent distress, facilitate parent understanding, increase parent ability to use genetic information, and enhance the family experience with genetic counseling | • Creating an inviting environment  
• Address the emotional needs of the family  
• Address information needs of the family  
• Develop a plan                                                                                                                                                                                                                   |
<table>
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<tr>
<th>Authors</th>
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</table>
| Tyler & Horner, 2008     | Touch point Model            | Young children whose development is shifting | To promote physical, social, emotional, and cognitive outcomes in young children by partnering with families.                                                                                             | • Value the relationship among team members  
 • Use understandable language  
 • Focus on the parent child relationship  
 • Value disorganization  
 By looking for opportunities to facilitate goal achievement  
 • Recognize the beliefs and biases of interventionists  
 • Be willing to communicate about issues beyond the traditional role of the interventionists  
 • Assume the parent is the expert, has strengths, wants to do the right thing with their child, have something to share at every developmental state, have ambivalent feelings, and that parenting is a process  
 • Assumptions about interventionists are that each interventionist is the expert within the area of his or her practice setting, interventionists want to be competent, and need to reflect on their contribution to parent-provider relationships |
| Shelton, Jeppson, & Johnson (1989) | Family Oriented Services | Families receiving intervention services | Ensure that families are receiving services which are family oriented                                                                                                                                   | • Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuate  
 • Facilitating parent/professional collaboration  
 • Sharing unbiased and complete information with parents about their children's care on an ongoing basis in an appropriate and supportive manner  
 • Implementing appropriate policies in programs that are comprehensive and  
 • Provide support to meet the needs of families  
 • Recognizing family strengths and individualities and respecting different methods of coping  
 • Understanding and incorporating the developmental needs of infants, children, adolescents, and their families into health care delivery systems  
 • Encouraging and facilitating parent-to-parent support  
 • Assuring that the design of health care delivery systems is flexible,  
 • Accessible, and responsive to family needs |
| Tyler & Horner, 2008     | Brief Negotiation Approach   | Families in need of healthcare support. (Weight, exercise, sleep, and nutrition) | Adaptation of the motivational interview. It should be used in healthcare setting to promote health and lifestyle behavior.                                                                             | • Client centered  
 • Establish partnership with client  
 • Develop an understanding between current behavior and goals  
 • Explore and resolve ambivalence about practicing new behavior  
 • Elicit statements that are self motivating  
 • Refrain from unsolicited advice  
 • Resistance  
 • Support self efficacy  
 • Approaches in practice include: collaborative agenda setting, decisions and goals are up to the clients, explore interest, confidence, and readiness to change, and exchange information |
Table 3 Continued

<table>
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<tr>
<th>Authors</th>
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| Vangalder, 1997              | The CREFT Model              | Young children receiving intervention | Child relationship enhancement family therapy is used to teach the caregiver skills to use with the child to promote development. | • Child and caregiver are involved in play therapy  
• Therapist trains and empowers the caregiver as the primary agent of change for the child.  
• The caregiver learns therapeutic skills from the professional  
• The caregiver applies the skills using role play practice sessions |
| Xu, 2008                     | Double ABCX Model            | Children receiving early intervention | Developing meaningful IFSP outcomes by using a family centered approach | • Identify family demands or concerns  
• Access to family resources (formal and informal supports)  
• Evaluate family priorities based on family perceptions  
• Family adaptation with coping strategies for reaching family outcomes |
| Pediatric Coordinated Services, 1996 | Personalized Pediatric Coordinated Services Model (PPCS Model) | For families who have children with chronic health care needs | This model is designed to provide family centered, community based coordinated services for families. | • Family centered service coordination  
○ Resources and concerns  
○ Assisting the family to locate and coordinate services  
○ Monitoring the quality of services  
• Specialized respite care services  
○ Recruitment and training of professionals  
○ Matching professionals to families  
○ Monitoring quality of services  
• Community development through training, team consultation, and technical assistance  
• Training, team consultation, and technical assistance to agencies working with young children to develop responsive community programs and activities that promote inclusion of all children in the community |

Reported Family Experiences with Early Intervention


Table 4 summarizes the studies and documents the broad range of experiences families have had with early intervention. Family experiences with early intervention are diverse (see Table 4). Families have indicated positive and negative experiences with early intervention services. When families have shared information with researchers, new insights have been developed regarding family experiences with early intervention. The research reviewed
immediately below does not include research limited to families of young children at risk for or identified as having ASD. Research including families of young children with ASD is reviewed in a separate section and compared to the research that studies families of young children with disabilities/developmental delays outside of ASD.

**Positive Experiences**

Families have indicated successful interactions with early interventionists, identifying behaviors and affective characteristics of early interventions that contribute to positive experiences with early intervention. Attributes of effective early interventionists include a nonjudgmental stance; creativity; consistency; a sincere and caring spirit; sound professional practice; good communication skills; a supportive and responsive attitude; and the ability to relate to parents and children (Applequist & Bailey, 2000; Hurtubise & Carpenter, 2011; Minke & Scott, 1995; Tocci et al., 1997; Wade et al., 2007). Other positive qualities of intervention providers are respect for the family and the ability to listen to their opinions (Bailey et al., 2003). Families also emphasized the importance of individualized services and the professional’s level of confidence in the family (Hurtubise & Carpenter, 2011).

Research suggests parents value their role as a decision maker. Specifically, families have indicated being involved in team meetings and developing child goals as positive aspects of early intervention (Applequist & Bailey, 2000; Bailey et al., 2003; Harrison et al., 1996; Mahoney & Filer, 1996).

Participants in early intervention research have discussed feeling satisfied with specific aspects of the services they are receiving. Aspects that have created family satisfaction include feeling supported and as though their needs have been met and having an understanding of their child’s needs, services, and rights (Dempsey & Carruthers, 1997; Epley et al., 2011; Otero, 2004; Tocci et al., 1997; Wade et al., 2007). In addition, family focused intervention is reported to be a positive aspect of services (Mahoney & Filer, 1996). Further, parents appreciate home-based services, learning about the strategies implemented with their child, and the flexibility of services (Mahoney & Filer, 1996; Tocci et al., 1997).

Families have indicated feeling supported and these supports contribute to the positive experiences of families. These supports are related to family and more formal supports (Bailey et al., 1999). For example, families have suggested feeling as though they had help when initially expressing concerns about their child (Bailey et al., 2003). Parents have said they appreciate the
financial support that early intervention provides (Tocci et al., 1997). Additionally, families feel little effort was needed to obtain intervention services (Bailey et al., 2003). Transportation and learning about other services are specific resources families have suggested as helpful (Wade et al., 2007).

**Negative Experiences**

Families have, however, indicated experiences in which they have been unsatisfied. These include aspects such as inadequate services, a lack of resources, and a lack of family involvement. Parents also have reported concerns about specific intervention programs and specific service providers. Some families have reported difficulty in obtaining intervention services and a lack of resources (Bailey et al., 2003). Parents have indicated feeling as though the services they are receiving do not match the need’s of their child (Otero, 2004; Shannon, 2004). Families have expressed dissatisfaction regarding the wait time between diagnosis and referral and have felt assessment procedures delay services (Wade et al, 2007). Parents have described the services they receive as fragmented (Tocci et al., 1997).

In addition, families have suggested a lack of resources. For example, families have reported inadequate informational, financial, or social supports (Bailey et al., 2003; Hurtubise & Carpenter, 2011; Jackel et al., 2008; Mahoney & Filer, 1996; Otero, 2004; Shannon, 2004; Wade et al., 2007; Wesley et al., 1997; Wilcox et al., 2006). Parents have discussed that a lack of information caused them to conduct their own research regarding intervention strategies to ensure their child is receiving appropriate services (Jackel et al., 2008). Certain families were unaware of a written plan for goals and services and an intervention coordinator (Bailey et al., 2003). Families have said they have a lack of choices or difficulty in making choices because of a lack of information (Wesley et al., 1997).

Participants of some studies shared challenges experienced with specific intervention programs (Haring & Lovett, 2001). One study focused on the home-based applied behavior analysis intervention. These difficulties were specific to working with the local educational authority, maintaining their personal and family life, and collaborating with therapists and program administrators. Other challenges were related to incorporating strategies into their daily lives.

Families also have reported challenges experienced with early intervention personnel (Haring & Lovett, 2001; Wade et al., 2007; Wesley et al., 1997). Parents have suggested feeling
as though their early intervention provider did not have the knowledge necessary to meet their child’s needs, were not available, and did not know how to provide intervention in daily routines (Haring & Lovett, 2001). Families indicated frustration with the actions and inactions of interventionists (Wade et al., 2007). Families expressed confusion when working with multiple intervention providers (Wesley, 1997).

Caregivers have reported a lack of involvement with the services their family is receiving. Specifically, families have expressed a lack of involvement in assessment and the process. Families have identified wanting to have a more active role in the assessment procedures of their child (Applequist & Bailey, 2000). In addition to assessment procedures, families have identified a lack of involvement in creating the IFSP (Harrison et al., 1996). Specifically, families reported a lack of participation in noting their priorities within the IFSP. Additionally, families have described having little input regarding the services their family receives (Bailey et al., 2003).

Noteworthy, demographic information has been related to family experiences with early intervention. Families of children with developmental delays reported more frustration with accessing services when compared to families of children with an established condition or who are identified as at risk (Bailey et al., 2003). Also of particular concern is the finding that ethnicity, language spoken at home, eligibility of child, gender of child, household income, number of adults in a household, and education levels of parents have been associated with intervention experiences (Bailey et al., 2003; Sontag, 1994). These differences include families feeling dissatisfied regarding certain early intervention aspects that include help from early intervention staff regarding family concerns, difficulties obtaining intervention services, unknowledgeable regarding the Individual Family Service Plan, little input, and services which do not match the needs of the family.

Experiences of Families Who Have a Young Child with an Autism Spectrum Disorder

Research is limited regarding early intervention experiences of families who have a child with an autism spectrum disorder (Beals, 2004; Grindle, Kovshoff, Hastings, & Remington, 2009; Patterson & Smith, 2011; Rodger et al., 2008; Webster et al., 2004). These studies have had specific purposes which include families sharing their personal experiences with making decisions, specific intervention programs, and rationale for dissatisfaction with services. The
results of these studies suggest both positive and negative aspects to early intervention services from the perspective of the family.

**Positive experiences.** Families who have young children identified with an autism spectrum disorder have had positive experiences with early intervention. One family shared their personal experiences in decision making (Beals, 2004). This family indicated helpful aspects of intervention that included resources, home visits, and intervention strategies.

Other families who have young children with an autism spectrum disorder have shared their experiences with a home based ABA program (Grindle et al., 2009). Practical benefits included growth in language, communication, social skills, and play skills. These families also discussed supports in the home, social networks, and improved family interactions as positive aspects of this program. Improved interactions occurred among siblings as they learned how to interact with one another. Parents felt that their interactions with the child with ASD improved because their child began communicating more.

Parents who have young children with autism have shared their experiences with the More Than Words intervention program (Patterson & Smith, 2011). Families viewed this program as a good starting point for families who have a young child with an autism spectrum disorder. They valued their level of engagement, the tools they were given to communicate, and child progress. Families also suggested positive experiences with other parents as this provided them with information and comfort.

Another program which families have identified positive experiences is the Early Intensive Intervention Program (Webster et al., 2004). Families who participated in this study valued the increase in their child’s communication, appropriate behavior, and the help provided. Families also identified flexibility in the services and a team approach as positive aspects to intervention services.

**Negative experiences.** Families who have young children with autism have identified negative experiences. One family indicated the difficulty they had with making decisions because they felt there are different beliefs in the most effective program for young children with autism (Beals, 2004). They felt that there are no agreements among autism professionals leading to inconclusiveness. This family identified feeling desperate for supportive services and the need for detailed, workable, and child friendly intervention.
Families who participated in the home based ABA program had difficulties with the local educational authority, therapists, and family relationships (Grindle et al., 2009). They indicated the educational authority was cautious as to whether they should receive services due to the cost. They reported therapists were unorganized, unknowledgeable, and unreliable. They also reported feeling like their privacy was reduced and their routines were disrupted. They had difficulty with family relationships as they felt siblings received less attention, and the child with autism missed social opportunities due to intervention.

Families who participated in the More than Words intervention expressed a need for explicit child and parent program expectations, sensitivity to the emotional and information needs of families, and more individualized intervention (Patterson & Smith, 2011). Parents suggested expectations were unclear and they were uncertain of the goals. Families felt like they were incapable of providing intervention services. Parents also identified unique emotional and information needs which were unmet that left them feeling confused. Families felt overwhelmed regarding intervention strategies and felt frustrated when they saw differences among children’s development. Parents suggested that each family’s unique needs should be considered such as how to provide information to working parents.

Parents who participated in the early intensive intervention discussed negative experiences that included the wait time between concerns and diagnosis and between assessment and placement, a lack of help once a diagnosis was given, feeling isolated, and managing intervention (Webster et al., 2004). In addition, these families had concerns regarding the expectations regarding the intervention program. Families found it difficult to relate to intervention providers when they were inflexible. They suggested this intervention took time to organize, and they expressed concerns regarding transition.

Families have identified the rationale for dissatisfaction with services (Rodger et al., 2008). Low satisfaction has been related to the level of adaptive functioning of the family. Families have suggested an increase in stress can impact family experiences with intervention. Parents indicate the relationship with the provider can lead to dissatisfaction with services. The amount and relevance of information provided to the family has the potential to cause dissatisfaction with services.

**Summary.** There are similarities and differences between studies that are specific to families who have young children with autism and those that are include other disability types.
Both groups of participants identify positive and negative experiences with intervention. Both groups of families identify supports as a positive aspect to intervention services such as services in the home and developmental progress.

Although there are some consistencies between these groups there are also differences. For example, families who have young children with an autism spectrum disorder identify specific developmental areas which concern them that include social emotional and communication development. These families also express specific needs for social networks and resources.

**Participants Who Have Been Included in Family Experience Research**

Participant quantity varied among studies from one to 3,339 families (See Table 4), depending on the research methodology and the focus of the study. That is if it was a quantitative survey, it had more participants, but if it was a qualitative case study, it had fewer participants.

Eligibility criteria for study participants varied. Families had children experiencing autism, hearing loss, developmental delays, and/or visual impairment (Beals, 2004; Grindle, 2009; Harrison et al., 1996; Jackel et al., 2010; Otero, 2004; Patterson & Smith, 2011; Rodger et al., 2007; Sontag, 1994; Webster, 2004). One study included children identified with varying developmental disabilities (Bailey et al., 1999). Children who were eligible for services because of a developmental delay, diagnosed condition, or were considered at risk participated in one study (Bailey et al., 2003). Additionally, children who were identified with one of multiple conditions such as Bronchopulmonary Dysplasia, Williams Syndrome, Prader Willi Syndrome, Down Syndrome, Cerebral Palsy, Spina Bifida, hearing loss, language delay, viral encephalitis, brain damage, or undiagnosed participated in one study (McBride et al., 1993).

Several studies, however, did not specify the type of disability experienced by the children (Applequist & Bailey, 2000; Bailey et al., 2003; Bjorck-Akesson & Granlund, 1995; Dempsey & Carruthers, 1997; Haring & Lovett, 2001; Hurtubise & Carpenter, 2011; Lovett & Haring, 2003; Mahoney, 1996; Minke & Scott, 1995; Shannon, 2004; Thompson, 1998; Tocci et al., 1997; Wade et al., 2007; Wesley, 1997). These researchers described child participants by indicating they were receiving early intervention services.
Methodology and Measures Used to Research Experiences

Study designs varied (see Table 4). These included both qualitative and quantitative methods in relation to family experiences with early intervention. Qualitative studies reviewed utilized designs and procedures such as naturalistic inquiry, focus groups, document analyses, observation, and case studies and analyses have included Content Analysis and Constant Comparative Analysis. All quantitative studies included a survey design. Researchers have conducted a variety of analyses to include Descriptive Statistics, Chi Square, Analysis of Covariance, and MANOVA. Surveys used in the studies were to assess parent perceptions of early intervention included the Client Satisfaction Questionnaire (CSQ; Larsen, Attkisson, Hargreaves & Nguyen, 1979), Orientation of Community and Agency Services (FOCAS; Bailey, 1991), Canadian Occupational Performance Measure (Law et al., 1998), and the Measure of Processes of Care (MPOC; King et al. 1995).

Some of these measures are considered reliable and valid. Authors of the CSQ report an internal consistency of .93 (Attkisson & Zwick, 1982), and Cox, Brown, Peterson, and Rowe (1982) report an alpha of .92. Client ratings on the CSQ are reported to be positively correlated (.56) with therapists’ measures of client satisfaction, (Levois, Nguyen, & Attkisson, 1981), which indicates some degree of concurrent validity. A high level of correlation (.70) between the CSQ and the Ladder of Service Satisfaction Scale (Levois, Nguyen, & Attkisson, 1981) has been reported. Preliminary reports of reliability for the FOCAS are .88 (Cronbach’s alpha; McWilliam & Snyder, 1994). It should be noted that there is limited information regarding validity and reliability for the Canadian Occupational Performance Measure (Law et al., 1998) and the Measure of Process of Care (MPOC; King et al., 1995).

Family Experiences Measured

Researchers have focused on a variety of family experiences (see Table 4). Although several studies have concentrated on the general family experiences with early intervention (Dempsey & Carruthers, 1997; McBride et al., 1993; Shannon, 2004; Thompson, 1998; Wesley, 1997), other research has been more focused.

Researchers have investigated general family experiences. These have been in relation to family centered services (Dempsey & Carruthers, 1997; McBride et al., 1993; Shannon, 2004). Other studies have been related to parents’ perceptions of occupational therapy (Thompson, 1998). Researchers have examined families’ perceptions of barriers and supports, service
coordination, and their views of what an ideal system of intervention would look like (Wesley, 1997). Research assessing general family experiences has included national studies (Bailey et al., 2003; 2004). Bailey, Scarborough, and Hebbeler (2003), used surveys and interviews to investigate families experience with early intervention. This provided a nationally representative sample of families. Studies have occurred in other countries to determine family experiences with early intervention in Sweden (Bjorck-Akesson & Granlund, 1995).

Research that has been more focused has included families with specific characteristics. For example, one study included parents with intellectual disabilities (Wade et al., 2007), while others included only families from a cultural minority (Applequist & Bailey, 2000; Bailey et al., 1999; Sontag, 1994) or families from rural communities (Haring & Lovett, 2001). Other focused studies investigated experiences of families who had a child with a specific disability such as autism (Beals, 2004; Patterson & Smith, 2011; Webster et al., 2004), hearing loss (Beals, 2004; Harrison et al., 1996), a visual impairment (Jackel et al., 2010; Otero, 2004). Additional focused studies have centered round studying particular aspects of early intervention such as parent involvement, role negotiation, diagnosis process, therapy activities, or the relationship between the family and provider (Hurtubise & Carpenter, 2011; Jackel et al., 2010; Mahoney & Filer, 1995; Minke & Scott, 1996) or around a specific intervention program or strategy (e.g., Grindle et al., 2009; Patterson & Smith, 2011).

**Analysis and Summary of Research Reviewed**

Families have reported positive early intervention experiences including effective and supportive collaborative interactions with early interventionists and the service delivery system. Families value the opportunity to learn new skills to support their child’s development and learning, to interact with other families of children with disabilities, and to learn about and become connected to community resources. Families have reported feeling satisfied with specific intervention programs and intervention outcomes and have suggested family relationships evolved in positive directions through participation in early intervention services. In contrast, other families have described negative experiences with early intervention. One reason for family dissatisfaction is feeling as though the services and resources are insufficient and that specific programs and service providers are not an appropriate match with their family and child needs. Families have indicated that intervention services have negatively affected their personal life by creating stress.
Although the current literature provides insightful information to the early intervention experiences and perceptions of families of young children with disabilities, there are limitations and inconsistencies that should be noted and support the need for additional research. Many of the limitations involve inadequate research design and methodology and may contribute to the inconsistent findings.

The majority of studies focus on the experience of families who have young children with a variety of disabilities. Research suggests that child abilities can impact family experiences with early intervention services (Rodger et al., 2008). Families who have children with lower functioning abilities compared to families who have children with higher functioning abilities have expressed differences regarding their experiences with early intervention (Rodgers et al., 2008). Therefore, including families who have children with different disabilities within one study has the potential to limit the findings by creating confounding variables.

The majority of the qualitative studies use only one type of data such as an interview or questionnaire. Researchers suggest using multiple methods of data collection in order to establish credibility in qualitative research (Bratlinger et al., 2005; Patton, 2002).

It should be noted that there are limitations regarding the measures used. There is limited information regarding reliability and validity. Current research regarding family experiences with early intervention are either lacking authentic measures or have used only one data source which is a limitation of current research findings. Therefore, more research should be done using multiple data sources to ensure rigor and allow families to share their experiences and perceptions with early intervention services using authentic measures such as interviews and observations.

**Implications for Needed Research**

Additional research that is more rigorous in design and methodology is needed to better understand family perceptions of and experiences in early intervention. Therefore, in this dissertation, a homogenous group of participants was included – mothers of children birth to age 3 years who are at risk for ASD. Specifically, studying only mothers’ experiences with one disability type (i.e., autism spectrum disorder) eliminates confounding variables of a heterogeneous group of participants.

In addition, rigorous qualitative methodological procedures were used to establish credibility of data. Information was collected using three methods – observation, interview, and
document analysis – allowing for triangulation of data. Data analysis procedures were based on grounded theory and reliability of coding was conducted, further lending credibility to the findings. Further, the conceptual framework designed by Trivette and Dunst (1998) was used in this study, enhancing data organization and interpretation.

Thus, the study seeks to answer the following questions in order to inform early intervention practice and personnel preparation:

1. In what way does the attitude of the practitioner affect mothers of children at risk for an autism spectrum disorder and their early intervention experiences with early intervention?
2. What types of practitioner interpersonal skills do mothers of children at risk for an autism spectrum disorder report as most effective in developing a partnership with the service provider(s)?
3. In what ways do mothers of children at risk for an autism spectrum disorder report the family being involved as choice makers?
4. In what ways do mothers of children at risk for an autism spectrum disorder report practitioner responsiveness impacts family early intervention experiences?

Table 4

Summary of the Literature

<table>
<thead>
<tr>
<th>Author</th>
<th>Data Collection Method</th>
<th>N</th>
<th>Family Experience with Early Intervention Measured</th>
<th>Measure Used</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Applequist &amp; Bailey, 2000</td>
<td>Interview</td>
<td>52</td>
<td>Perceptions of Navajo caregivers about typical and desired family-related early intervention practices</td>
<td>Client Satisfaction Questionnaire (CSQ; Larsen, Attkisson, Hargreaves &amp; Nguyen, 1979) and the Family Orientation of Community and Agency Services (FOCAS; Bailey, 1991)</td>
<td>Families reported a high degree of satisfaction with services. Families indicated family involvement and participation in services as aspects in which they are satisfied. Families express satisfaction with family centered programs. Affective and behavioral characteristics of service providers are positive aspects to services. Families indicate a lack of involvement and participation when it comes to assessment. Family differences were not associated with experiences with services.</td>
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<tr>
<td>Bailey, Correra, Arcia, Reyes-Blanes, Rodriguez, Vazquez-Montilla, &amp; Skinner, 1999</td>
<td>Survey and Interview</td>
<td>200</td>
<td>Needs and supports of Latino families</td>
<td>Family needs survey, Family support scale</td>
<td>All items in needs scale were needed by at least 20% of families with information being the highest. Other needs were in relation to family resources. Families indicated feeling supported. Supports and needs were not correlated. The only family factor which accounted for family differences was English language proficiency.</td>
</tr>
<tr>
<td>Bailey, Scarborough, &amp; Hebbeler, 2003</td>
<td>Survey and interview</td>
<td>33 38</td>
<td>National experience with early intervention using NEILS</td>
<td>National Early Intervention Longitudinal Study (NEILS), Interview</td>
<td>The early intervention process is working well for some families while it is not for others and this is tied to demographic information. Some families indicate help from the person they initially discussed their concerns with while others do not. Some families indicate little effort in obtaining services while other families suggest a lot of effort was necessary to obtain services. Some families were not aware of an IFSP while others helped develop goals for the IFSP. Some families indicate a lack of input in the kinds or amount of services their family receives. Some families feel they do not receive the services they need, and others discuss services as highly individualized and being satisfied with the amount and quality of services. Overall families suggest feeling satisfied with the EI provider(s) by suggesting they effectively communicate, respect the family, and listen to the family opinions. Differences were related to family demographics which included language of family, number of adults in household, income, education level, child eligibility, age of child, gender of child, and family race.</td>
</tr>
<tr>
<td>Beals, 2004</td>
<td>Case study</td>
<td>1</td>
<td>Personal experience hearing loss and autism</td>
<td>Family description</td>
<td>Described the difficult process of making language decisions between signs and speech. The family had to pay private practitioners to utilize the strategy they desired. Positive aspects included resources, home visits, and strategies.</td>
</tr>
<tr>
<td>Bjorck-Akesson &amp; Granlund, 1995</td>
<td>Rating scales</td>
<td>73</td>
<td>Family experiences with early intervention in Sweden</td>
<td>Bailey rating scales</td>
<td>Families indicated desiring more family involvement in services. Families discussed that involvement barriers were related to the early intervention system.</td>
</tr>
<tr>
<td>Dempsey &amp; Carruthers, 1997</td>
<td>Survey</td>
<td>273</td>
<td>A measure of family centered services</td>
<td>Family centered survey created by authors</td>
<td>The majority of families report being satisfied with the services they are receiving.</td>
</tr>
<tr>
<td>Epley, Summers, &amp; Turnbull 2011</td>
<td>Survey</td>
<td>77</td>
<td>A measure of part c early intervention services, early childhood outcomes, and quality of life.</td>
<td>Early Childhood Services Survey, ECO Center Family Outcomes Survey, Beach Center Family Quality of Life Survey</td>
<td>Overall, early intervention services families received met their needs. A relationship exists between Part C early intervention services with Early Childhood Outcome recommended family outcomes and family quality of life.</td>
</tr>
<tr>
<td>Author</td>
<td>Data Collection Method</td>
<td>N</td>
<td>Family Experience with Early Intervention Measured</td>
<td>Measure Used</td>
<td>Results</td>
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</tr>
<tr>
<td>Grindle, Kovshoff, Hastings, &amp; Remington, 2009</td>
<td>Interview</td>
<td>53</td>
<td>Home based ABA program</td>
<td>Interview</td>
<td>Practical benefits were an outcome of services for children with autism. Language, communication, social skills, and play skills improved. Other positive aspects included supports in the home, gave families release to do chores and other household activities, wider social network, and siblings enjoyed intervention. The child participants improved relationships with both the parents and siblings. Difficulties included increasing complexity of their personal and family life, local educational authority, therapist, administration, siblings, and child with autism. The husband and wife relationship deteriorated. Some families were happy with child progress while others were stressed.</td>
</tr>
<tr>
<td>Haring &amp; Lovett, 2001</td>
<td>Interview, document analysis, attendance records, family photo review, and case studies</td>
<td>23</td>
<td>Experiences, perceptions, and feelings of parents and family members in the EIEC process.</td>
<td>Review of medical and EI records, project staff attendance at EI staff meetings, interviews of significant others, review of family photo albums, baby books, videotapes, and paperwork (e.g., IFSPs), and attendance at parent support groups.</td>
<td>Prenatal medical care was identified as a problem. Early intervention service delivery was problematic in hiring and retaining service personnel, personnel did not have the necessary knowledge to work with the families, personnel were not available for therapy, and families did not understand how to incorporate early intervention strategies into their daily lives.</td>
</tr>
<tr>
<td>Harrison, Dannhardt, &amp; Roush, 1996</td>
<td>Survey</td>
<td>401</td>
<td>Hearing loss and roles in decision making</td>
<td>Author created survey</td>
<td>Families have various roles in making decisions and in the development of the IFSP. While some families indicate being key decision makers others suggest the contrary. Likewise some families reported being a part of the IFSP process, and others did not.</td>
</tr>
<tr>
<td>Hurtubise &amp; Carpenter, 2011</td>
<td>Interview</td>
<td>11</td>
<td>Perceptions and experiences with role negotiation</td>
<td>Author created interview</td>
<td>Two themes emerged that included parent roles and expectations of professional roles and evolution of a symbolic relationship was found. The first theme consisted of parent roles and parent expectations of professionals as the two subthemes. Parent roles were those that indicated how they were involved in services (learners, advocates, etc.). Families expect professionals to be the knowledge translators, supporters, and system navigators. However, many families indicated being unhappy with their role, as they did not feel they had the knowledge to be fulfilling these roles. The symbolic relationship described a relationship that evolved among the professionals and families. The subthemes included: readiness to engage, understanding of service/system, and development of rapport. Families’ readiness to engage was contingent on the families’ adjustment to the diagnosis, their understanding, and other life demands. Families indicated feeling overwhelmed and anxious about managing life demands. Families indicated a lack of understanding of the program which made it impossible to have realistic expectations.</td>
</tr>
</tbody>
</table>
Important service elements that families identified included development of a supportive and caring environment and the professionals’ understanding of the family. Families reported positive interventionist qualities that included sound professional practice, good communication skills, and the ability to relate to parents and children. Specific characteristics included: “gentle,” “kind,” “welcoming,” “honest,” “non-judgmental,” “feeling listened to,” and “flexible.” Families also emphasized the importance of individualized care delivery and the opportunity to work with a consistent team. Families also appreciated the professional’s level of confidence in the family.

<table>
<thead>
<tr>
<th>Author</th>
<th>Data Collection Method</th>
<th>N</th>
<th>Measure Used</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jackel, Wilson, &amp; Hartmann, 2010</td>
<td>Survey</td>
<td>80</td>
<td>Online author created survey</td>
<td>Parents were most frequently the ones to notice the vision disability. Families were given very little information upon receiving a diagnosis. Families had to conduct their own research to obtain information regarding supports and interventions so that their child could receive an appropriate education.</td>
</tr>
<tr>
<td>Lovett &amp; Haring, 2003</td>
<td>Interviews</td>
<td>48</td>
<td>Author created interviews</td>
<td>Themes included families experiencing a birth crisis have difficulty understanding information shared with them, transition from hospital to home is comfortable for some families, transition from EI to preschool may cause a lot of anxiety for other families</td>
</tr>
<tr>
<td>Mahoney &amp; Filer, 1996</td>
<td>Questionnaire</td>
<td>357</td>
<td>Family Environment Scale Family Resource Scale</td>
<td>Results suggest early intervention programs provided higher levels of family centered services regarding child information, strategies to enhance development, and family involvement in comparison to family and resource support. Services were rated higher in home-based programs and center-based programs with home-based components than in programs that took place in a center without a home component. Families suggested having unmet needs regarding the services they are receiving. The types of services families received were partially dependent upon their residential location. No significant relationships were found between characteristics of children and the types of services families received. However, families with optimal patterns of family functioning were more likely to receive services than were families who had risk conditions.</td>
</tr>
<tr>
<td>McBride, Brotherson, Joanning, Whiddon, &amp; Denmitt, 1993</td>
<td>Interview</td>
<td>15 (F) 14 (P)</td>
<td>Author interviews</td>
<td>Findings from semi-structured interviews indicated that families are satisfied with the professional’s empathetic nature to family concerns, help in accessing resources, and respect for family values and routines. Families reported various roles in choices in decision making. Families reported services lead to an increase in confidence, improvement in emotional well being, and enhanced family functioning.</td>
</tr>
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Table 4 Continued

<table>
<thead>
<tr>
<th>Author</th>
<th>Data Collection Method</th>
<th>N</th>
<th>Family Experience with Early Intervention Measured</th>
<th>Measure Used</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>McWilliam, Snyder, Harbin, Porter, &amp; Munn, 2000</td>
<td>Questionnaires</td>
<td>118</td>
<td>The extent of family centered practices, professional and family values regarding these practices, and the extent to which specific characteristics explained this variance.</td>
<td>FOCAS (Bailey, 1991) Brass Tracks Evaluation (McWilliam &amp; Winton, 1990)</td>
<td>Families indicated receiving family centered services although these were not rated as high as professionals felt they were delivering family centered services.</td>
</tr>
<tr>
<td>Minke &amp; Scott, 1995</td>
<td>Video-tapes, interviews, observations, and written documents</td>
<td>10 (F) 4 (A) 10 (P)</td>
<td>Parent professional relationship the development of the IFSP</td>
<td>Interview, observations, document analysis</td>
<td>Parents and staff emphasized the importance of strong relationships between parents and EI staff by explaining their experiences with positive caring relationships.</td>
</tr>
<tr>
<td>Otero, 2004</td>
<td>Interviews and Observations</td>
<td>6</td>
<td>Family involvement with the orientation and mobility services they are receiving</td>
<td>Author created interview and observations</td>
<td>Families suggest they are having challenges with the system that include not receiving the services their child needs and a lack of information and understanding. Families do have positive attitudes about the program and feel as though it is supporting their child in gaining independence.</td>
</tr>
<tr>
<td>Paterson &amp; Smith, 2011</td>
<td>Case study</td>
<td>4</td>
<td>Family learning experiences with the More Than Words Parent Education Program</td>
<td>Case study</td>
<td>Caregivers viewed MTW as a good starting point. Caregivers expressed a need for explicit child and parent program expectations and that the program be sensitive to the emotional and information needs of families of newly diagnosed children. Furthermore, suggestions regarding the delivery of the program include a desire for more individualized one-on-one modeling and parent-to-parent contact in order to navigate the program.</td>
</tr>
<tr>
<td>Rodger, Keen, Braithwaite, &amp; Cook, 2008</td>
<td>Case study</td>
<td>2</td>
<td>Rationale for dissatisfaction with services</td>
<td>The maladaptive Behavior subscale; Children were video recorded; Mothers ratings; The Canadian Occupational Performance Measure; The Parent Sense of Competence (PSOC); The Parenting Stress Index Measure of Processes of Care (MPOC) Questionnaire</td>
<td>Low satisfaction was due to adaptive functioning, elevated stress, relationship with facilitator, dissatisfied with the amount and relevance of information shared</td>
</tr>
<tr>
<td>Author</td>
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</tr>
<tr>
<td>Shannon, 2004</td>
<td>Interview</td>
<td>22</td>
<td>Barriers to receiving or providing family centered services</td>
<td>Interview</td>
<td>Themes arose around the part C service delivery system, provider’s external to part C, and individual family characteristics that interact with service provision. Families indicated feeling as though the services they were receiving were those that were billable opposed to those that best fit the family, and felt as though they were not told about all services so they would not request all possible services outside of professional recommendations. Families indicated they did not realize they had a service coordinator. Families indicate that motivation and persistence are two family characteristics that families need to be successful with services. Families suggested that intervention professionals create positive experiences by meeting their basic needs and providing family-to-family support. Families indicated needing more information in regard to development, the early intervention system, paying for services, and parenting skills. Families also said that it would be helpful for providers to facilitate family empowerment.</td>
</tr>
<tr>
<td>Sontag, 1994</td>
<td>Interview</td>
<td>536</td>
<td>Ethnic differences in parent perceptions of their information needs and their sources of information, the nature of parent participation in early intervention, and participation preferences</td>
<td>Interview</td>
<td>Families have an unequal amount of information and level of participation when examining families by cultural group</td>
</tr>
<tr>
<td>Thompson, 1998</td>
<td>Questionnaires and interviews</td>
<td>10</td>
<td>Identify and explore parents’ perceptions of occupational therapy services on the life of the family</td>
<td>Author created semi structured interview and questionnaire</td>
<td>Mothers discussed concerns related to the services and how they work for families practically speaking. Mothers discussed the impact of the services provided, and discussed the method they felt would better fit their needs. Families discussed desiring a relaxed and family friendly relationship with intervention providers. Families indicate wanting the EI provider to provide information, a trusting relationship with caregivers, and support for child and family needs.</td>
</tr>
<tr>
<td>Tocci, McWilliam, Sideris, &amp; Melto, 1997</td>
<td>Interview</td>
<td>75</td>
<td>National experiences with early intervention at different points in time</td>
<td>Author created interviews</td>
<td>Positive aspects included consistency of staff, home visits, programs providing financial support, professionals who support families and respond to their needs, professionals who show parents how developmental play stimulates the child's development. Parents provided suggestions for other parents and service providers which included parents need to fight for services and advocate for their child; parents should get involved in an early intervention program; parents want information; parents value support from and connection with other parents; parents need to take care of themselves emotionally.</td>
</tr>
</tbody>
</table>
### Table 4 Continued

<table>
<thead>
<tr>
<th>Author</th>
<th>Data Collection Method</th>
<th>N</th>
<th>Family Experience with Early Intervention Measured</th>
<th>Measure Used</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wade, Mildon, &amp; Matthews, 2007</td>
<td>Interview</td>
<td>32</td>
<td>Helpful and unhelpful practices according to parents with an intellectual disability</td>
<td>Author interview</td>
<td>Families said the most helpful service was the name of the service they received. Family needs met, finding out about other services, transportation, and behaviors of providers were all helpful aspects of services which parents mentioned. Unhelpful aspects included transportation, actions or inactions of providers, wait time, and cost. In sum, parents reported that family centered practices were more helpful than professional centered practices.</td>
</tr>
<tr>
<td>Webster, Feiler, Webster, &amp; Lovell, 2004</td>
<td>Interviews Questionnaires</td>
<td>9</td>
<td>Identify parent views of early intensive intervention who have a young child with autism.</td>
<td>Author created interviews and questionnaires</td>
<td>Family responses developed into themes of: diagnosis, initial lack of help, priorities for practical help, assessment, impact on families life, aspects of intervention that are valued, aspects of intervention which cause concern, transition points, and views about future provision. Families indicated a concern regarding their child’s development substantially sooner than a diagnosis was made. Families also indicated there was a lack of help after their child received a diagnosis. Family priorities included help regarding their child’s language and behavioral challenges. Another theme was in regard to assessment and waiting on reports which delayed early care placement and supports. Families indicated that the diagnosis impacted their family by reducing parents workload and living in more of an isolated environment compared to other family members and friends. What families valued most about intervention was their child’s increase in communication, appropriate behavior, and the help provided to them. Families also appreciated flexibility in services and the team approach among interventionists and the early care facility. Managing intervention was an aspect to intervention which families suggested was challenging. Families also expressed concerns regarding transition. Families felt the best environment for their children was a small school where the teachers have specialized training for children with ASD.</td>
</tr>
<tr>
<td>Wesley, 1997</td>
<td>Focus groups</td>
<td>13 (F) 32 (P)</td>
<td>Participants’ awareness of early intervention services, their perceptions of barriers and supports to inclusion, their notions of service coordination, their experiences with a statewide initiative to improve early childhood services for all children,</td>
<td>Focus group interviews</td>
<td>Families indicated learning about services through informal ways such as seeking out information on their own. Parents described choices as complicated and difficult to understand. Other families suggested they have not been given choices. Families indicated they should be able to make decisions about their child. Families indicated they feel there are barriers to inclusive services. Families were confused about intervention teams as they often reported working with several interventionists from different agencies.</td>
</tr>
</tbody>
</table>
### Table 4 Continued

<table>
<thead>
<tr>
<th>Author</th>
<th>Data Collection Method</th>
<th>N</th>
<th>Family Experience with Early Intervention Measured</th>
<th>Measure Used</th>
<th>Results</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>and their views of what an ideal system of early intervention would look like</td>
<td></td>
<td>When asked about their ideal early intervention program, families said they would like a program that empowers families and decreases the complexity of the referral process.</td>
</tr>
<tr>
<td>Wilcox, Tempe, Campbell, &amp; Guimond, 2006</td>
<td>Computer assisted telephone interviews</td>
<td>924</td>
<td>Provide information about families' experiences with AT for their infants and toddlers who are receiving early intervention services</td>
<td>Archived results to a computer assisted telephone interview</td>
<td>Families identify using, and paying for various devices do so Without professional assistance. Most devices they have tried, or are trying, are perceived as having limited success.</td>
</tr>
</tbody>
</table>
CHAPTER THREE

METHOD

This chapter discusses the study’s methodological components of (a) design, (b) setting, (c) participants, (d) procedures, (e) data collection, (f) data analysis, and (g) the measures taken to safeguard participants’ rights. Each encompasses several interrelated procedures that were thoroughly monitored to ensure credibility (internal validity), transferability (external validity), dependability (reliability), confirmability (objectivity), authenticity (balanced view of all perspectives), triangulation (credibility), and trustworthiness (scientific merit or methodological rigor) of the research study.

Design

A qualitative research approach was used to investigate mothers’ perceptions of early intervention experiences. Other early intervention research has provided evidence of family experiences with early intervention services by utilizing qualitative methods (See Table 4.). Because of the nature of the problem and the purpose of this study, this method was most suitable for reasons that included the following:

1. The present lack of information regarding early intervention experiences of mothers who have a child at risk for an autism spectrum disorder.
2. The need to obtain firsthand information from mothers regarding their early intervention experiences.
3. The need to explore mothers’ early intervention experiences in order to understand the nature of their experiences when they have a young child at risk for an autism spectrum disorder.
4. The need to learn more about mothers’ experiences with and perceptions of services (James & Chard, 2010) as they relate to family centered practice discussed by Trivette and Dunst (1998).

Grounded Theory

Strategies of inquiry are diverse within each methodological practice. Denzin (1997) indicated, “The grounded theory approach is the most influential paradigm for qualitative research in the social sciences today” (as cited in Patton, 2002, p. 124). Qualitative methodologists suggest that theories should be grounded in data from the field, especially in the
actions, interactions, and social processes of people (Creswell, Hanson, Clark Plano, & Morales, 2007). As Creswell, Hanson, Clark Plano, and Morales (2007) stated, grounded theory is a qualitative research design in which the inquirer generates an explanation of a process, action, or interaction designed by the views of a large number of participants. This theory seeks to determine results that emerge from systematic comparative analysis and are grounded in fieldwork to explain what has been and is observed. “Grounded theory begins with basic description, moves to conceptual ordering, and then to theorizing” (Patton, 2002, p. 490).

Grounded theory provides a set of “Coding procedures to help provide some standardization and rigor to the analytical process” (Patton, 2002, p. 489). Specifically upon gathering “Description,” a three-tiered coding scheme within the phase of conceptual ordering is used. This begins with open coding, a process by which data is sorted into broad categories or the “core phenomenon” (Creswell et al., 2007, p. 252; Larossa, 2005). Next is axial coding. Axial coding is the process of developing information around the core phenomena (Creswell et al., 2007; Larossa, 2005) and refers to taking information within their large categories and developing subcategories or focal points of information (Larossa, 2005). After open and axial coding, the theorizing phase begins (Creswell et al., 2007; Larossa, 2005). Within theorizing, selective coding is used to interrelate the information gathered (Creswell et al., 2007; Larossa, 2005); selective coding is developing the “story” which underlines the analysis (Creswell et al., 2007, p. 250). Descriptive coding, the last step, is making sense of the analyzed data.

When analyzing data, specific techniques are utilized in grounded theory (Larossa, 2005). Within each of the phases of analysis, a constant comparative method is used while coding the data to determine similarities and differences (Larossa, 2005). Additionally a didactic relationship should exist between induction and deduction while organizing information (Larossa, 2005). Induction and deduction is the process of going from broad information to focused information and from focused information to more broad information (Larossa, 2005).

Additionally, triangulation was used since this practice strengthens research by combining methods (Patton, 2002). Triangulation means using a variety of data sources in a study, multiple perspectives to interpret a single set of data, or the use of multiple methods to study a single problem. In this research, information was collected from various data sources including families, early intervention providers, and intervention documents.

In order to ensure experimental rigor, grounded theory formed the framework for the
research study. The systematic analytic procedures suggested by Strauss and Corbin (Creswell et al., 2007) were used. The phases of Grounded Theory, which include, description, conceptual ordering, and theorizing were practiced in this study (Creswell et al., 2007; Larossa, 2005).

Participants

The five mothers who participated in this study had a child who was at risk for an autism spectrum disorder and were receiving early intervention services at Children’s Corner. Children were younger than 36 months of age. In addition to mothers, intervention providers participated in this study, as they were present for observations. Intervention providers who participated were speech language pathologists and occupational therapists. All five children were receiving occupational therapy and two of the children were also receiving speech language services.

Demographic data for families of the mothers and children are presented in Table 5. Four families had a male child, and one family had a female child. Children ranged in age from 20 to 34 months. Gross household incomes varied. Two families reported incomes of over $100,065; one mother reported her income as $33,000 and the father’s as $40,000 (shared custody of child). Two families reported their income as $61,736 to $100,065. Three mothers reported their age and the fathers’ age were 25-34, and two mothers reported that she and the father were 35-44. Three families reported being married and two indicated single-family household. Families’ education varied.

All participants were receiving Part C early intervention services through Children’s Corner. Families varied in the amount of services they were receiving (see Table 5). One family received occupational therapy and the other four families received both occupational therapy and speech language therapy. Families participated in one hour of services per week for each of the services (i.e., occupational therapy, speech language therapy) they received. Families who participated in this research received all early intervention services at Children’s Corner.

Table 5

<table>
<thead>
<tr>
<th>Family Demographic Information</th>
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<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>-------</td>
</tr>
<tr>
<td>George</td>
</tr>
<tr>
<td>Katie</td>
</tr>
</tbody>
</table>
Demographic data for interventionists is reported in Table 6. Intervention providers ranged in age from 25 to 54 years of age. Three providers had Masters degrees and two had Bachelors degrees. Providers varied in their licenses, endorsements, and credentials. Intervention providers were providing services on average for 7 years (from 9 months to 12 years), and had provided services in various settings.

### Table 6

**Intervention Provider Demographic Information**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Educational Background</th>
<th>Licenses, Endorsements, or Credentials</th>
<th>Length of time providing services</th>
<th>Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>25-34</td>
<td>Masters Speech Language Pathology</td>
<td>ASHA CCCs</td>
<td>7 years</td>
<td>Children’s Corner State service agency Self Employed</td>
</tr>
<tr>
<td>Ileen</td>
<td>25-34</td>
<td>Masters Occupational Therapy</td>
<td>OT license and registered as an OT</td>
<td>Nine months</td>
<td>Children’s Corner and Tallahassee Memorial Rehab</td>
</tr>
<tr>
<td>Madelyn</td>
<td>25-34</td>
<td>Masters Communication Disorders</td>
<td>CCC and SLP</td>
<td>5 years</td>
<td>School system and Children’s Corner</td>
</tr>
<tr>
<td>Bailey</td>
<td>45-54</td>
<td>Bachelors Occupational Therapy</td>
<td>Pediatric certification</td>
<td>12 years</td>
<td>Nurse and sensory therapist</td>
</tr>
<tr>
<td>Lucy</td>
<td>45-54</td>
<td>Bachelors Occupational Therapy</td>
<td>Pediatric certification</td>
<td>12 years</td>
<td>Nurse and sensory therapist</td>
</tr>
</tbody>
</table>
Procedures

**Researcher’s Role**

As the sole investigator, the researcher implemented the majority of the procedures within this study. This included observing, interviewing, analyzing documents, and coding data. The researcher is considered an instrument of analysis (Patton, 2002). Because of this, the researcher’s bias could influence the results. The researcher spent time in reflexivity where potential biases were examined (Bratlinger et al., 2005). A researcher journal was kept which the researcher used to identify topics where bias could have occurred. By engaging this process, the researcher was able to separate bias, data collection, and data analysis.

**Participant Recruitment**

Purposeful sampling, but more specifically, criterion sampling was used to gain a deeper understanding of mothers who have children at risk for an autism spectrum disorder and their early intervention experiences (Patton, 2002). Criterion sampling is a form of purposeful sampling used when researchers want to learn more about a specific group of participants. “The logic of criterion sampling is to review and study all cases that meet some predetermined criterion of importance” (Patton, 2002, p. 238). In this research, the criteria mothers met in order to participate was having a child between the ages of birth to 36 months who was at risk for an autism spectrum disorder and who was currently receiving early intervention services.

Participants were recruited through Children’s Corner. The director of Children’s Corner provided recruitment letters to parents. If families were willing to participate, they returned their letter to the agency director who informed the research of the parents’ interest. The families were then contacted by the researcher to discuss the procedures.

Children’s Corner is a non-profit agency that provides comprehensive services. Children’s Corner has two domains that include the therapy center and the developmental education center. The agency serves people birth through adulthood utilizing a multidisciplinary approach. Children’s Corner is compensated through insurance reimbursement, Medicaid Part C, and Private Pay. The agency serves 50 individuals.

Children’s Corner is an agency where the Trivette and Dunst framework of family help giving practices are of high value. See Appendix F for the rating form completed by the director of Children’s Corner. The center was a large building with multiple rooms available. The rooms were designed for speech language services, occupational therapy services, and physical therapy
services. Depending on the type of service the family was receiving would determine where the child received intervention.

If the child was receiving speech language services, the child, intervention provider, and at times the mother would be in a small room that contained toys and a small table. If they were receiving occupational therapy services the child, the intervention provider, and sometimes the mother would be in the sensory room where there were puzzles, ball pits, sensory buckets, chalk boards, and glow in the dark toys. At other times occupational therapy took place in the large motor room where there were structures for climbing, hanging, crawling, swinging, jumping, and sliding.

**Researcher’s Relationship with Participants**

As Patton (2002) explains, interpersonal communication factors have the potential to influence the process in interviews and observations. In order to nurture, sustain, and maintain quality relationships with participants, the importance of the contributions of mothers in terms of knowledge, experiences, attitudes, and feelings was emphasized. Mothers were frequently thanked for their willingness to participate in the study and their willingness to share their perspective. Courteous and professional demeanor was adopted by considering the participants’ individual needs and preferences. This was exemplified by determining participants’ preferences in terms of contact method, best time to get in touch with mothers, and logistics for interviews.

While developing optimal relationships with participants, neutrality was maintained to prevent bias from occurring. “Rapport is built on the ability to convey empathy and understanding without judgment” (Patton, 2002, p. 366). A “balanced rapport,” as suggested by Fontana and Frey (2005) was maintained by acting “casual and friendly on the one hand, but directive and impersonal on the other” and “must perfect a style for interested listening that rewards the respondent’s participation, but does not evaluate the responses” (p. 650).

**Procedures for Protecting Anonymity of Participants and Confidentiality of Information Shared**

In order to encourage participants to share freely and reduce hesitations in sharing important information, measures were used to preserve their anonymity and confidentiality of the information they share. These measures were implemented in every phase of the research. Participants choose the time and place of the interview to ensure convenience and comfort when discussing their experiences and perceptions regarding intervention services. In order to ensure
all data was secure, was stored on a password protected computer that only the researcher could access. Code names were developed to maintain participant confidentiality.

**Data Collection**

Data were collected from mothers and documents. Interviews, observations, and document analyses were used to gather information regarding mothers’ experiences with early intervention.

**Credibility**

Credibility of the data, as discussed by Brantlinger, Jimenez, Klingner, Pugach, and Richardson (2005), was established by (see Table 7):

- *Data triangulation* - use of varied data sources. Data were collected from multiple sources: the family, early intervention provider, and intervention documents. Observations and interviews included the family as well as the intervention provider as a source of information.

- *Disconfirming evidence* - evidence inconsistent with themes. Information that was inconsistent with themes was coded as outlying information (Miles & Huberman, 1994).

- *Member checks* - review and confirmation of accuracy of coding data by participants. Participants were provided an electronic copy of all data and were asked to review the information and indicate how and why they agreed and/or disagreed with the data.

- *External auditors* - using outsiders (to the research) to examine if, and confirm that, a researcher's inferences are logical and grounded in findings. Committee members will review an electronic document of the completed research to examine and confirm that the results are logical.

- *Researcher reflexivity* - researchers attempt to understand and self-disclose their assumptions, beliefs, values, and biases. Prior to analyzing the data, time was spent in reflection to determine if any bias exists. Further, a researcher journal with personal notes regarding data collection was maintained. This was a strategy used to separate bias and personal feelings from the data collected.

- *Audit trail* – records of data collection. Records of when observations occurred and interviews conducted, field notes from observations, and records of interviews with
mothers and early intervention provider are securely stored in order to maintain records of data collection.

- **Thick, detailed description** - reporting sufficient quotes and field note descriptions to provide evidence for researcher’s interpretations and conclusions. Field notes include a description of the physical environment, social environment, informal interactions, special program language, nonverbal communication, nonoccurrence, and other notable observations that are impossible to plan.

- **Particularizability** - documenting cases with thick description so that readers can determine the degree of transferability to their own situations. Participants were carefully selected to maintain the most homogenous sample while still gathering information about young children identified with an autism spectrum disorder.

Table 7

**Research Quality and Rigor**

<table>
<thead>
<tr>
<th>Qualitative Term</th>
<th>Strategy Employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal validity</td>
<td>Credibility</td>
</tr>
<tr>
<td></td>
<td>• Prolonged engagement in field</td>
</tr>
<tr>
<td></td>
<td>• Data triangulation</td>
</tr>
<tr>
<td></td>
<td>• Member checks</td>
</tr>
<tr>
<td>External validity</td>
<td>Transferability</td>
</tr>
<tr>
<td></td>
<td>• Thick description</td>
</tr>
<tr>
<td></td>
<td>• Purposive sampling</td>
</tr>
<tr>
<td></td>
<td>• Particularizability</td>
</tr>
<tr>
<td></td>
<td>• Disconfirming evidence</td>
</tr>
<tr>
<td>Reliability</td>
<td>Dependability</td>
</tr>
<tr>
<td></td>
<td>• Audit trail</td>
</tr>
<tr>
<td></td>
<td>• Code recode strategy</td>
</tr>
<tr>
<td></td>
<td>• Data triangulation</td>
</tr>
<tr>
<td></td>
<td>• Disconfirming evidence</td>
</tr>
<tr>
<td>Objectivity</td>
<td>Confirmability</td>
</tr>
<tr>
<td></td>
<td>• Data triangulation</td>
</tr>
<tr>
<td></td>
<td>• Researcher reflexivity</td>
</tr>
<tr>
<td></td>
<td>• Disconfirming evidence</td>
</tr>
</tbody>
</table>

**Observations**

Patton (2002) describes observations as a purposeful data collection method. Observational data allow the researcher to describe the setting, the activities that take place, the people who are participating, and the meaning of what was observed from the perspectives of those observed. Direct observations allow the researcher to identify the context in which people interact. Another purpose of observational data is to gain experience with a setting and the people in the setting allowing the researcher to be open, discovery oriented, and inductive.
Additionally, observations provide opportunities to notice things that may routinely escape the awareness among the people in the setting. Observations allow researchers to learn things that people would be unwilling to discuss in an interview. Researchers are also able to use their perceptions in observations by drawing on personal knowledge during the interpretation stage of analysis after having a firsthand experience.

Observations were conducted until saturation was reached with each mother during early intervention sessions (see Table 8). Saturation was reached when the research questions were answered. If a family received early intervention services from multiple providers, the researcher observed the family receiving services from each provider. The researcher observed Jose receiving early intervention three times with the occupational therapist, Lucy. Katie was observed three times receiving early intervention from the occupational therapist, Lucy and one time from the speech language pathologist, Laura. The researcher observed George receiving intervention three times from the occupational therapist, Bailey. Jonathan was observed three times receiving intervention from the speech language pathologist, Madelyn, and two times with the occupational therapist, Ileen. Mark was observed four times receiving intervention from the occupational therapist Ileen.

Table 8

<table>
<thead>
<tr>
<th>Child</th>
<th>Provider</th>
<th>Provider Title</th>
<th>Quantity of Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jose</td>
<td>Lucy</td>
<td>Occupational Therapist</td>
<td>3</td>
</tr>
<tr>
<td>Katie</td>
<td>Lucy</td>
<td>Occupational Therapist</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Laura</td>
<td>Speech Language Pathologist</td>
<td>1</td>
</tr>
<tr>
<td>George</td>
<td>Bailey</td>
<td>Occupational Therapist</td>
<td>3</td>
</tr>
<tr>
<td>Jonathan</td>
<td>Madelyn</td>
<td>Speech Language Pathologist</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Ileen</td>
<td>Occupational Therapist</td>
<td>1</td>
</tr>
<tr>
<td>Mark</td>
<td>Ileen</td>
<td>Occupational Therapist</td>
<td>4</td>
</tr>
</tbody>
</table>

During early intervention observations, field notes regarding what took place, who was present, and additional details describing interactions among the professional, mothers, and children were taken. The observations provided an understanding of mothers’ experiences with early intervention as they relate to the framework created by Trivette and Dunst (1998). Notes included a description of the physical environment, social environment, informal interactions, special program language, and nonverbal communication. In addition, nonoccurrences (those
aspects expected to happen that do not happen and other notable observations which are impossible to plan; Patton, 2002) were recorded. However, observational description was specific to interpersonal skills, asset based attitudes, family choice and action, and practitioner responsiveness.

**Mother Interviews**

“We interview people to find out from them those things we cannot directly observe” (Patton, 2002, p. 340). Because researchers are unable to observe everything, interviews allow a researcher to enter into the other person’s perspective. Interviews are the most common form of collecting qualitative data (DiCicco-Bloom & Crabtree, 2006). The purpose of individual, semi-structured interviews is to obtain detailed narratives and stories of the participants (DiCicco-Bloom & Crabtree, 2006).

Semi-structured, open-ended interviews were used (Patton, 2002). Interview questions were based on opinions and values, which are questions that focus on the cognitive understanding and interpretive processes of people. Each mother was interviewed over the phone one time to obtain more direct information and to develop clarity on observation notes. Interviews lasted 45 minutes to 1 hour. Mothers were provided the questions prior to conducting the interview to allow mothers the opportunity to reflect on their responses. See Appendix C. The questions focused on family centered help giving practices within the checklist created by Trivette and Dunst (1998). Mothers were asked the questions in a way that matched the research questions in order to gain valuable information from mothers regarding their experiences and perceptions of early intervention. The questions are listed in Appendix C and grouped into their help-giving category as identified by Trivette and Dunst (1998).

Patton (2002) makes several recommendations regarding interviews that were implemented. That is, interviews began with a noncontroversial question. Patton (2002) suggested wording interview questions so they are truly open ended and contain only one idea. If the mother responded with information that was unclear or if the mother provided incomplete information to any of the questions, probes were used in an attempt to gather more information. Probes are the specific questions and comments used that encourage participants to expand on a specific topic (Patton, 2002). The researcher took written notes during the interview.
Document Analysis

Document analyses are considered a high quality indicator of qualitative research assuming they are meaningful and are meaningfully described (Bratlinger et al., 2005). This type of analysis is frequently used as a third measure in qualitative research to perform triangulation among data sources (Patton, 2002).

Document analysis was conducted by reviewing one progress summary form for each family. Intervention providers created progress summaries after completing each intervention session in order to keep records of child and family progress. The director of Children’s Corner provided the researcher with a progress summary form. A document summary form was used to record information obtained from each of the documents (Miles & Huberman, 1994). Information from the summary includes: (a) name of the document, (b) significance or importance of the document, and (c) a summary of document content. Data were analyzed for information related to the Trivette and Dunst family help giving practices framework (1998).

Data Analysis

The researcher transcribed data from all data sources into a word file. The researcher used a separate word file for each data source and session. Every observation, interview, and document analysis had a separate word file. Then the researcher imported all word files into one Nvivo© file. Open coding involved sorting data into broad starter codes (Miles & Huberman, 1994). Starter codes are those categories predetermined to conducting fieldwork (Miles & Huberman, 1994). Starter codes served as initial themes in data analysis. Axial coding was then used to code units of meaning within each of the broad starter code themes (see Table 10). Meaning units are phrases, sentences, or paragraphs corresponding to a specific topic (Miles & Huberman, 1994). Next, pattern coding was used to form subthemes (Larossa, 2005). Pattern coding is a process in which the researcher reviews the meaning units and clusters them together (Miles & Huberman, 1994). Upon analyzing all data, selective coding was implemented which is the process of making sense of the data and forming results (see Results; Creswell et al., 2007; Larossa, 2005). Descriptive coding was the process of making sense of all of the results (see Discussion).

The researcher used NVivo© to organize data coded (i.e., open coding) into the four broad themes which were used as starter codes: (a) asset based attitudes, (b) interpersonal skills, (c) choice making, and (d) practitioner responsiveness (see Table 9, Iteration One). A colleague
reviewed 25% of the initial analysis to obtain inter-rater reliability (see Table 9, Iteration Two). The colleague was an early childhood special educator, intervention provider, and doctoral student studying visual impairments. The researcher trained the colleague by providing definitions and examples of themes and subthemes. Disagreements were discussed until agreement was reached regarding the most suitable code for the data (see Table 9, Iteration Three). The researcher used axial coding by analyzing data within each theme by phrases, sentences or paragraphs dependent upon units of meaning (see Table 9, Iteration Four).

Using the starter codes as themes, the researcher identified subthemes by using pattern coding (see Table 9, Iteration Five). More specifically, the researcher chunked the smaller meaning units into subthemes (Miles & Huberman, 1994).

The updated NVivo© file that contained the analyzed data was sent to the same colleague described above to conduct inter-rater reliability. The colleague read a random 25% of the first author’s coding patterns to achieve inter-rater reliability of at least 85% agreement (see Table 9, Iteration Six; Miles & Huberman, 1994). In the case of a disagreement, the researcher and colleague discussed the rationale behind each other’s coding and determine the best solution together (see Table 9, Iteration Seven).

Table 9

*Iterations of the Data*

<table>
<thead>
<tr>
<th>Iteration One: Open Coding</th>
<th>The researcher used NVivo© to organize data into the four starter codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asset Based Attitudes</td>
<td>Interpersonal Skills</td>
</tr>
<tr>
<td></td>
<td>Family Choice and Action</td>
</tr>
<tr>
<td></td>
<td>Practitioner Responsiveness</td>
</tr>
</tbody>
</table>

| Iteration Two              | A colleague checked 25% of the first author’s initial analysis to obtain inter-rater reliability to achieve at least 85% agreement. The colleague and the researcher reached an adequate agreement of 87%. |

| Iteration Three            | The researcher and colleague discussed the rationale behind each other’s coding and determined the best solution together. |

<table>
<thead>
<tr>
<th>Iteration Four: Axial Coding</th>
<th>The data within each theme was analyzed by phrases, sentences or paragraphs dependent upon units of meaning.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Progress</td>
<td>Communication</td>
</tr>
<tr>
<td>Family Competence</td>
<td>Sources of Information</td>
</tr>
<tr>
<td>Provider Attributes</td>
<td>Decision Makers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Iteration Five: Pattern Coding</th>
<th>Using the starter codes as themes, the researcher identified subthemes among participant responses by using pattern coding.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Progress</td>
<td>Communication</td>
</tr>
<tr>
<td>Family Competence</td>
<td>Sources of Information</td>
</tr>
<tr>
<td>Provider Attributes</td>
<td>Decision Makers</td>
</tr>
</tbody>
</table>

| Iteration Six                  | Inter-rater reliability was reached by a colleague reading 25% of the first author’s coding patterns to achieve at least 85% agreement. The colleague and researcher reached an adequate agreement of 96%. |

| Iteration Seven                | In the case of a disagreement the researcher and colleague discussed the rationale behind each other’s coding and determine the best solution together. |
### Units of Meaning (Axial Coding)

<table>
<thead>
<tr>
<th>Asset Based Attitudes</th>
<th>Interpersonal Skills</th>
<th>Family Choice and Action</th>
<th>Practitioner Responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learn what to do at home</td>
<td>Mother discussed trusting staff</td>
<td>Listen to mother</td>
<td>Feedback from ELC and PP</td>
</tr>
<tr>
<td>Doing all that can</td>
<td>Mother likes to talk in person</td>
<td>Try to understand mothers</td>
<td>ESI</td>
</tr>
<tr>
<td>Doing something to help</td>
<td>Mother likes the expectations of the interventionist and her recognizing the progress of her child</td>
<td>Question mother regarding child</td>
<td>Playgroup</td>
</tr>
<tr>
<td>Feel successful in implementing strategies and feeling confident to try other things</td>
<td>Need to hear positive progress</td>
<td>Set goals</td>
<td>Attentive and intuitive to child</td>
</tr>
<tr>
<td>Noting child progress (talking, eye gaze, beads, signing, developmentally appropriate activities, engaging with an adult, affect, response to intervention, table time, play)</td>
<td>Comfortable talking to interventionist</td>
<td>Ask for mothers input</td>
<td>Build off what child knows</td>
</tr>
<tr>
<td>Decrease in anxiety</td>
<td>Mutual respectful relationship</td>
<td>Mothers discuss information in meetings regarding observations and evaluations</td>
<td>Practical solutions</td>
</tr>
<tr>
<td>Home support</td>
<td>Receiving the level of communication needed</td>
<td>Ask how the family’s day is</td>
<td>Potty training, big girl bed, transitions, birthday parties</td>
</tr>
<tr>
<td>Mother learning strategies</td>
<td>Confident, good, and caring</td>
<td>Ask about visiting Santa</td>
<td>Services altered child’s life</td>
</tr>
<tr>
<td>Changes in the expectations of mothers</td>
<td></td>
<td>Explain an experience to the interventionist</td>
<td>Identify problems and what they will work on</td>
</tr>
</tbody>
</table>

### Anticipated Risks Versus Benefits Analysis

Participants reported no risks in this research. On the contrary, the anticipated benefits include:
1. The opportunity for participants to share their experience and perspective of family experiences with early intervention.
2. The possibility of participants influencing policy decisions by contributing to the formulation of the constructed reality of their perspective.
3. The benefits that come with sharing opinions and communicating their thoughts in a safe, non-judgmental environment.

Human Subjects’ Committee Approval

The Human Subjects’ Committee (HSC) of the Institutional Review Board (IRB) at Florida State University approved the application for this research prior to data collection. The researcher submitted the application to the committee on September 26, 2011. See Appendix J.

In addition, the director of Children’s Corner agreed to participate in this research. The researcher met with the director of Children’s Corner and shared all information regarding this research with the director. At this meeting, the director of Children’s Corner agreed to participate.
CHAPTER FOUR

RESULTS

The purpose of this qualitative study was to investigate the early intervention experiences of mothers who have a young child at risk for an autism spectrum disorder. Specifically, this research addressed how mothers perceive family help giving practices and how these experiences impact families. Observations, interviews, and documents were used to gain a deeper understanding of help giving practices and their impact on families.

Results were confirmed by member checking. Each mother was sent a copy of observation notes, interviews, and progress summaries; and was asked to indicate if they agreed or disagreed with the information on the document and why. All participants reported that the information was an accurate portrayal of observations, interview responses, and progress.

Research Question One: In What Way Does the Attitude of the Practitioner Affect Mothers of Young Children at Risk for ASD and Their Experiences with Early Intervention?

The theme identified within the first research question was asset based attitudes. The intervention providers’ attitudes affected mothers by creating family progress and a feeling of family competence. Mothers identified feeling successful, having the ability to work with their child, and feeling they were doing all that they could for their child. The two subthemes within asset based attitudes were family progress and family competence. Methods of data collection included interviews (7 codes), observations (13 codes), and document analysis (7 codes). A total of 27 codes are included in this theme which is 11.44% of the total data.

Family Progress

These data suggest the attitude of the provider led to family progress. The subtheme of family progress included 22 codes which made up 81.48% of the data within asset based attitudes. Evidence of this subtheme was exemplified in interview responses (two codes), observations (13 codes), and documents (7 codes). Family progress was illustrated through changes in the expectations mothers had of their children and child development, a decrease in maternal anxiety, and the learning of intervention strategies to implement with the child.

During the interviews, mothers discussed lessons learned since starting intervention. These were in relation to parent expectations and anxiety. Katie’s mother explained, “I just think for me, Laura specifically, if ever a person had a gift she does. For me, Laura has shown me the
line between behavior and ability, and here is how to attack this, and this is what you need to expect. Interventionist has allowed me the guiltless way to expect things. You can expect this for her. She can do this. Personal experience as a teacher for 14 years and my ESE endorsement, I think all teachers should see that. There is a specific level of guilt if your child is experiencing delays. They don’t need your help; they don’t want your help. Laura has done that for me and I needed that.” This statement suggests Katie’s mother experienced a transformation in terms of her expectations of her child as a result of Laura’s attitude.

Katie’s mother discussed the amount of anxiety transitions created prior to working with her interventionist. When these data were collected, a transition of a classroom change was about to occur and this mother addressed the difference she expected to see in this transition from previous transitions. Katie’s mother discussed the attitude of the intervention provider and how this has changed her view on transitions. Katie’s mother said, “Every time I get anxious I hear Laura saying it was not a big deal the last time in the back of my head.” Although Katie’s mother identifies past challenges with anxiety, she indicated Laura’s attitude facilitated a decrease in anxiety.

Observations provided evidence of the provider’s belief in the family to achieve desired outcomes with the result of child progress. One observation note said, “Bailey discussed his ability to sign and (how) the George’s mother has been working hard with him on signing.” The provider attributed George’s progress with sign language to the family and how they have been working with George using sign language. Progress was noticed in fine motor skills, attention, developmentally appropriate practice, engagement, communication, and positive response to an intervention strategy (i.e., pivotal response training). These data suggest the provider believed in the family to achieve outcomes, and progress was noted in the developing child.

Progress summaries also supported family progress. The summaries included specific areas where the family had progressed such as play, eye gaze, family support, fine motor skills, communication, and family experiences. George’s progress summary noted, “Good progress overall with play and eye contact, great home support, mother has been through this one time with older child, so she started him young, her first child did not start therapies until almost two.” Jose’s document exemplified belief in the family to achieve outcomes when it included information regarding the mother learning strategies. It noted, “Mom is beginning to see the importance of backing off and having expectation for Jose to perform task and to wait for him to
acknowledge her using nonverbal communication, and decreasing the amount of words she uses with him.”

When the providers exemplified an attitude of belief in the family, the family progressed. Katie’s mother discussed how the attitude of the provider altered the expectations she had for her child. A decrease in maternal anxiety was another way in which provider attitude facilitated family progress. These data suggest intervention providers’ belief that the family could achieve desired outcomes led to progress.

**Family Competence**

Results of data analysis suggest the attitudes of practitioners affect mothers and their experiences with early intervention. Five codes emerged within this subtheme which made up 18.52% of the data in asset based attitudes. All five codes were from interview data. These data suggest that intervention providers’ belief in the family as competent led to mothers believing in their family as capable interventionists. Family competence was exemplified when mothers discussed learning strategies to implement at home, providing help, feeling successful in implementing strategies, and feeling confident to try other things.

Mothers identified feeling as though they were doing all that they could for their child. For example, during one interview Mark’s mother said the intervention provider supported her when she explained, “Reassures me that I am doing all that I can for Mark.” Mark’s mother continued by saying, “I feel like I am doing something to help Mark. It was horrible watching him struggle like he was. He still will need more therapy, a consistent schedule, and lots of love and understanding…”

George’s mother discussed that the attitude of the interventionist allowed her to feel successful when she said, “I think I just feel like I can be successful in implementing the strategies and makes me feel more confident to try things that would be outside of my comfort zone.” George’s mother discussed one of her roles in the life of her son. When asked her about intervention services, she explained that she provides intervention in the home. Jose’s mother said, “I am a stay at home mom and I can work with Jose every day on whatever he needs help with.”
Research Question Two: What Types of Practitioner Interpersonal Skills Do Mothers of Children at Risk for ASD Report as Most Effective in Developing a Partnership with the Service Provider?

The second theme from the analysis of the data is interpersonal skills. Mothers have preferences regarding the way in which a partnership is most effectively formed with early intervention providers. Subthemes include communication, trust, and attributes of the provider. These data were gathered from interviews (13 codes) and observations (23 codes). The researcher coded 36 codes within interpersonal skills which make up 15.25% of the total data.

Communication

Mothers indicated their preferred mode for receiving information. Communication included 30 codes collected from interviews (10 codes) and observations (20 codes). The communication subtheme composed 83.33% of the interpersonal skills data.

Katie’s mother said, “I like a person talking to me discussing things with me. I love technology in my classroom and I am not afraid of technology but I think things get lost in translation. I have $100,000 worth of technology so it is not that I am afraid of it. There is a lot more communication that takes place [during face to face communication]. [When face to face does not occur] there is a lot that is lost and I feel more comfortable when I know that I am not on the record. In this day and age it is important to have that face to face. I think this is really important.”

Preferred methods of communication were also noted when the interventionist provided mothers with information in a way that matched their needs. Katie’s mother described her feelings regarding effective communication strategies when she said, “The encouragement that we see the potential. I do not have a magic ball but hang with us. Parents need to hear the positive progress that their child is making. It is a burden to show up and do this and that. It is stressful so it is important to see the progress. I don’t judge it. Just personally it is a big deal for parents to see this is what is making.”

Katie’s mother discussed how the interventionist provided clear and complete information. She said, “I think the intervention team expects her to do well, and look for the things she does do well. Laura does not blow smoke up your behind. She is not just saying she does not do this. She knows we are doing everything we can at home. She has given me strategies to see what is behavior and what is her ability and made it a positive experience. She
has noticed the progress not the milestones. Maybe you are not meeting this benchmark but look at how far she has come. All of the sudden she is making progress. For a long time that was not the case.”

Observational data supported the information mothers shared regarding effective communication. For example, one observational note demonstrated how Ileen provided encouragement during an assessment when she said, “Do not worry this is the 5 year old stuff.” Notes regarding listening were included in observation notes. For example, one observational record noted, “The provider was demonstrating active listening by nodding her head.” Providers also communicated using affectionate gesture (i.e., hugs) which appeared to be an effective interpersonal practice during intervention.

**Trust**

Trust was an interpersonal skill data suggests as important in forming partnerships. There were 4 codes included in this subtheme representing 11.11% of the data in interpersonal skills. Methods of data collection were observations (3) and an interview (1).

During an interview, Katie’s mother indicated her comfort level in talking to intervention staff when she said, “I feel comfortable enough talking to them.” When the mother indicated that she was comfortable sharing information with the provider, trust was demonstrated. Observational data supported trust as an effective interpersonal skill in forming partnerships. For example, during an observation, Mark’s mother said, “I feel like I can trust the staff here.”

**Attributes of the Provider**

Mothers recognized positive interventionist attributes. Attributes included two codes that made up 5.56% of interpersonal skill data. These data were collected during mothers’ interviews and included the qualities “helpful,” “caring,” “confident,” and “good.” During an interview, Mark’s mother said, “All of the ladies Mark and I have worked with for the past few months have all been so helpful.” George’s mother said, “They are good, confident, and caring.” These statements suggest that the interventionist interactions with the family were warm and empathetic.

**Research Question Three: In What Ways Do Mothers of Young Children at Risk for ASD Report the Family Being Involved As Choice Makers?**

Family choice and action is the third theme. Mothers indicated being involved as choice makers when they discussed their level of participation, assessments, intervention strategies, and
the setting in which they chose to receive intervention. Some mothers decided to take an active role in intervention while others preferred to observe. Mothers determined where and why they chose the setting in which their family would receive intervention services. They discussed feeling as though intervention providers listen, value their opinion, discuss their concerns with them, participate in goal setting, identify things the child likes and dislikes, identify child progress, and provide information regarding upcoming transitions. The subthemes were sources of information and decision makers. Methods of data collection included interviews (30) and observations (41). There were 71 codes included and are 30.08% of the total data.

**Sources of Information**

Mothers reported involvement in choice making by providing information to interventionists. They indicated interventionist listened and attempted to understand them, valued their input, and asked them questions regarding their family concerns and preferences. Fifty-nine statements (83.10% of the data) were coded within family choice and action. Methods of data collection included observations (22) and interviews (37).

Interview data provided evidence of being involved in choice making by mothers acting as sources of information. Participants discussed feeling as though the intervention provider listened to them. Mark’s mother said, “They really listen to me.” Mothers felt the information they shared was valued and was used to make choices.

George’s mother described how she worked with different interventionists and how they were all interested in her concerns. She said, “The thing that is really nice is they all ask specifically what are our concerns. The approach is different but they all (intervention providers) have similar beginnings where they ask, how is this impacting you, what do you need the most. It is helpful, it makes me feel that the services are more appropriate to our situation.” George’s mother discussed feeling everyone was really concerned when they asked her for information. She said, “Everyone is really concerned about his comfort and ability to get the most out of the session. She asked me how do you think he will get the most out of a session.”

George’s mother discussed sharing her opinion with the intervention provider regarding how to address her concerns. She said, “They do ask my opinion. For example the OT when we started [seeing her] said, ‘What are your biggest concerns?’ I laid them out, she said, ‘How would you like me to approach this?’ She gave me options. They are not only asking what should we work on but how should we work on this. When someone asks you should I proceed this way
or this way and it is my child, I feel better begin allowed to be a part of [the]decision process.” Mothers indicated involvement in choice making by sharing opinions regarding goals and intervention methods for their child.

Mothers were involved in choice making when they discussed family challenges and goals. George’s mother said, “They ask what to work on and tailor what they do. What are the things you have trouble with? For us these were things like sitting in the high chair, changing the diaper, and brushing teeth.” The mother felt the intervention was tailored to her child and the needs of her family.

Mark’s mother said she participated in goal setting. “We set goals for what we would like to work on with Mark. Sometimes it is for 1 month, 3 months, or 6 months. It depends on the goals we are setting for him.” This mother felt she was involved in choice making when she suggested specific targets for her family.

Treating mothers as a source of information was also apparent during observations. Intervention providers and mothers discussed the children’s likes and dislikes. For example, one observation note stated, “The provider asked Mark’s mother, ‘Does he like bubbles?’ Then Mark’s mother said, ‘Yes.’ Mark’s mother explained that he could say ‘bubbles,’ as in ‘bath bubbles.’ Mark’s mother talked about how they make smoothies and he tells her what he wants in it.” By sharing child preferences, the mother was working with the provider to make choices about what intervention activities would match family preferences.

During another observation, Laura and Katie’s mother began talking about an approaching school transition. The provider asked how the mother was feeling about this transition, as she knew the last had created some anxiety for the mother. The mother explained that she did not feel as worried about this transition. She talked about how the child has a friend in this class who speaks another language. Katie’s mother provided information regarding an upcoming transition. Sharing this information helped the provider to determine supports which might be necessary.

In addition to discussions, the researcher noticed that mothers were sources of information during assessment procedures. The observation record noted, “The provider let the mother hold the assessment book to see if mother prompting the child to do something would change the child’s response.” Providers also involved the mothers in assessment procedures by interviewing them about specific tasks. For example, the OT asked Katie’s mother, “How many
blocks does she stack?” When mothers were involved in assessment procedures, they helped to make choices regarding the development of the child.

Mothers acted as sources of information by discussing child progress. Mark’s mother talked about day care and the progress with separation anxiety. She said that the separation has gotten much better and the other day the child said, “Bye mommy.”

Analysis of the data suggests mothers are involved in choice making by acting as sources of information. Findings regarding this subtheme were specific to the intervention providers listening to families’ concerns and preferences. Mothers were sources of information regarding the development of their child and their progress with activities such as transition and separation anxiety. When mothers were involved as sources of information, choices were made about intervention such as goals, activities, and supports to match the information the family provided.

**Decision Makers**

In addition to providing information, mothers were involved in choice making by making decisions. Decision making was related to their level of participation, communication strategy (signs or words), intervention strategy, and assessment procedures. Six were coded into this subtheme which is 16.90% of the data in family choice and action. Sources of data include observations (5) and an interview (1). These codes were in relation to mothers’ level of participation, assessments, intervention strategies, and the setting where they chose to receive intervention.

Mothers decided how much they wanted to interact in intervention sessions. Some mothers were involved with intervention by engaging in the routines that were taking place while other families took more of an observational approach. For example, in one observation, “The mother came in at this point and sat down on the other side of the mat. The child had a smile on her face upon realizing her mother was there but continued to play as she was.” Mothers decided their level of participation whether they were engaged or took an observational role during intervention sessions. Intervention providers allowed mothers to determine their level of involvement.

In addition, mothers made choices regarding how they would like for the intervention provider to communicate with the child. During an observation, Ileen, the occupational therapist said, “Whatever you would like to use let me know so we can be consistent.” This was also evident when Madelyn was explaining her intervention method. She talked about intervention
programs she preferred, but said, “This choice is mostly determined by the family because it is important for me to have their buy in.” Madelyn’s statement exemplifies how mothers would determine the intervention strategy used because she wanted to be sure it was one the family would use. These examples demonstrate how mothers determined the intervention strategy to use with the child.

Mothers also made decisions during assessment procedures. Providers would suggest taking more of an interview approach but would give mothers the opportunity to indicate if the child should perform the task or if the provider would interview the mother to determine if a certain skill was mastered. For example, an observational report noted, “The provider explained that there is an option to interview or allow the child to explain and she felt it was better to interview and asked if the mother agreed. Mark’s mother also agreed.” Mark’s mother decided a more accurate picture of the child would be provided during the assessment if the interventionist interviewed her opposed to going through each of the assessment steps.

The setting of intervention services was another decision made by mothers. Mark’s mother talked about her feelings in terms of the decision she made regarding the intervention setting. She said, “I like that Mark has had a familiar setting for the past 2 years and the same people taking care of him throughout the day. I love the consistency.” Mark’s mother also discussed the setting as a place to get help when she said, “I am so glad that there was a place for me to go for help. I was struggling with Mark for a good year and felt as though I didn’t have anywhere to go for help. The ELC stepped in and has been there with me every step of the way.” She continued by discussing a feeling of belonging in their choice of intervention center. This mother said, “I am just so glad that he and I both have a place we can go and feel like we are surrounded by others in the same boat as us…. I feel like we have a place where there are other families overcoming the same obstacles as Mark and I. I love all that they do for my son. It’s a great facility and has great therapists.”

**Research Question Four: In What Ways Do Mothers Report Practitioner Responsiveness Impacting Family Experiences with Early Intervention?**

The theme of the final research question was practitioner responsiveness. Positive reactions were one way in which practitioner responsiveness impact mother experiences with early intervention. Mothers discussed their positive reactions to intervention services when they indicated the practitioner was knowledgeable, helpful, and looking for growth. Mothers also said
they love services and feel accomplished. Mothers reported practitioner responsiveness impacts family experiences with intervention by giving them access to helpful resources, facilitating child development, and providing positive reactions to the services they receive. Feeling hopeful and accomplishing goals were also positive reactions to intervention services that mothers shared during interviews. Three subthemes emerged from meaning units and pattern coding which included facilitating child development, positive feelings regarding practitioner responsiveness, and helpful resources. Data sources include interviews (38) and observations (64). One hundred two statements in practitioner responsiveness were coded into this theme which is 43.22% of the total data. Findings indicate data were specific to individualized intervention.

**Facilitating Child Development**

Mothers suggested practitioner responsiveness impacts family experiences with intervention by facilitating child development. Sources of data included interviews (17 codes) and observations (64 codes). Eighty-one codes were included in practitioner responsiveness which is 79.41% of the data within practitioner responsiveness.

Mothers’ interview responses included information about individualized intervention, family challenges, child progress, and family goals. All of these topics were in relation to facilitating child development in an individualized, flexible manner.

Mothers discussed individualized intervention. It was evident in mothers’ responses that they felt intervention was specific to the needs of their child. Katie’s mother said, “I think at this age there are so many things available for them to work on and feel like they build off of what she knows and what she is interested in. She is two and a half. It is colors. It is everyday things not so much homework and skills like that.” Katie’s mother identified facilitation of her child’s development because the interventionists are building off of what she knows.

Katie’s mother suggested she receives individualized intervention when she indicated the intervention providers know her child. She said, “…. They help me come up with really practical solutions. I can read a book they know my child!” Katie’s mother suggested the interventionists are facilitating child development because they know her child and for this reason intervention is individualized to her.

In addition to individualized intervention, mothers addressed specific challenges they face and strategies they have been given. Katie’s mother identified these challenges by saying, “Potty training, big girl bed, transitioning classes in school, birthday parties, things that are hard
for all kids at one point or another. They have given me strategies.” Mothers said that providers recognized problems, provided strategies, and identified child strengths. George’s mother said, “I think they do a good job of telling me the problems they see. They each have done good jobs of explaining where he is and what specific things they are working on.” Similarly George’s mother said, “They pinpoint specific problems. They try to replace the less desired activity or outcome with the more desired behavior. The other therapist gives us more global strategies like mouth shaping, blow bubbles, and specific activities or tips. Bailey will give me thoughts on whether to address it or how to address it. Sometimes Bailey tells me the best thing is to not worry about it. Pointing open handed instead of full finger and that was concerning to me and I wondered how to mold that better. The occupational therapist said, ‘Let’s just see how that evolves because I feel he is making progress there.’ Sure enough now he is a great pointer. You don’t waste time on things that will come around and spend time sharpening those things that need more. The nice thing is people have really tried to put things in context. Look this is a good sign this is something you can build on and generally a good indicator. They have been honest in his deficiencies but there is always much more positive. They are honest but they want us to see the good signs.” George’s mother said, “Well definitely they tailored what advice they gave us and what services they provided George to what we said was important to us. They showed it with actions.” Mothers suggest their child’s development is facilitated when the provider and family identified problems and challenges and found solutions and strategies that addressed them. The strategies are flexible to the needs of the family.

George’s mother identified specific goals toward which they were working. “Most of the time it is developmental goals. How do I get him to look at me, repeat sounds? They have given us tricks get his attention first. Don’t give him what he wants until he gives us an eye gaze…” George’s mother said, “You are a parent you know the kid is thirsty give them a drink, but it is important to make them work for it. They help by providing different activity ideas. Blowing, pausing…the most monstrous thing. I want an answer so I just give in so I just need that reinforcement.”

 Mothers suggested the result of practitioner responsiveness and how these practices facilitated child development. Katie’s mother explained, “…My child has received services that have tremendously altered her life.”
Researcher observations also provided evidence of practitioner responsiveness and how these practices facilitate child development. For example, observation note said, “Bailey and George spent time in the kitchen area where the child would grab a piece of fruit and bring it to Bailey and she would label the item which the child gave to her. The provider commented on the way the child was sitting and indicated she was observing this and wanted to make a mental note in order to work on this.” This provider was following the child’s lead and implementing the strategies of labeling items within the child’s play.

Another researcher observation note exhibited the practitioner’s response to a child who was upset, “Lucy rocked Katie. Then Lucy placed Katie in her lap and began applying deep pressure. Katie calmed down immediately. The provider showed her the puzzle and the child initially pushed it away but the provider said, ‘My turn.’ After watching the provider put in three pieces, the child engaged in putting pieces in the puzzle. At one point the provider said, ‘Police car goes here’ and assisted the child in placing it where it goes. Lucy was using a soft whispering voice. The provider sang a song about the worms ‘little fish swimming in the water.’ The provider said, ‘You are doing a good job…ta-da.’ Lucy got the glow paper and markers out. The provider mentioned that this activity helps with the grasp of the writing utensil. The provider narrated what the child was doing with the writing utensil. The provider said, ‘good, you made a circle.’ The provider pointed out how the child was drawing on one side. The provider was supporting the child drawing across the paper by using hand-over-hand. The child was prompted to sign all done after each activity. The provider did this by using hand over hand.” The provider in this example was using strategies to calm the child and then began implementing strategies in activities the child was interested.

Providers also used several strategies to encourage interaction and language production. One example of this took place when the researcher observed a speech language pathologist providing intervention; “Madelyn demonstrated excitement by saying, ‘Yay Jonathan, giraffe.’ Jonathan walked over to the books and said, ‘Elmo.’ The provider opened the drawer and the child got out the Elmo book. He was imitating the words and sounds the provider said as she pointed out objects in the book. The child spontaneously said, ‘The end.’ The provider was in constant motion positioning herself in a place where she and the child could engage with one another.” This provider was following the child’s lead and implementing strategies
(reinforcement) that matched the child’s interests. The provider was responsive to the child while facilitating child development.

Practitioner responsiveness was demonstrated when strategies were used that lined up with the goals of the family. Lucy demonstrated strategies to encourage interaction and language production. She did this by providing choices and encouraging interaction. The provider said, “Do you want more?” The provider would hand-over-hand help the child say more and would do it again. The provider got some pegs and asked the child if she wanted blue or purple. The child gazed at another provider and then signed more. The provider positioned Minnie and board near her face.”

During another researcher observation, Lucy used strategies to encourage interaction and joint attention. The observation note said, “The provider took the child to the bean bin and the provider began playing with the beans by scooping and dumping. The child imitated the provider and grabbed the provider’s hand to have her do what she wanted to do. The provider said, ‘Hey Katie!’ The child had no response. The provider pointed to another child and said look. The child followed her point. The provider began saying 1, 2, 3 flip and flipped the child upside down.”

Another strategy intervention providers used was one that Bailey described when she said, “I am looking for the criteria and am not finding it but that does not mean he does not have it. He has it and I just don’t know what it is. So my whole goal is looking for what he is avoiding and what he is seeking and pulling those two together to create balance.” Bailey identified observations as an intervention strategy she frequently uses to determine what the child is seeking and avoiding.

**Positive Reactions to Intervention Services**

Mothers suggested that practitioner responsiveness led to positive feelings in regard to intervention services. Seventeen statements (16.67% of the data) were coded within practitioner responsiveness. These data are from all mothers’ interviews.

When mothers identified practitioner responsive practices, topics included feeling as though the provider was knowledgeable and looking for growth, families felt hopeful, and families felt that intervention was helpful. Jose’s mother responded by saying things like, “Love it” as a response to their feelings regarding the services they are receiving.
Katie’s mother explained the provider is looking for growth when she said, “I really feel like they are looking for opportunities for her growth and for our best regarding outings and experiences to be enjoyable to make them as successful as possible which is great what else can you ask for.” George’s mother said, “I think in the beginning it made me feel hopeful that we were headed in the right direction based on where they thought we needed to be and what we needed at the time and now it makes me feel accomplished now that we have met so many goals and we are really starting to make the progress and hopeful that these people know what needs to come next.”

**Helpful Resources**

One way in which practitioner responsiveness impacted mothers’ experiences with intervention was by providing access to helpful resources. Four codes were found in helpful resources which is 3.92% of the practitioner responsiveness theme. All of these data were from mother interviews (four codes).

During interviews, two mothers discussed resources outside of their primary intervention providers who offered individualized support. Four statements (3.92%) were specific to these resources. The two resources the mothers identified were the early learning coalition (ELC) and the early social interaction project (ESI). George’s mother talked about how ESI was the most helpful because the information was specific to autism. George’s mother said, “Especially with ESI project we are starting with the playgroup, we go over specific situations. The ESI stuff is specific to autism and is most helpful to George.”

Another mother brought up the ELC and how resourceful this agency has been to the family by providing specific strategies for the family. Mark’s mother stated, “I have gotten a lot of feedback from the ELC as well as Children’s Corner as to what are other activities Mark and I could do at home….”

Mothers indicated that practitioner responsiveness was helpful to them as a family as these practices resulted in available resources for the family. They said that the ELC and ESI project were specifically developed to their needs and for this reason, these resources were most helpful.

**Conclusion**

Findings suggest that help giving practices lead to positive intervention experiences for mothers who have young children at risk for an autism spectrum disorder (see Table 11, 12, and
Asset based attitudes led to family progress and competence. The findings further suggest that provider attributes, communication, and trust are the most effective interpersonal skills in developing partnerships between the family and intervention providers. Mothers reported involvement in choice making by acting as sources of information and making decisions. These data indicate practitioner responsiveness led to helpful resources, facilitating child development, and positive reactions to intervention services.

Table 11

Research Question in Relation to Data Methods

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<td>Observations, Document Analysis, Interview Questions 8, 9</td>
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<td>What types of practitioner interpersonal skills do mothers report as most effective in developing a partnership with the service provider?</td>
<td>Observations, Interview Questions 6, 7</td>
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<td>In what ways do mothers report the family being involved as choice makers?</td>
<td>Observations, Interview Question 10</td>
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<td>In what ways do mothers report practitioner responsiveness impacting family experiences with early intervention?</td>
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Table 12

Themes and Data Collection Methods

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<td>Practitioner Responsiveness</td>
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Table 13

Themes and Subthemes

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<td>Family Competence</td>
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<td>16.90%</td>
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<td>22</td>
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<td>2</td>
<td>Attributes</td>
<td>5.56%</td>
<td>8.33%</td>
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CHAPTER FIVE
DISCUSSION

The purpose of this study was to gain a deeper understanding of the early intervention experiences of mothers who have a young child at risk for an autism spectrum disorder. Specifically, this study explored family help giving practices (Trivette & Dunst, 1998) that occurred and that impacted families. Qualitative methodology was used to analyze data from interviews with mothers of young children at risk for an autism spectrum disorder, observations of early intervention sessions, and documents containing information about the participating families and their progress since the start of early intervention services. Five mothers who have young children under the age of 3 years at risk for an autism spectrum disorder, their child, and their intervention provider(s) participated in this study. Intervention providers represented the fields of speech language pathology and occupational therapy.

The findings of this study are consistent with previous findings that suggest families who have young children with autism value resources and forming a relationship with intervention providers (Grindle, 2009). In addition, analysis of the data supports former findings that indicate intervention facilitated child progress and decreased family stress (Grindle, 2009; Patterson & Smith, 2011; Webster, 2004). Also consistent with previous findings, families value support from other families (Patterson & Smith, 2011).

Relational and Participatory Practices

Relational and participatory practices as defined and described by Trivette and Dunst (1998) provided the framework for this study. Both relational and participatory practices had positive impacts on mothers of young children at risk for an autism spectrum disorder and their early intervention experiences.

Relational practices include asset based attitudes and interpersonal skills. Asset based attitudes led to family progress and competence. Mothers suggested a strong partnership was formed when providers were confident, good, and caring.

Participatory practices include family choice and action and practitioner responsiveness. Mothers reported involvement in choice making. Participants suggested practitioner responsiveness led to gaining access to helpful resources, facilitating child development, and reacting positively to intervention services. Further, family help giving practices led to family
progress and competence. Mothers suggested feeling they made progress when they discussed a decrease in anxiety or learning new intervention strategies. Competence was exemplified when mothers explained providing intervention services to the child. Mothers identified feeling they had a mutual respectful relationship with early intervention providers. Information was shared about children and decisions were made about aspects of services such as the setting or assessment procedures. Access to resources such as ESI or ELC were aspects of family centered practice which mothers identified. Mothers indicated their children made developmental progress and had positive reactions to intervention services.

The results of this study suggest relational and participatory help giving practices have the potential to decrease family challenges with early intervention identified in previous studies. Challenges included arguments over which intervention style is most effective (sign language versus speech or developmental versus behavior; Beals, 2004), difficulty working with the educational authority, and disruption of privacy and family routines. Families have identified frustration with therapists who were disorganized, unknowledgeable, and unreliable (Grindle, 2009); and concerns related to uncertainty of expectations, difficulty in relating to interventionists, the time it takes to organize intervention and transition (Webster et al., 2004). However, when providers use relational and participatory practices, families who have young children at risk for autism have interventionists they trust, can communicate with effectively. In addition, the interventionists can work to promote competence and family progression; allow families to act as sources of information and make their own choices; deliver services that are based on the unique needs of the family in order to facilitate development; and provide helpful resources.

**Summary of Findings**

Five families participated in this research. Families demonstrated how participatory and relational practices affect their experiences with early intervention. Although there were consistencies in what mothers valued in early intervention services, each family had unique characteristics.

**George’s Family**

George’s family identified family centered practices as critical because George’s older brother was identified with an autism spectrum disorder, and his mother did not feel like there were strategies that matched the needs of George’s brother and the family. Intervention
strategies utilized were important to George’s mother because they provided the family with strategies specific to autism which they could use at home. George’s mother said, “They are just really specific. They will ask or I will volunteer what is concerning me or a problem. They will give me thoughts on how to address it.” It was important to George’s mother to learn intervention strategies that would enhance George’s language development and social interaction. George’s mother discussed using wait time. She said, “I am his mother and I know when he wants his juice, but instead of handing him his juice I wait for eye gaze and then give him his juice.” His mother discussed how this social communication strategy led to the progress George made with skills such as eye gaze.

George’s mother explained the importance of partnership and choice making. These practices were important to George’s mother because, although she worked full time, she wanted to be involved in intervention services. George’s mother felt this was possible through communicating with intervention providers. George’s mother talked about going to Children’s Corner for the first time. George’s mother explained, “When we started services the OT said, ‘What are your biggest concerns?’ I laid them out. She said, ‘How would you like me to approach this and gave me options.’ When someone asks you should I precede this way or this way and it is my child, I feel better being allowed to be a part of the decision process.” During observations the interventionist continued this practice when she started each intervention session by talking to the mother about how the child was doing and asking if there were any new concerns.

Jonathan’s Family

Family centered practices were important to Jonathan’s family because his mother was familiar with early intervention. Jonathan’s mother participated in early intervention services with her older son. Because of this, she was familiar with the early intervention system. His mother was already experienced in receiving early intervention services and she saw the results of effective intervention with her older son who was diagnosed with Down syndrome. Jonathan’s mother also worked as an early interventionist at Children’s Corner. She felt that she had a strong partnership with the early intervention providers not only as her son’s early intervention provider, but also because she collaborated with them daily. Jonathan’s mother said, “The interventionists and I talk all the time about the kids. Madelyn and I bounce ideas off of one another. Ileen answers my questions and takes my input into consideration all of the time.
I am able to read progress notes on the computer.” Jonathan’s mother identified satisfaction with services because Jonathan was progressing and she could use the intervention strategies at home. The researcher noted progress during an observation when Madelyn said, “He responds well to pivotal response training. He has a lot of affect and eye gaze.”

Jose’s Family

Jose’s mother identified family centered practice as an important element to the services she received because she had two other children who were typically developing and she wanted to help Jose in any way that she could. Jose’s mother was offered home-based services; however, it was important to her to focus her whole attention on Jose during intervention so she chose to receive services at Children’s Corner. By leaving her other two children at home with a nanny, she felt she could take Jose to Children’s Corner and direct all of her attention to him during intervention sessions.

Jose’s mother discussed how much Jose developed since they began intervention. She discussed how he started using more words and how much she loved receiving services at Children’s Corner because she was able to see his progress. When the researcher asked Jose’s mother about Children’s Corner, she said, “It helps my son do the things he couldn’t do. For example speak.” During observations, it was evident Jose’s mother was able to direct her whole attention to Jose by watching the intervention strategies and discussing with the intervention provider concerns and progress. During the interview Jose’s mother said, “Talking as we are doing therapy, the therapist is always telling me information about what she is doing with Jose, why she is doing it, why Jose needs it, and how it is going to help my son. She asks for my opinion and then I can tell her if that is going to work for us or not. So far it is always something that works for us.” Jose’s mother also discussed what she learned at Children’s Corner and using the strategies at home. Specific strategies Jose’s mother identified were related to counting and language development.

Katie’s Family

Family centered practices were important to Katie’s mother because she received services through another agency prior to Children’s Corner which she discussed as a negative experience when she said, “I did not care if my child would never speak. I was done with [a prior service provider].” Katie’s mother explained that the current intervention team knew her child and intervention was tailored to Katie and the concerns of the family. Hearing about positive
progress was something Katie’s mother identified as important to her because her prior intervention experiences were focused on things her child was not able to do. During the interview Katie’s mother said, “The thing is they expect her to do well, and look for the things she does do well. They do not blow smoke up your behind. She knows we are doing everything we can at home.” Katie’s mother discussed how she felt the current intervention team was looking for positive outcomes and recognized progress in Katie. This progress was also evident in Katie’s progress summary where it noted, “Katie has made good progress overall. She is using more words and has begun to interact more with intervention providers.”

Katie’s mother identified communication and trust as effective practices in developing a partnership with intervention providers. She discussed past experiences where she felt there was not a relationship with intervention providers, and this was challenging to her. She explained receiving emails that listed all of the areas where her child needed improvement, creating anxiety for her. Katie’s mother expressed how she felt so much was lost in electronic communication. She explained how she appreciated the face-to-face communication she had with Bailey and Laura. During the interview Katie’s mother said, “I feel comfortable talking to them and they help me come up with really practical solutions.” Katie’s mother discussed feeling comfortable in sharing information with Bailey and Laura and suggested the importance of a trusting relationship with intervention providers. This finding was also evident in observations. During an observation Katie’s mother discussed how Katie had a fear of Santa Claus but the mother wanted to get a picture of her with Santa. The provider explained that they were going to have Santa come to Children’s Corner and because it would be in a familiar setting, she might be more successful.

Mark’s Family

High priority was placed on family centered practices by Mark’s mother because she was new to early intervention services and wanted to be involved by doing all that she could for her son. She asked questions about the other children receiving intervention services at Children’s Corner suggesting curiosity of how her son would progress. For example, during an observation, Mark’s mother asked Ileen about another child when she said, “Does that little boy have autism?”

Initially Mark’s mother discussed how she felt she hindered her son because when she was in the room he just wanted her to hold him. She would leave the room crying at times;
however, as observations continued, she discussed how much Mark progressed since starting intervention services. She explained that he handled transitions better and used more language since starting intervention at Children’s Corner. Mark’s progress summary stated, “Mark just started services, but is making progress. He is doing better with feeling comfortable here and is beginning to use words.”

Maintaining a trusting partnership with interventionists was important to Mark’s mother since she was a single parent sharing custody of Mark with his father. Mark’s mother was the primary caregiver participating in intervention. Mark’s mother said, “I just really like having someone to talk to. A lot of times I feel like I am at fault for my son’s delays. It is nice to talk to someone.”

The setting of services was a way Mark’s mother was involved in decision making. Children’s Corner was her choice because she felt other children there were similar to Mark. Mark’s mother said, “I am just so glad that he and I both have a place we can go and feel like we are surrounded by others in the same boat as us.” This was important to her because Mark also attended a child development center where there were no families with whom she could identify.

**Summary of Families**

All families identified asset based attitudes, interpersonal skills, family choice and action, and practitioner responsiveness as important aspects to the services they received. Because Jonathan’s mother collaborated daily with the professionals both professionally and personally, she had more opportunities than the other families to discuss Jonathan and his progress and to review data regarding her child. Although she had these opportunities, results suggested the help giving practices she saw as critical are the same as the other families. This finding suggests that although she had more opportunities to collaborate with the interventionists, this did not effect families experiences with family centered help giving practices.

Jose and Mark’s mothers discussed choosing the setting of services, however, their rationale for these decisions were different. Jose’s mother chose Children’s Corner because receiving services outside of the home allowed her to focus on Jose during intervention sessions. This may have been a result of Jose’s mother having three children. Mark’s mother also discussed choosing the setting of services, however, she chose Children’s Corner because she felt as though she could identify with other families. This finding may be a result of Mark’s mother experiencing early intervention for the first time.
Families had differences in their personal circumstances and reasons for which these practices were important. For example, Katie and George’s families had negative experiences with early intervention. George and Jonathan’s families had experiences with an older child receiving early intervention. It is important to note that family centered practices were taking place as families have discussed these practices being absent from the services they received (Beals, 2004; Grindle, Kovshoff, Hastings, & Remington, 2009; Patterson & Smith, 2011; Rodger et al., 2008; Webster et al., 2004). Practices families have identified as taking place are described as family centered practices (Trivette & Dunst, 1998). Mothers of young children at risk for an Autism Spectrum Disorder suggest they have positive outcomes.

**Implications for Personnel Preparation**

The results of this research have implications for early intervention personnel preparation programs. Research indicates there are variations in the degree to which help giving practices are being used by intervention professionals (Dunst & Dempsey, 2007). The way in which intervention is provided is equally important as the intervention provided (Trivette & Dunst, 1998; Summers et al., 2007). Therefore, it is important to explore frameworks that suggest key components to providing effective help giving intervention such as the family help giving practices framework.

Programs preparing pre-service early interventionists to work with families should include family help giving practices as a core topic in their curriculum in order to ensure that families are indeed receiving intervention services that are family centered. Specific competencies would include participatory and relational practices (Trivette & Dunst, 1998). Participatory practices are practitioner responsiveness and family choice and action. Practitioner responsiveness are practices which are unique to the family. Family choice and action is how the family is involved in reaching choices and intervention services. Relational practices are asset based attitudes and interpersonal skills. Asset based attitudes are the beliefs that the family are competent intervention providers. Interpersonal skills are interacting with the family in a warm and caring manner.

**Implications for Current Intervention Practice**

Interventionists who are currently providing early intervention services should consider this framework and make relational and participatory practices the foundation of their practice. Because there is variation in the degree to which help giving practices are being used, reviewing
the help giving framework would familiarize professionals with family centered practice and allow them the opportunity to self reflect regarding their current intervention practice to determine if asset based attitudes, interpersonal skills, family choice and action, and practitioner responsiveness are the foundation of their practice (Dunst & Dempsey, 2007). The findings from this research can be used in professional development in order to demonstrate the impact of help giving practices on families who have young children at risk for autism and their experiences with early intervention.

**Implications for Future Research**

As families and intervention services continue to evolve, it is important to continue conducting research involving family experiences with early intervention. Particular topics are family centered practice and families who have young children with autism. There are more families who have young children with autism who are receiving services now than ever before (Henderson, 2009).

Therefore, researchers might consider recruiting families who have young children with autism to participate in research as they have discussed frustrations with intervention personnel, services, and resources (Beals, 2004; Grindle et al., 2009; Rodger et al, 2008; Webster et al., 2004). These families have also discussed their unique emotional needs and how these have been unmet (Patterson & Smith, 2011). As families who have young children with autism increase, it is important to learn more about these families and how their needs can be most adequately met. This study suggests the family help giving framework leads to positive outcomes. More research should be done with this framework to learn more about these practices and how they impact these families. Research questions might include:

1. How do interventionists exemplify asset based attitudes, interpersonal skills, family choice and action, and practitioner responsiveness?
2. What do families who have young children with autism identify as unmet needs?
3. What do families who have young children with autism express as positive experiences with intervention?
4. What do families who have young children with autism express as intervention areas needing improvement?
5. What challenges do early interventionists suggest as barriers to delivering help giving practices?
Limitations

Because this study included only five families, generalization of the results must be made with caution. Further, although all families had a young child at risk for an autism spectrum disorder, there are other differences such as culture, socio economic status, and amount of time receiving early intervention that may influence family experience with intervention. Despite these differences, common themes and experiences were found among family members.

This study was conducted at one intervention program - Children’s Corner. As such, participants are not a representative sample of the population. All families participating in this research chose to receive services at Children’s Corner. While one family received early intervention services with an alternate agency prior to Children’s Corner, the other four families’ first experiences with early intervention, Part C services were with Children’s Corner. This had the potential to impact results, as one family was comparing their current experiences to past experiences while the other families were discussing their first experiences with early intervention.

Families who participated in this study indicated high-income levels. Family income may be tied to obtaining resources that are meeting family needs (Bailey et al., 2003; Epley et al., 2011), as families with higher income have the financial ability to pursue private resources. Although these families were receiving services early intervention Part C services, their income level may have correlated to being aware of Children’s Corner and having the resources to pursue services at a desired location. If this is the case, the positive experiences of these families may be related to their income level.

Conclusion

Families who have young children at risk for an autism spectrum disorder have initial experiences that differ from other families who have children with disabilities. Families have discussed the impact of learning their child has a disability on the family (Nelson, 2002). Families who have young children at risk for an autism spectrum disorder are frequently unaware of this disability until the child is approximately two years of age while other families are aware of a disability much sooner (Layne, 2007). Although these initial experiences differ, the analysis of the data supported that families who have young children at risk for an autism spectrum disorder value the same help giving practices as other families. This information suggests that while families who have young children with an autism spectrum disorder are increasing
(Henderson, 2009), family centered practice is of high value to all families. Because service adequacy has an effect on family quality of life, it is vital to continue emphasizing the importance of family centered practice for all families in personnel preparation and professional development programs and to continue listening to the voices of families in early intervention research (Epley et al., 2011; Summers et al., 2007).
APPENDIX A

Mother Questionnaire

1. When did your child receive a diagnosis?

2. Please list the types of services your child receives and when your child began receiving these services:

<table>
<thead>
<tr>
<th>SERVICE (EXAMPLES: PHYSICAL THERAPY, OCCUPATIONAL THERAPY, SPEECH LANGUAGE THERAPY, ETC.)</th>
<th>WHEN DID YOUR FAMILY BEGIN RECEIVING THIS SERVICE? (MONTH/YEAR)</th>
<th>How often does your family receive this service? (I.e., 1 hour per week)</th>
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</tbody>
</table>

3. Your highest degree earned is: circle one for each adult living in the home where the child lives.

   o GED

   o High school diploma

   o Two year degree

   o Bachelors degree

   o Masters degree
4. **Type of household:**
   - Two parent household
   - Single parent household
   - Other:

5. **Number of children:** ________

6. **List the birthdate and gender of all of your children:**

<table>
<thead>
<tr>
<th>Birthdate: d/m/y</th>
<th>Gender: M or F</th>
<th>Currently receiving Early Intervention (Yes or No)</th>
<th>IF YES, for what reason is your child receiving services (developmental delay, an established diagnosis)</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>

7. **Race:**
   - White not Hispanic
   - Black
   - Asian
   - Hispanic (any race)

8. **Age of Parent(s):** (You may circle two different age groups if there are two parents who are within two different categories):
   - 15 to 24
   - 25 to 34
o 35 to 44
o 45 to 54
o 55 to 64
o 65 and older

9. **Gross Household income:**

  o Less than 20,000
  o 20,001 to 38,043
  o 38,044 to 61,735
  o 61,736 to 100,065
  o 100,066 or higher
APPENDIX B

Intervention Provider Questionnaire

1. Gender:
   - o Male
   - o Female

2. Age:
   - o 15 to 24
   - o 25 to 34
   - o 35 to 44
   - o 45 to 54
   - o 55 to 64
   - o 65 and older

3. Your educational background is a ________________ (i.e., Bachelors, Masters, PhD) in ________________ (i.e., Special Education, Communication Disorders, etc.).

4. The length of time you have been providing intervention services is ____________.
   a. What agencies?

5. If applicable, list any specific licenses, credentials, or endorsements you possess:

6. How would you define family centered services?

7. How do you do family centered services?
APPENDIX C

Mother Interview Questions

Rapport Building

1. How are you doing?
2. Tell me about your child.
3. Tell me about the services your family is receiving.
4. I am interested in learning more about family experiences with the intervention services you are receiving. The purpose of this study is to learn about family experiences in order to improve current practice and enhance personnel preparation. The information that you share with me today will remain confidential.
5. I would like to collect some general information about your family. Can you please fill in this form?

Interpersonal Questions

6. In what ways does the service provider(s) share information with you?
   a. Can you provide me with an example?
   b. What do you like?
   c. What don’t you like?
7. What does the early interventionist do to make you feel good?
   a. Can you provide an example?

Asset Based Attitude Questions

8. What does the early interventionist do to make you feel like you can teach your child?
   a. Can you give me an example?
   b. How does this make you feel about the services you receive?
9. What does the early interventionist do to understand what is important to your family?
   a. Can you provide an example?
   b. How does this make you feel about the services you receive?

**Family Choice and Action Questions**

10. How do you and the service provider(s) work together so your child learns what is important?
   a. Can you provide me with an example of how you and the service provider work together to make decisions?
   b. Can you provide me with an example of how you and the service provider work together to allow for family participation?
   c. How does this make you feel about the services you receive?

**Practitioner Responsiveness Questions**

11. How does the service provider(s) help you come up with solutions with problems you are facing?
   a. Can you provide me with an example of how the provider(s) help you make a plan to deal with these challenges?
   b. How does this make you feel about the services you are receiving?

12. How does the service provider(s) show you that they value your opinion?
   a. Can you provide me with an example?
   b. How does this make you feel about the services you are receiving?

13. How does the service provider show you that the services you are receiving are based on the needs of your family?
a. Can you provide me with an example?

b. How does this make you feel?
APPENDIX D

Document Analysis Summary

Adapted from Miles and Huberman, 1994

Date retrieved:

Date created:

Participant:

Name of document:

Description of document:

Summary of contents:
APPENDIX E

Observation Protocol

Date:

Observation Location:

Interpersonal skills taking place:

Asset based attitudes taking place:

Family choices taking place:

Practitioner responsiveness taking place:

Other observations taking place:
## APPENDIX F

### Family Centered Help Giving Practices Rated by the Director of Children’s Corner

*(Trivette and Dunst, 1998)*

<table>
<thead>
<tr>
<th>Components</th>
<th>Rate of Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0: not important</td>
</tr>
<tr>
<td></td>
<td>5: somewhat important</td>
</tr>
<tr>
<td></td>
<td>10: very important</td>
</tr>
</tbody>
</table>

### Interpersonal Skills
- Communicate clear and complete information in a manner that matches the family style and level of understanding
- Interact with the family in a warm, caring, and empathetic manner
- Treat the family with dignity and respect and without judgment.

---

### Asset Based Attitudes
- Communicate to and about the family in a positive way
- Honor and respect the family’s personal and cultural beliefs and values.
- Focus on individual and family strengths and values
- Acknowledge the family’s ability to achieve desired outcomes

---

### Family Choice and Action
- Work in partnership with parents/family members to identify and address family-identified desires.
- Encourage and assist the family to make decisions about and evaluate the resources best suited for achieving desired outcomes.
- Seek and promote ongoing parent/family input and active participation regarding desired outcomes
- Provide family participatory opportunities to learn and develop new skills.

---

### Practitioner Responsiveness
- Assist the family to consider solutions for desired outcomes that include a broad range of family and community supports and resources.
- Support and respect family member’s decisions.
- Work with the family in a flexible and individualized manner.
- Offer help that is responsive and matches the family’s
| interests and priorities.  
| • Assist the family to take a positive, planned approach to achieving desired outcomes. |
Families,

I am a Doctoral Student at Florida State University in Special Education, and would like to learn about your experiences with early intervention. I am looking for approximately five families who will allow me to observe their family receiving early intervention and participate in one interview. If you are willing to participate, please read and sign the official letter of consent attached, and I will be in touch soon.

Thank you for your time and consideration,

Christian Grygas Coogle
September 26, 2010

Dear Parent(s),

Christian Grygas Coogle, a Doctoral Student in the Department of Special Education and her supervisor, Dr. Mary Frances Hanline, Florida State University Faculty, are interested in researching parent perspectives of intervention their children are receiving. Specifically, the researcher is interested in families who have children on the autism spectrum. The purpose of this study is to learn about family experiences so that personnel preparation and family experiences with early intervention may be improved.

In order to do this, we would like to invite qualifying families (those who have children ages 0-3 who are at risk for an autism spectrum disorder or identified with autism, and receiving early intervention) to participate. Participation in this research will involve allowing the researcher to observe your family receiving early intervention services, participating in one interview that will last no longer than 60 minutes, and allowing the researcher to review the Individual Family Service Plan. The researcher will observe one to five intervention sessions. During observations, the researcher will take notes using her password protected computer. The researcher will use an audio recording device (tape recorder) to record family responses. When reviewing the document, the researcher will use a document analysis summary form to include information that supports family experiences with intervention.
This study has very little risks. The records of this study will be kept private and confidential to the extent permitted by law. Audio recordings will be uploaded to a computer and deleted from the tape recorder immediately following the interview. In order to ensure all data is secure, it will be stored on a password protected computer that only the researcher has access to. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Specifically, code names will be developed in any sort of report that may be published to maintain participant confidentiality (example, Sue will be named Mary in a report). Research records will be stored securely and only researchers will have access to the records.

The benefits of this study include impacting personnel preparation and family experiences with early intervention by sharing your personal experiences with early intervention. This information will be gathered through observations, one interview, and a document analysis of the individual family service plan. It is the researcher’s intent to provide families with a gift card to compensate their time in this research.

The researchers conducting this study are Christian Grygas Coogle who will be supervised by Dr. Mary Frances Hanline. If you have any questions, please contact the FSU researchers at the following phone numbers and e-mail addresses:

• Christian Grygas Coogle
• Mary Frances Hanline

If you have any questions or concerns regarding this study and would like to talk to someone other than the researchers, you are encouraged to contact the FSU Institutional Review Board (IRB) at 2010 Levy Street, Research Building B, Suite 276, Tallahassee, FL 32306-2742, or 850-644-8633, or by email at humansubjects@magnet.fsu.edu.

If you would like to participate, please return this letter after completing this information below. Families who agree to participate will receive a family gift even if you feel you need to withdraw from the study before it is complete.
Sincerely,

Mary Frances Hanline, Ph.D.
Associate Professor

Christan Grygas Coogle
Doctoral Candidate

______________________________________________________________________________

I would like to participate in the research described above. I will allow the researcher to observe approximately three intervention sessions, participate in one interview, and allow the researcher to review one intervention document.

________________________________________
Parent Name Printed

________________________________________
Parent Signature

Email address: ______________________________________________

Phone number: ________________
September 26, 2010

Dear Intervention Provider,

Christan Grygas Coogle, a Doctoral Student in the Department of Special Education and her supervisor, Dr. Mary Frances Hanline, Florida State University Faculty, are interested in researching parent perspectives of intervention their children are receiving. Specifically, the researcher is interested in families who have children on the autism spectrum. The purpose of this study is to learn about family experiences so that personnel preparation and family experiences with early intervention may be improved.

In order to do this, we are inviting qualifying families (those who have children ages 0-3 who are at risk for an autism spectrum disorder or identified with autism, and receiving early intervention) to participate. Families who have agreed to participate work with you as their family’s early intervention provider, and therefore consent is needed from you to be included in the research. Participation in this research will involve allowing the researcher to observe the family receiving early intervention services, completing an online survey which contains approximately 10 questions, and allowing the researcher to review the Individual Family Service Plan. The researcher will observe anywhere from one to five intervention sessions. During observations, the researcher will take notes using her password protected computer. The researcher will use an audio recording device (tape recorder) to record family
responses. When reviewing the document, the researcher will use a document analysis summary form to include information that supports family experiences with intervention.

This study has very little risks. The records of this study will be kept private and confidential to the extent permitted by law. Audio recordings will be uploaded to a computer and deleted from the tape recorder immediately following the interview. In order to ensure all data is secure, it will be stored on a password, protected computer that only the researcher has access to. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Specifically, code names will be developed in any sort of report that may be published to maintain participant confidentiality (example, Sue will be named Mary in a report). Research records will be stored securely and only researchers will have access to the records.

The benefits of this study include impacting personnel preparation and family experiences with early intervention by sharing your personal experiences with early intervention. This information will be gathered through observations, one interview, and a document analysis of the individual family service plan. It is the researcher’s intent to provide families with a gift card to compensate them for their time in this research.

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- Christian Grygas Coogle
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If you would like to participate, please return this letter after completing this information below. Families who agree to participate will receive a family gift even if you feel you need to withdraw from the study before it is complete.

Sincerely,

Mary Frances Hanline, Ph.D.
Associate Professor

Christian Grygas Coogle
Doctoral Candidate

I would like to participate in the research described above. I will allow the researcher to observe approximately three intervention sessions, participate in one interview, and allow the researcher to review one intervention document.

_____________________________________________________
Intervention Provider Name Printed

_____________________________________________________
Intervention Provider Signature

Email address: ________________________________
Phone number: ________________________________
APPENDIX J

IRB Approval Letter

Office of the Vice President For Research
Human Subjects Committee
Tallahassee, Florida 32306-2742
(850) 644-8673 · FAX (850) 644-4392

APPROVAL MEMORANDUM

Date: 11/14/2011

To: Christian Coogle

Dept.: SPECIAL EDUCATION & REHABILITATION COUNSELING

From: Thomas L. Jacobson, Chair

Re: Use of Human Subjects in Research

AN EXPLORATORY STUDY OF FAMILY CENTERED EXPERIENCES WITH EARLY INTERVENTION

The application that you submitted to this office in regard to the use of human subjects in the research proposal referenced above has been reviewed by the Human Subjects Committee at its meeting on 10/12/2011. Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals, which may be required.

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 10/10/2012 you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date; however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition,
federal regulations require that the Principal Investigator promptly report, in writing any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the Chair of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is FWA00000168/IRB number IRB00000446.

Cc: Mary Hanline, Advisor
    HSC No. 2011.7123
REFERENCES


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*Personalized pediatric coordinated services (PPCS): A family-centered model of coordinated services for young children with chronic illness and disabilities.* (1996).


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BIOGRAPHICAL SKETCH

Christian Grygas Coogle was born in Charlotte, North Carolina. She received both her Bachelors and Masters degrees at Florida State University in Special Education with an emphasis on preschool disabilities. She returned to Florida State University where she completed her Doctorate Degree of Philosophy in Special Education with an emphasis on early intervention. Dr. Coogle has worked as a teacher of children with special needs in both inclusion and self contained settings. In addition, she worked at Florida Center for Reading Research where she collaborated with preschool teachers around the country by providing and creating professional development opportunities. Currently she works at West Virginia University as an Assistant Professor in the Department of Special Education.