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CHALLENGED BY FAMILIES WITH CHALLENGES:  
AN INVESTIGATION OF FAMILY SUPPORTS  
IN EARLY INTERVENTION

By

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Anna Christine Friend

B.S. University of Kansas, 1991  
M.S. Pittsburg State University, 1995

Submitted to the Department of Special Education and the  
Faculty of the Graduate School of the University of Kansas  
In partial fulfillment of the requirements for the degree of  
Doctor of Philosophy

Dissertation Committee:

---

Co-Chair, Ann P. Turnbull, Ed.D.

---

Co-Chair, Jean Ann Summers, Ph.D

---

H. Rutherford Turnbull, LLM

---

Winnie Dunn, Ph.D, OTR, FAOTA

---

Mary Jane Brotherson, Ph.D

Dissertation defended: November 2007

The Dissertation Committee for Anna Christine Friend certifies  
that this is the approved version of the following dissertation:

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AN INVESTIGATION OF FAMILY SUPPORTS  
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Dissertation Committee:

\_\_\_\_\_  
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\_\_\_\_\_  
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\_\_\_\_\_  
H. Rutherford Turnbull, LLM

\_\_\_\_\_  
Winnie Dunn, Ph.D, OTR, FAOTA

\_\_\_\_\_  
Mary Jane Brotherson, Ph.D

Date approved: \_\_\_\_\_

## Abstract

This dissertation presents the findings of a grounded theory study examining family supports in early intervention. The purpose of the study is to understand how practitioners perceive families with challenges and how their perceptions influence the practices and supports they provide to families with challenges. We observed practitioner and family interactions during home visits and interviewed both parties at three Part C agencies in the Midwest. We found that practitioner perceptions and assumptions about families with challenges influenced the practices they implemented during home visits, which, in turn, impacted the outcomes families received. We present our findings in a dynamic framework depicting the interactional process of the family and practitioner relationship. The dissertation details the components of our framework based upon evidence in the data. Our discussion focuses on four key themes from the findings: (a) definition of families with challenges, (b) the meaning of empowerment, (c) boundaries and relationships with families, and (d) unmet needs of families with challenges. Implications for further research, policy, and practice are presented.

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## CHAPTER 1: INTRODUCTION

The purpose of this study is to investigate how early intervention practitioners' perceptions about the nature of families with challenges influence their interactions with and services to, those families. The following sections summarize the current state of the literature with respect to this issue, and establish the importance of the study. The following sections examine (a) who's fairing well and who's fairing poorly in early intervention? (b) who are families with challenges? (c) why are family supports elusive? and (d) why do families with challenges lack supports?

### *Who's Faring Well and Who's Faring Poorly in Early Intervention?*

The literature suggested that, despite evidence that families for the most part were highly satisfied with early intervention services, families from racially and economically diverse backgrounds tended to be less satisfied and expressed more unmet needs. One goal of early intervention programs has been to enhance the families' capacity to meet the needs of their infant or toddler with a disability (Bailey, 2001; Hebbeler et al., 2007). Although a slight majority (59%) of families receiving early intervention supports have reported their own families were better off as a result of the services, families living in poverty and families from racially diverse backgrounds have fared less well (Hebbeler et al., 2007). Data from the National Early Intervention Longitudinal Study (NEILS) indicated a discrepancy between white families and families of economic and racial diversity (Hebbeler et al., 2007). Early intervention services have not been equally accessible to all families; families

2from poverty and racially diverse backgrounds in the NEILS study felt that accessing services took extra effort (Hebbeler et al., 2007).

At the beginning of receiving early intervention services, most families detailed positive encounters with practitioners (Hebbeler et al., 2007). In the NEILS study, 99% of families believed practitioners were respectful of their values and cultural backgrounds. Only 7% of families felt practitioners ignored their opinions. Yet, nearly half of all families stated practitioners made the decisions for the Individualized Family Service Plan (IFSP). Although the majority of families were satisfied with their role in the decision-making, families from racial diverse backgrounds and lower socioeconomic status (SES) wished to be more involved in the IFSP process (i.e., 37% of African-American families, 29% of Latino or Asian families, and 34% of families having mothers with less education).

A large majority of families in the NEILS study denoted satisfaction with early intervention programs, nevertheless 22% of families reported they should have received more services (Hebbeler et al., 2007). Racially diverse families were 2.1 times more likely than white families to be less positive about early intervention services. Many families felt that services were only somewhat individualized to their families' unique needs (31%).

Darling and Gallagher (2004) researched the differences in needs and supports of families with young children who have disabilities that come from an African-American or an European-American background who live in differing geographic areas (rural or urban). The authors found that family need was significantly different

between African-American and European-American families, but did not differ for geographic location. African-American families reported more family needs than European-American families. In contrast, family supports were significantly different for families in differing geographic areas, rural or urban, but not for families of differing ethnicities. Families in urban areas indicated they had less family supports than families in rural areas. European-American families in rural settings reported the highest levels of spousal support; whereas, African-American families living in urban areas expressed more needs for personal and family growth.

Reports in the NEILS study by both families and practitioners indicated services focused primarily on the child (Hebbeler et al., 2007). The services that were provided to families focused on parenting skills, which included learning how to play with and talk with their child more effectively, understanding their child's developmental or special needs, and including the child in the daily routine. Families told practitioners they needed community supports for their child, such as child care, recreational supports, and connections with other community agencies; however, they often did not receive these services.

#### *Who Are Families with Challenges?*

To address the question of defining families with challenges, the relevant literature focused on identification of risk and protective factors that predict poor developmental outcomes in children. In this section we reviewed the literature which identified those factors.



Poverty has been well-established as one of the strongest predictors of poor developmental outcomes in children (Sameroff, 1998). One-fifth of children under the age of 6 have lived in families with income below the poverty line (RAND Corporation, 2005). Results of a study examining the datasets for 13 years indicated an increase in childhood disability among those living in poverty and single parent families (Fujiura & Yamaki, 2000). Turnbull, Stowe, and Huerta (2007) described the theory of comorbidity in which disability has been highly correlated with poverty, ethnic, cultural, or linguistic diversity, single-family structure, and certain geographic places of residence.

Based upon the NEELS data, there has been an overrepresentation of low-income children among early intervention recipients (27% compared to 21% of the general population for three year olds) (Hebbeler et al., 2007). In addition to low SES, children and families entering early intervention were also likely to have the following characteristics: (a) live in a single parent household (68%), (b) have a mother who did not attend college (48%), (c) be African American (21% compared to general population of 14%), (d) have a difficult birth history (57% compared to 48% for nonpoor), and (e) be in poor health (23% compared to 12% of nonpoor).

The Rochester Longitudinal Study (RLS) examined the impact of environmental risk factors on children (Sameroff, 1998). In the study, children and their families were assessed through infancy to the age of 4 and again in adolescence. The RLS reported that SES was the best variable for predicting a child's future development. Further, at age 4 years, the RLS found that the combined impact of risk

factors influenced the child's social-emotional and cognitive development. The family's SES affected parenting, parenting attitudes and beliefs, and family interaction. "It is in families that have multiple risk factors that the child is placed in jeopardy" (Sameroff, 1998, p. 1289).

Keogh (2000) defined risk as the negative conditions that impede a child's development. The most commonly identified environmental risk factors in the literature include: (a) low SES or poverty; (b) unsafe neighborhoods; (c) low parent education; (d) large family size; (e) children closely spaced in age; (f) overcrowded home; (g) frequent changes in residence; (h) frequent parent absence or single parenthood; (i) mother's mental health; (j) parent criminality; (k) parent substance abuse; (l) head of household in unskilled occupation or unemployed; (m) culturally diverse background status; (n) violence or physical abuse; (o) lack of social supports; and (p) identified developmental disability in the child by age 3 (Keogh, 2000; Landy & Menna, 2006; Sameroff, 1998). Many of these risk factors were related to poverty or low-income status. Environmental risk factors have been associated with gaps in school readiness and have further translated into a child's poor academic achievement, prosocial behavior, and educational attainment, as well as greater likelihood of unemployment and criminal activity (Rand Corporation, 2005; Sameroff, 1998). The cumulative number of risk factors listed above has the most detrimental impact on a child's development. NEELS data indicated that at least one-half of the children and families in early intervention had two or more risk factors,

and 1 in 5 children and families were identified with four or more risk factors (Hebbeler et al., 2007).

Protective factors could be considered the opposite of risk factors. Protective or promoting factors buffer the impact of life's stressful events or may aid in positive child development (Keogh, 2000; Sameroff, 1998). Environmental protective factors that were commonly listed in the literature include: (a) safe neighborhoods; (b) stable residence; (c) adequate income; (d) fewer than four children in the home; (e) spacing between children; (f) parents present; (g) parents good mental and physical health; (h) social support network; and (i) services available to the family (Keogh, 2000; Sameroff, 1998).

Although environmental risk and protective factors have been used to describe family circumstances, they do not explain how families function. Culture has been documented as a strong influence on family functioning, the family life cycle, and events that could be viewed as stressors (Sylva, 2005). Culture has been described as the characteristics of the family (i.e., race, economics, ethnicity, disability, age) which significantly add to their experiences and shape their values and belief systems (O'Conner, 1993). How families function has varied greatly within groups, such as low SES (Keogh, 2000). "One of the first issues professionals meet when working with low-income families is facing the realities of how a poor environment affects the normal workings of family life" (Lambie, 2005, p. 2). Low SES or poverty circumstances have placed huge stressors on family systems (Lambie, 2005). Stereotypes about culture or ethnic groups derived more from socioeconomic

differences than differences in ethnicity (Lambie, 2005). Families that have been constantly struggling to provide the basic needs of food, clothing, and shelter, often found it difficult to focus on their child's special needs (Landy & Menna, 2006). For practitioners, understanding how families have interacted over time would be important to completely appreciate how risk and protective factors impact a family (Keogh, 2000; Landy & Menna, 2006).

*Why Are Family Supports Elusive? .*

Policies for early intervention have attempted to address family supports and outcomes. The literature, however, indicated that disability-related policies for infants and toddlers with disabilities and their families have been vague about the nature and accountability of family supports.

The Division for Early Childhood's (DEC) position statement on family cultures, values, and languages (2002) noted that "for optimal development and learning of all children, individuals who work with children must respect, value and support the culture, values, and languages of each home and promote the active participation of all families" (p. 1). In order to promote family-based practices, DEC has recommended professional practices which encourage practitioners to implement individualized practices that promote collaboration with families, strengthen family functioning, and build on family's strengths or assets (Trivette & Dunst, 2005).

Despite the efforts of the early intervention field to promote best practices, culturally diverse families have not always been the recipient of family-centered services which has been due, in part, to the poor implementation of IDEA

(Kalyanpur, Harry & Skrtic, 2000). Practitioners have failed to include families from low-income or poverty in decision-making; have scheduled appointments at inconvenient times for families; and have provided important information written in English to families who do not speak the language (Kalyanpur et al., 2000).

In addition, early intervention services have not always been individualized for families and their unique needs. Data from the NEILS study found that 44% of families felt services only focused on the child (Hebbeler et al., 2007). The study also pointed out that on average practitioners spent only 1.5 hours a week in the home, and 63% of families received less than 2 hours of service a week (Hebbeler et al., 2007). Further, practitioners estimated that families missed 23% of services offered in a 6-month time period due to child illness, families missed appointments, or practitioner illness (Hebbeler et al., 2007). That would be approximately  $\frac{1}{4}$  of the services for which families were scheduled; therefore, families have been getting a very limited amount of face-to-face time with practitioners (Hebbeler et al., 2007). Conversely, Mahoney and Filer (1996) discovered families with protective factors, who are likely to have the fewest needs for supports, received the greatest amount of early intervention services.

IDEA Part C has provided the legislative context for practitioner services and practices, but it has not federally mandated them (Bailey, 2001; Turnbull et al., 2007). The statute has stated in its purposes that early intervention should enhance the development of infants and toddlers with disabilities, maximize individuals' potential to live independently, and enhance families' capacities to meet the needs of their

infants and toddlers with disabilities (20 U.S.C. Sec. 1431(a)). However, the only services authorized to families include family training, counseling, and home visits; psychological services; service coordination services; and social work services (20 U.S.C. Sec. 1432(4)). Part C does go a step further in regard to family and practitioner partnerships. The provisions in Part C have outlined the nature of the expected partnership between practitioners and families (Turnbull et al., 2007). The statute has required practitioners to meet the following four expectations when working with families: (a) provide notice of meetings, (b) obtain written consent for services, (c) include families in the development of the IFSP, and (d) conduct a family-directed assessment to determine the resources and priorities of the family and identify supports and services needed for the family to meet their child's needs (20 U.S.C. Sec. 1436).

Based upon a comprehensive statutory analysis of IDEA Part C and other federal statutes, Turnbull and colleagues (2007) have concluded that family-related disability policies failed to highlight the needs of family. The authors have also stated these policies lacked explicit requirements for family supports and services and accountability provisions for family outcomes. Further, Bailey (2001) argued that early intervention programs should be held accountable for (a) providing families the legally required services in IDEA, (b) providing families supports that are consistent with DEC recommended practices, and (c) achieving family outcomes.

### *Why Do Families with Challenges Lack Supports?*

Families with challenges have oftentimes struggled with receiving supports for their child and family in early intervention. Many of the barriers which inhibited family supports could be attributed to the disconnection between practitioner and family perceptions. The literature suggested that pragmatic, attitudinal, and cultural factors deterred developing family-practitioner partnerships.

Practitioners have developed perceptions that families with multiple challenges or risks are *hard-to-reach* (Landy & Menna, 2006). The perception of practitioners that families are hard-to-reach or challenged must shift to include thinking about what makes the services that have been offered hard to accept for a particular family (Landy & Menna, 2006). Bruder (2000) has asserted the lack of family involvement in services is due, in part, to the attitudes of practitioners as the “expert” and the families as “clients” of services (p. 110). The author has maintained that family diversity and the family-practitioner partnership should be the impetus within a family-centered approach to early intervention (Bruder, 2000).

A qualitative study by Bernhard, Lefebvre, Kilbride, Chud, and Lange (1998) examined the apparent difference of perceptions between practitioners and families. They found, for example, that practitioners felt families were not involved if they did not show up for meetings. In contrast, families felt meetings were irrelevant to their family life, they had difficulty understanding due to language barriers, and they wished for more content that was meaningful to their child. In regard to communication issues, practitioners said that families were not eager to interact;

whereas, families wanted open exchanges about their child's day but were afraid to ask too many questions.

From their research with practitioners, Wesley, Buysse, and Tyndall (1997) have listed a number of barriers to effective service coordination for families. Practitioners cited problems with large caseloads, large number of nontraditional or families with challenges on their caseloads (i.e., teen moms, combined families, single parents), and scheduling difficulties (Wesley et al., 1997). Further, practitioners also noted they lacked knowledge about community resources and interpersonal skills for working with families (Wesley et al., 1997). In order to understand why challenged families have been lacking services and supports in early intervention; insight could be gained by understanding the pragmatic, attitudinal, and cultural factors which contribute to the practitioner perception of families with multiple challenges (Landy & Menna, 2006).

Pragmatic factors have included those barriers that pertain to practical and daily concerns of interaction with families. For example, difficulty contacting the family due either to language barriers or the family's lack of having a phone would be a pragmatic factor (Landy & Menna, 2006). Language barriers or illiteracy have made it more difficult to provide families with written material about the program or interventions (Landy & Menna, 2006). In addition, pragmatic factors included difficulties that have arisen in scheduling appointments due to the families work schedule or lack of access to transportation (Landy & Menna, 2006). High family mobility has made it difficult for practitioners to maintain contact with families



(Brookes, Summers, Thornburg, Ispa, & Lane 2006). Additionally, practitioners may have faced the pragmatic issue of maintaining their own safety when visiting families that lived in unsafe neighborhoods (Landy & Menna, 2006).

In addition to the pragmatic factors directly related to families, time and training are the most commonly cited barriers for practitioners (Atkins-Burnett & Allen-Meares, 2000; Lee, Ostrosky, Bennett, & Fowler, 2003; Wesley et al., 1997). Practitioners most often cited that they did not have the time, materials, or training to implement culturally-appropriate practices (Campbell & Halbert, 2002; Lee et al., 2003). Obtaining culturally appropriate knowledge and training was considered time-consuming and often had to be completed during nonwork hours (Lee et al., 2003).

Attitudinal factors pertained to issues of both practitioner and family attitudes (Landy & Menna, 2006). Most of these factors dealt with building trust or rapport between the practitioner and families. Trust, respect, and equality between practitioners and families were themes identified for an effective family-practitioner partnership (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). In addition to trust, respect, and equality, Nelson, Summers, and Turnbull (2004) found that families wanted practitioners who were available and accessible, were professionally committed to the family by going above and beyond their job responsibilities, and were willing to blur the boundary lines between practitioner relationship and friendship.

However, building partnerships with families facing multiple challenges could be difficult. Harry (2002) found that the practitioners' role as the expert or keeper of

the information tended to dominate their interactions with families. Early intervention, by nature, could be viewed as intrusive to families; having an expert come into the home and tell families what to do may compete with their own autonomy (Able-Boone, 1996; Bruder, 2000; Campbell & Halbert, 2002; Powell, Batsche, Ferro, Fox, & Dunlap, 1997). Families with multiple challenges could be reluctant to tell family business to outsiders and may have felt that seeking help signified weakness or inadequacy (Landy & Menna, 2006). Also, families would not want to disclose violent or illegal activity for fear of involvement with child protective services or the court system (Landy & Menna, 2006).

Another attitudinal barrier to services has been the families' willingness to engage in intervention or acknowledge the need for help (Landy & Menna, 2006). Families may not have viewed the services offered as being relevant to their needs (Bernhard et al., 1998; Landy & Menna, 2006). In one study, practitioners believed that families' experiences with early intervention were a result of the families' intrinsic characteristics, such as motivation and persistence (Shannon, 2004). The practitioners labeled families as unmotivated if they were not accessible, did not participate, or did not follow through (Shannon, 2004). On the other hand, "mothers seemed to get more attention from home visitors when the mothers were readily accessible *and* when there was a clear problem" (Brookes et al., 2006, p. 31). Families in crisis were more likely to receive immediate attention when practitioners could easily contact the families at their home (Brookes et al., 2006). However, when stressors, i.e., frequent moves, phone service disruptions, and new jobs, interrupted

regular contact with practitioners, families in crisis would fail to get the supports they needed (Brookes et al., 2006). In a separate study, families with multiple challenges were limited in their access to information and resources, and thus, were less engaged in their child's educational decisions; they tended to look to the practitioners as experts to guide them (Hanson et al., 1998). These families seemed to be “confused and uninformed” (p. 203) about the process and services available to them (Hanson et al., 1998). The disconnect between families' needs and practitioners' expertise may have made families hard-to-reach.

In addition to the families' attitudes, practitioners' personal beliefs can be barriers. Philosophically, transitioning to a family-centered approach could be challenging for practitioners because they have been expected to switch their focus from the child, as is the case in traditional intervention approaches, to the family and other adults in the child's environment (Gilkerson, 2004). An individualized approach to family needs and capacities has often been difficult for practitioners because they have tried to fit the family into a static model of service delivery, rather than fitting the program to the family (Bailey, 2001; Powell et al., 1997). Incorporating best practices in early intervention could be difficult as practitioners reported they were most likely to adopt practices that match their own beliefs or values (Campbell & Halbert, 2002).

Finally, cultural differences between practitioners and families presented challenges (Landy & Menna, 2006). Language impacted the ability to communicate successfully and, even with interpreters, nuances and subtleties may be missed

(Landy & Menna, 2006; Park, Turnbull, & Park, 2001). Cultural traditions of dress, family dynamics and roles, and values could conflict with the practitioners' belief system (Landy & Menna, 2006). Instead of individualizing for each family, practitioners have tended to provide goals and services to characteristics of larger cultural groups (Harry, Rueda, & Kalyanpur, 1999). Park and colleagues (2001) interviewed Korean- American families who reported a feeling of racial discrimination from practitioners because they were from a different culture; they believed there was a conflict with cultural values and practices between themselves and the practitioners.

Practitioners' own cultural values, biases, training, and experiences have played a part in how they viewed families and how they viewed their roles in relationship to families (Gilkerson & Stott, 2000). Practitioners should become aware of their feelings in interactions with families, which they may have been trained to avoid (Gilkerson, 2004). Lee et al. (2003) found that practitioners who were African American or Latino were more likely to examine their own cultural attitudes, beliefs, and orientation than practitioners who were European American. Also, practitioners with more education were less likely to participate in cultural awareness or sensitivity training or to review books or articles to learn more about the family's culture (Lee et al., 2003). The authors concluded that providing culturally appropriate services was another added responsibility for early intervention practitioners, rather than a critical part of quality family supports (Lee et al., 2003). When working with families facing multiple challenges, practitioners' values may not have coincided with the families

priorities which may have impeded the approach for intervention (Able-Boone, 1996).

What practitioners do with families in early intervention was not available from the NEILS data but was noted as an area of needed research (Hebbeler et al., 2007). Bruder (2000) argued that the early intervention field needed to clarify values about services and practices and focus on building trusting partnerships with families. Services for families should be built around the family's values and the needs they identified for their child (Bruder, 2000).

#### *Purposes of This Research*

This research study will develop a grounded theory to understand how early intervention services are provided to families with multiple challenges. This dissertation, which describes a component of a larger research project, focuses on the family supports experienced by those families perceived as challenged while receiving services from Part C agencies. The research question guiding this study is: How do early intervention practitioners perceive challenged families and how do their perceptions influence the supports they provide to challenged families? We recognize using the term *challenged families* is not person-first terminology. We acknowledge that we first used this term for literary simplicity when recruiting participants in our study; however, upon inspection of the data, the perception of this term among practitioners evolved into the primary focus of this study. Therefore, throughout the presentation of our methods and findings, we will use this term.

## CHAPTER 2: METHODOLOGY

Grounded theory is an approach for systematically examining qualitative data aimed at the generation of theory (Strauss & Corbin, 1998). A theory is generated through the relationships among the concepts that emerge naturally from the data; data grounded in the actions, words, and social interactions of the people (Creswell, 1998). This is a grounded theory study about how practitioner perceptions about a family shape the services they provide in Part C agencies. This research is grounded in the data and the theories that emerge from observing groups of families and practitioners within the context of early intervention services. The methods will describe: (a) the research design, (b) the participants, (c) the data collection, (d) the data analysis, (e) the validation of the study, and (f) the limitations of the study.

### *Research Design*

This research study did not follow one particular approach to grounded theory but blended both an objectivist and constructivist point of view. In practical research, the lines between approaches are often blurred (Charmaz, 2006; Creswell, 1998; Maxwell, 1996; Miles & Huberman, 1994). The objectivist approach prescribes a systematic way of analyzing data from which a single substantive theory will emerge from the relationships among the concepts (Charmaz, 2006; Strauss & Corbin, 1998). The constructivist approach is noted for being less structured in which the process leads to the specific outcome (Charmaz, 2006; Maxwell, 1996) and places emphasis on the values of the researcher and how the researcher's biases can affect the data (Charmaz, 2006).

Throughout this study, we used a constant comparative approach (Glaser & Strauss, 1967) to analyze the data. The data were organized around a central phenomenon explaining early intervention supports and its impact on challenged families. Additionally, the research team was involved in a continual reflexive process in which we pondered new and different ways to interpret the data, always remaining aware of how our prior experiences and biases influenced our thinking.

### *Participants*

The agencies and families were selected using purposive sampling. Purposive sampling is a strategy in which particular settings, persons, or events are selected deliberately in order to provide diverse representation of the population in question (Maxwell, 1996; Strauss & Corbin, 1998). The sites were selected from different geographic regions in the Midwest, including (a) one program site operating in a single school district in an urban community, (b) one program site that operates in a large geographical area consisting of both rural and nonrural school districts, and (c) one program site operating across multiple rural school districts with a large population of transient families. All agencies selected in this study provided services to children from ages 0-3 and primarily provided early intervention services through home visiting models.

Once the agencies were selected, we asked the practitioners within each agency to recruit a minimum of two families that would best be described as typical and challenged. We deliberately did not provide definitions of typical and challenged families to the agencies; the terms were left to the agencies and practitioners to

interpret within their own program. When pressed by the urban agency to expand on the terms, we provided the following definitions. Typical families would be defined as those families who were most representative of the families the agency served, including the child’s disability, amount of service, and family characteristics.

Challenged families would be defined as those families who were most challenging to serve within the agency either because of the intensity of services, the severity of the child’s disability, or the family characteristics. Based on the interpretation of these terms by the agencies, 16 families were recruited to participate in the study; of these six were identified by the agencies as challenged. Table 1 describes the characteristics of the family participants in the overall sample.

Table 1

*Characteristics of Family Participants*

	Geographic Location						
	Rural		Non-rural		Urban		
Ethnicity	T	C	T	C	T	C	
African-American	0	0	0	0	0	1	
Caucasian	3	2	1	2	2	1	
Latino	2	1	0	0	0	0	
Other	0	0	1	0	0	0	
<b>Total</b>	<b>5</b>	<b>3</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>2</b>	<b>=16</b>

*Note.* T= Typical family; C=Challenged family. All respondents were mothers, with the exception of two males. One mother was an adolescent.



The research team also interviewed 21 early intervention practitioners either individually or as participants in a focus group. All of the practitioners who participated in the study were female and Caucasian, except one who was Latino. The majority of the professionals interviewed were practitioners who worked directly with families. Table 2 describes the characteristics of the early intervention professional participants.

Table 2

*Characteristics of Early Intervention Professional Participants*

Professional Position	Geographic Location		
	Rural	Nonrural	Urban
Special education administrator	1	0	1
Early childhood special education liaison	0	1	0
Early childhood special educators	3	2	3
Allied health professionals (includes OT, PT, and Speech pathologist)	3	2	2
Parent liaison	1	0	0
School psychologist/Part C coordinator	0	0	1
Social worker	1	0	0
Total	9	5	7 = 21

*Data Collection*

Two researchers, designated “site teams,” were assigned to each site. At each site, teams observed home visits, conducted focus groups, and interviewed

administrators, practitioners, and family members. Incentives were provided at all sites which included gift cards for individual practitioners and family members or a monetary donation to the agencies' library, based on agency preferences.

*Home visits.* Observation is a qualitative technique enabling researchers to understand the context within which the participants act and how the context influences their actions (Maxwell, 1996). We conducted observations during regularly scheduled home visits with practitioners. We observed from the role of a complete observer or outsider not participating in the home visit (Creswell, 1998). During the home visits, the researchers recorded data regarding the context of the home visit, the interaction between the family and practitioner, the interaction between the child and practitioner, specific interventions or assessments, and the types of family and child supports that were observed. Additionally, researchers noted their own reaction to the observation as reflective notes. Observations were documented using field notes and contact summary sheets.

*Focus groups.* In two of the program sites, the site team conducted a focus group with early intervention practitioners. The focus groups, advantageous to use when the participants are cooperative and similar to one another (Creswell, 2002), included from three to six early intervention practitioners and lasted an hour in length. The questions asked in the focus groups centered on practitioners' perspectives about family supports, as well as addressing family outcomes. In the rural site, the site team observed two full-day inservice training sessions and one staff meeting. Due to the on-site visit at this site, the agency preferred individual interviews and the

convenience of scheduling interviews with individual staff members. In this case the site team used the same questions used for the focus group in the individual interviews.

*Individual interviews.* At each program site, the site team conducted individual interviews with a program administrator, families who had been observed on the home visits, and the practitioners directly serving those families. In the qualitative interviews, we elicited the participants' perspectives and insights into the context in which supports are provided and the meaning all the participants attached to their experiences within early intervention (Maxwell, 1996). Interviews were scheduled at the families' convenience following the home visit. Three of the family interviews were conducted via telephone at the family's request. One challenged family in each of two sites was not available after repeated efforts to contact them for interviews; however, those families had provided a signed consent and they were observed in a home visit; therefore the field notes from those families' home visits, as well as interviews with their respective practitioners, were retained for use in the study.

#### *Data Analysis*

Data analysis began early in the study and functioned to coordinate the work of the site teams throughout the data collection. In weekly meetings, the team compared notes and contributed to an emerging list of themes, which formed the basis for emerging theories or hypotheses. This section describes the coding process for analyzing the data. Coding is the "bones of your analysis" that links the data

collected and the emerging theory to explain the data (Charmaz, 2006, p. 45).

Through coding, we define what is happening in the data and what we believe that means (Charmaz, 2006). Although the phases of coding are distinct, the team cycled back and forth through the phases during data analysis.

In the first phase, initial coding, our open codes tended to cluster around constructs from previous research at the Beach Center. As we moved into the second phase, axial coding, we used these constructs and other conceptual categories that emerged to generate a “codebook” for exploring our data, which is a bias of our research. Some of the categories included: family-practitioner relationships, family quality of life domains, community supports, family strengths, and family outcomes. Based on this initial codebook, each site team coded two transcripts using a check-coding procedure (Miles & Huberman, 1994) to reach consensus about the codes that emerged. When consensus in coding was established, the site teams coded all the documents from their program site using QSR N6 software.

We used a constant comparative method of data analysis to develop themes from the data. The constant comparative method refers to researchers identifying incidents, events, and activities and constantly comparing them to an emerging category to develop and saturate the category (Creswell, 1998). The process unfolded throughout the data collection phase until the emergent theme document contained an overall list of possible issues and themes that were common across the three sites. In the final coding phase, selective coding, we began to construct a theory of how these themes related to one another to tell a story (Charmaz, 2006; Harry, Sturges, &

Klingner, 2005; Strauss & Corbin, 1998). The theoretical framework developed through this process is reported in the findings section.

#### *Validation of Analysis*

Although qualitative researchers must be creative, the study must also be rigorous and credible. Several strategies were utilized throughout the study to verify the rigor of the study. In our study we used triangulation of data, peer debriefings, and member checks to ensure credibility.

First, triangulation of data is the process of using evidence from different individuals, different types of data, different data collection methods, and multiple investigators in establishing themes and descriptions in qualitative research (Creswell, 2002; Lincoln & Guba, 1985). For our study, we selected both family and early intervention professional participants. Data from interviews, observations, field notes, memos, and contact summary sheets were included in the analysis. Further, the data were collected and analyzed by a team of peer researchers. This multimethod approach reduces the risk of systemic bias and allows for a better assessment of generality for the conclusions and explanations drawn from the research (Maxwell, 1996).

Peer debriefing sessions provided feedback from others in the research process (Maxwell, 1996) much like a “devil’s advocate” role. We met weekly or bi-weekly to discuss the findings that emerged from the data. Additionally, we participated in a two-day team retreat at which time each researcher presented a bias statement designed to provide open communication about the different perspectives.

Last, we conducted member checks to check for accuracy in the data (Creswell, 2002) and rule out misinterpretation of the data (Creswell, 1998; Lincoln & Guba, 1985; Maxwell, 1996). We consistently asked for clarification from the participants to ensure that their thoughts, opinions, and experiences were clearly understood and recorded. In addition, a member checking document was distributed to participants at all three sites and follow-up interviews were conducted to seek their confirmation that the emerging themes reflected the perspective of those who were interviewed.

#### *Limitations of the Study*

The purpose of this study was to understand how practitioners perceive challenged families and how that perception then influences the supports and services that are provided to them. However, in interpreting the findings of this study there are several factors to take into consideration. First, the family perspectives provided in the interviews were primarily from the mother's point of view. Only two male family members were interviewed. Second, we did not have prolonged engagement with our sites. We collected our data in a short period of time. We did, however, have the opportunity to interview many of our participants, both practitioners and family members, a year later during member checking to verify our findings. Third, as noted previously as a bias of our study, we used constructs in our coding that were based upon earlier research conducted at the Beach Center. These constructs guided our coding and theme development. Last, this research study was part of a larger study investigating the outcomes of family supports in early intervention. The issue

of treatment of challenged families emerged from our observations. Our initial interview and focus group protocols were not specifically tailored to the research questions of this study. Had our protocols been developed with the focus on challenged families from the onset, participants could have provided more depth of opinion from the beginning of our investigation.

## CHAPTER 3: FINDINGS

We have developed a framework to understand how practitioners perceived challenged families and how their perceptions influenced the way they provided supports to challenged families. In Figure 1, we listed specific features forming each of the elements in the grounded theory framework. Using the data from interview transcripts and researcher notes, the sections that follow will provide more detail about these features. To clearly illustrate the framework, we contrasted the data from challenged families with examples from typical families. The following sections will present more detailed descriptions for each feature in the figure: (a) family characteristics, (b) practitioner characteristics, (c) family perceptions and assumptions of early intervention, (d) practitioner perceptions and assumption of families, (e) family-practitioner interactions, (f) practices and outcomes. In the summary of findings, we will further explain the interactional process of the components and features of our framework.



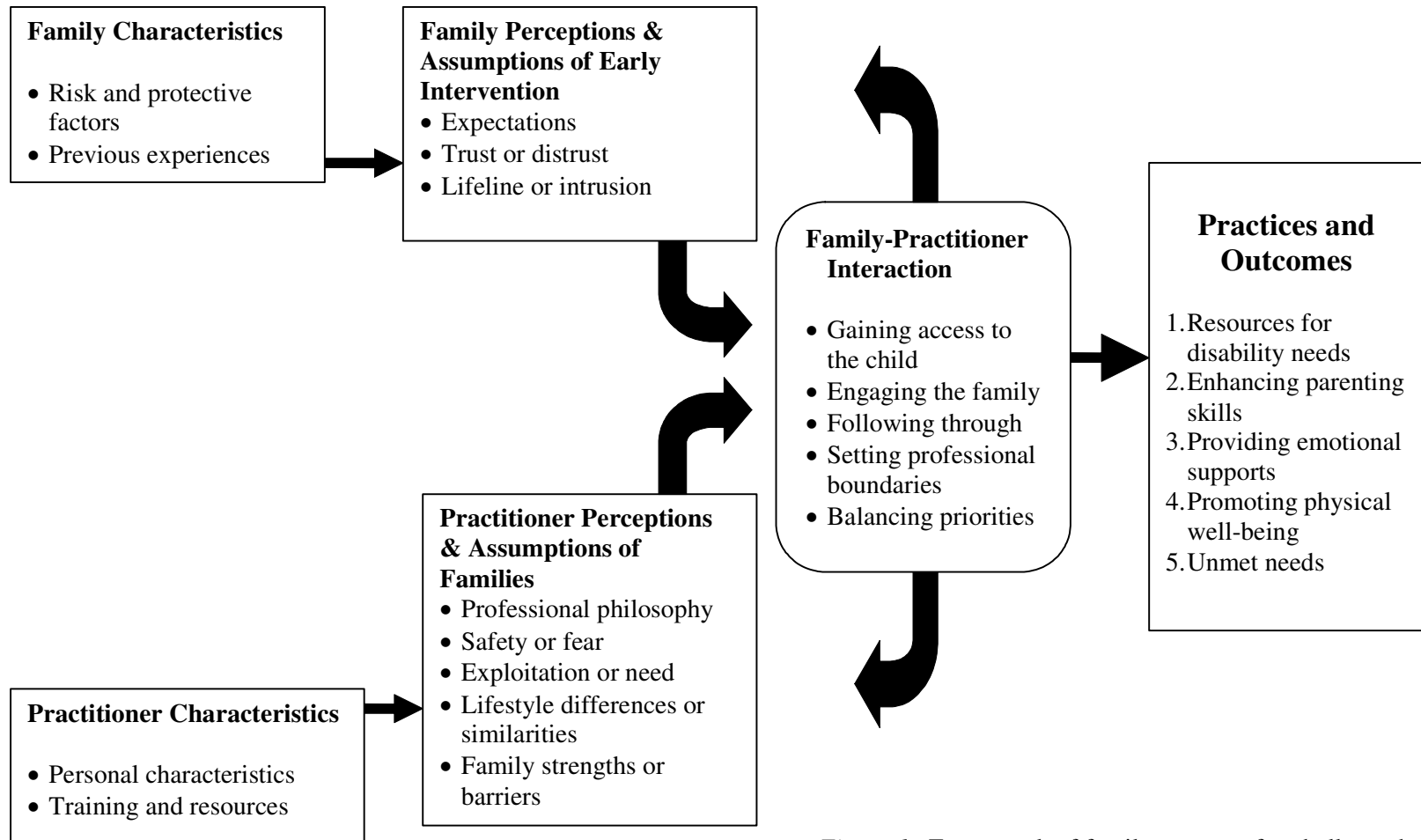


Figure 1. Framework of family supports for challenged families.

### *Family Characteristics*

Family characteristics are defined as the families' resources, culture, and previous experiences. To explore the differences in the characteristics between challenged and typical families, we contrasted the data with risk and protective factors from the literature. Further, the previous experiences of challenged families with other social agencies are identified.

*Risk and protective factors.* In this study, Part C agencies were asked to recruit both typical and challenged families. The terms typical and challenged were not defined for practitioners, but left to their interpretation, with the exception of one site which asked for clarification (see Methods section). When practitioners talked about differences in challenged and typical families, practitioners said the following:

I don't think there is a typical family anymore. Every family has unique circumstances; there is no "cookie-cutter" family. (Practitioner quote)

In the car, [the practitioner] talked about our next home visit. She described this visit as a "challenged family." She said it will be very different from the first one . . . She described [this mom] as "very needy" and that "we need to do a lot of listening." (Researcher observation notes)

Upon leaving the apartment, [the practitioner] states, "That was the challenged family, if you couldn't tell." When we get to our next visit she advises me to wash my hands because she "feels so dirty" after being there first thing in the morning. She apologizes for the living conditions we just experienced. (Researcher observation notes)

[The practitioner] defined challenged in terms of families that need more of both formal and informal outside supports. With challenged families, there are "other issues or concerns that need to be addressed." They may have "a lot of family issues." Typical families have supports in place. Practitioners have consistent visits and relationships are established with these families. (Notes from member check with practitioner)

From the data, we created composite profiles of how practitioners perceive challenged families and typical families (See Table 3). In the table, we compared the composite profiles of the sample families with the risk and protective factors most commonly cited in the literature (Keogh, 2000; Landy & Menna, 2006; Sameroff, 1998). The families that practitioners identified as challenged have specific characteristics which included many of the environmental risk factors from the literature. Typical families, in contrast, had more protective factors that promote a child's development.

The literature defines risk broadly as the negative conditions that are associated with reduced levels of child development (Keogh, 2000). In the table, the number in parentheses behind the risk or protective factor is the number of families in the sample that had that identifying factor. In our sample, we had seven challenged families and nine typical families. All of the challenged families in this study were from low SES or poverty circumstances. Many other environmental risk factors were associated with poverty or low SES which impacted a majority of the challenged families in this sample, such as unemployment, low parent education, and large family size. Primarily the challenged families in our study expressed worries regarding employment, finances, child care, their own health issues, and health insurance, as well as concerns about their child with disabilities and how they were growing and developing.

One identifying risk factor from the literature that did not seem to impact the families in this study was lack of social support. On the contrary, challenged families

in this study indicated their extended family (grandparents, brothers, in-laws) were a part of their daily interactions and available to them to “help out as much as they can.” When asked if they felt supported by family and friends to raise their kids, one mother said, “Sometimes more than you want.” Further, challenged families in the study advocated for their child or themselves to find services they needed within their community. The families had contacted church groups, social service agencies, and other families in order to find services for parent groups, counseling, and transportation needs. This interchange between the research interviewer and a teen mother discussing her desire to get more behavioral support illustrated the need for families to advocate for their own child.

I: How are you going about looking for that?

M: Well I'm going, I haven't started yet, but a lot like the [County] Center over there, [County] Mental Health them, I'm going to call them and you know, just see what they can say.

I: Do you feel like you could bring that up to [the Part C agency] again to see if you could get some support in getting....making those connections?

M: Uh-huh, I'm going to ask, but most likely since they already ran the tests and stuff and they done already had the final meeting, I'm quite sure they just going to give me some more papers.

In contrast to environmental risk factors are protective or promoting factors which buffer the impact of life's stressful events or may aid in positive child development (Keogh, 2000; Sameroff, 1998). Protective factors could be considered the opposite of risk factors. The typical families identified by practitioners had most of the protective factors as commonly identified in the literature. Typical families lived in safe neighborhoods, parents were married, one or both of the parents were

employed, and their income was adequate to meet their families' needs. Just like the challenged families in this study, the typical families also reported having social support from extended family members to assist with care giving.

*Prior experiences.* In addition to environmental risk factors, challenged families also had experiences with other social service agencies. All of the challenged families had previous or ongoing experiences, whether positive or negative, which impacted their experience with the Part C agency. Many families had older children who had previously participated in Part C services. These families were referred to by one agency as "frequent fliers." One mother had previous experience as a student in special education services through the school district that the practitioner reported as "being a matter of shame and something she would like to avoid for her kids." In addition to other educational agencies, families had experiences with child protective services, the legal system (either for criminal activity or child custody cases), and welfare benefits.

Table 3

*Risk and Protective Factors of Families*

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Composite Challenged Family Profile from sample families

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- Low SES-poverty (7)
  - Head of household in unskilled occupation or Unemployed (4)
  - Limited toys available (5)
  - Physical needs: transportation, health insurance (7)
- Unsafe neighborhood (3)
  - “Unclean” home environment (3)
- Low parent education (4)
  - GED or high school education or above (3)
- Large family size (4)
- Children closely spaced (5)
- Overcrowded home (5)
- Frequent changes in residence or homelessness (2)
- Frequent parent absence/single parenthood (3)
  - Teen parent (1)
- Mother’s (caregiver) mental health (3)
  - Parent has chronic medical disability (3)
- Parent legal issues (2)
  - Undocumented family (1)
- Parent substance abuse (1)
- Culturally diverse background status (2)
  - English as Second Language (1)

- Child with developmental delay at age 3 (7)
  - More than one child with delays (6)
- Violence or physical abuse (1)
- Lack of social supports (3)
  - Extended family support (4)<sup>#</sup>
  - Advocate for getting extra services for their child (4)<sup>#</sup>
- Other observations
  - Family does not follow through with interventions (5)
  - Family misses appointments or is unavailable for services (4)
  - Previous or ongoing interaction with other social service agencies (7)

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Environmental Risk Factors from the literature

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- Low SES-poverty
- Unsafe neighborhood
- Low parent education
- Large family size
- Children closely spaced
- Overcrowded home
- Frequent changes in residence or homelessness
- Frequent parent absence/single parenthood
- Mother's mental health
- Parent criminality
- Parent substance abuse
- Disadvantaged minority status

- Child with developmental delay at age 3
- Violence or physical abuse
- Lack of social supports

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#### Composite Typical Family Profile from sample

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- Safe neighborhood (8)
  - Clean home environment (9)
- Stable residence (8)
- Adequate income (8)
  - Father employed (8)
  - High school education or above (7)
- Fewer than four children (8)
- Spacing between children (6)
- Parents present (9)
  - Two parent household (9)
  - Stay at-home mother (7)
- Good mental and physical health (parents) (7)
  - Parent with disability (2)
- Kin and alternative caregivers available (8)
- Services available (9)
  - Family works with child between visits (9)
  - Very engaged in home visit (8)
- Disadvantaged minority status (2) <sup>+</sup>
  - English as Second Language (2)

---

#### Environmental Protective Factors from the literature

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- Safe neighborhood
- Stable residence
- Adequate income
- Fewer than four children
- Spacing between children
- Parents present
- Good mental and physical health (parents)
- Kin and alternative caregivers available
- Services available

*Note: + indicates an environmental risk factor; # indicates an environmental protective factor.*

### *Practitioner Characteristics*

Practitioner characteristics are the practitioners' resources, culture, and previous experiences. In terms of the framework, we identified two practitioner characteristics: personal traits and training. All of the early interventionists in this study, with the exception of one, were Caucasian, middle class, college-educated women. The personal traits of early intervention practitioners in our study were representative of practitioners nationally, as cited in the 2007 NEILS data (Hebbeler et al., 2007). The training and resources they had received from the agency is described in more detail.

*Training and resources.* In order to facilitate new practices and intervention, each Part C agency provided ongoing in-service training for their staff to improve or enhance their intervention skills. In the rural agency the staff had received recent training on Relationship-focused Intervention and Teachable Trash. The urban agency focused their training on Routines-based Intervention and assessments. The nonrural agency emphasized transition and transition planning. Sometimes practitioners embraced new ideas, strategies or tools, while others were much more reluctant to try new ideas especially when they felt their current practices were working sufficiently for families. One practitioner talked with enthusiasm about adopting teachable trash in her home visiting approach.

[I use] Teachable Trash. And some of my ideas come from the Parents as Teachers curriculum, but most of them are just from watching. Watching and [GETTING ITEM] this one is my nesting rod. And it's just coffee containers, some of them, the creamer, and they just have to learn you know which one is small, which one's medium, and which one's big. And either they can construct with it or do the nesting.



This was just one of many examples this practitioner gave regarding teachable trash items she used in her home visits. In contrast, there were practitioners who were more skeptical or disinterested in integrating new training or strategies into their approach. From observation notes, “[Observer] asked about the relationship-based intervention and [practitioner] shrugged. She said she didn’t think it was helpful and thought it was a little ’gimmicky’ to use the videotaping of the parents and children that the approach involved.”

#### *Family Perceptions and Assumptions*

Families held perceptions and assumptions about the purpose of early intervention which were shaped, in part, by the family characteristics. Family perceptions and assumptions are formed by their subjective viewpoint and expectations for early intervention services. Their assumptions focused on the families’ expectations of services and service delivery. Families developed perceptions about trust or distrust of practitioners which were oftentimes influenced by their previous experiences. Last, families created perceptions about the necessity of early intervention for their family life as either a lifeline or an intrusion.

*Expectations.* In this study, the service delivery model in all three sites was home visiting, supplemented by play groups in two of the sites. In this service delivery model, typically practitioners worked with families in relationship to providing intervention services (i.e., physical therapy, occupational therapy, speech therapy) to the child. Visits would occur usually once or twice a week and

practitioners expected and hoped that families would incorporate the activities or interventions into their daily routine with their child, as one practitioner clarified,

We want parents to realize that they are the teachers. And that [the practitioners] basically take on the consultant role; that we are there to share information, share different community or state resources; suggest activities or strategies to help the child's development.

Many of the challenged families, however, had the assumption that early intervention was provided in a clinical model; one in which the practitioner worked with their child to provide therapy during the visit. The families' role in a clinical model often deferred to the practitioners' expertise. Families vocalized that they wished the practitioner would schedule visits more often to work with their child to help them "catch up." The disconnect between families' assumptions about the practitioner or services for getting their child caught up and the practitioners' model of service delivery created tension. Practitioners expressed time and time again about the need to "empower families and not enable families." Practitioners did not want to be viewed as a clinical service to families, but rather to work with families to be empowered to carry through on the interventions when they were not there. One practitioner explained,

If we aren't clear about our intent of being that parent educator of saying we're not just here to work with the child...because sometimes if we're not clear enough about that from the beginning then the parents could perceive us more as like a clinical service. You know you come in once a week, you provide therapy to my child and then you leave and so if you can be here weekly, that would be more beneficial where we might be wanting to help them understand that it's not maybe not so much how often we are here but how much support we can give you that you're comfortable following through before we come back the next time to see how things are going.

*Trust or distrust.* Families' assumptions about their role in early intervention services may be influenced by their previous experiences with other social service agencies. As noted earlier, challenged families had previous experience with child protective services, welfare benefits, and the legal system. When families had negative encounters with social service agencies, they were more reluctant to accept practitioners from Part C agencies into their homes. One practitioner noted,

...We do have families who for whatever reason are really nervous about not accepting the services. Somehow or other they think they're going to be, you know, their kids are going to be taken away or, you know, another state agency is going to come in or whatever, and so they say, we're ready for the services but in fact they really....they don't desire the services, it's not a priority to them and so it's feeding, you know....it's taking care of their fear that they accept this at all. And I've had several families that that's been the case where they're really nervous about what other things are going to happen if they don't allow us to come.

One of the families we observed during a home visit later refused to be interviewed for this study. In the home visit, the parent indicated she was fearful she would be reported for child abuse or neglect. Her distrust of us as practitioners may have impacted her decision to participate. Previous experiences, whether positive or negative, lead to feelings of trust or distrust with practitioners from the program.

*Lifeline or intrusion.* The families' perception of how participating in early intervention impacted their family varied. Many typical families viewed early intervention as a lifeline for their child and themselves. Families viewed early intervention as critical in their child's development and in their own growth as a parent of a child with a disability, as one father explained,

And all the progress that we're taking on right now may help us to conquer the obstacles that might show up later on. . . And so that's why we're doing

everything to get him as much of a head start or intervene now before drastic intervention was necessary.

In contrast, some challenged families perceived early intervention as an intrusion into their life. Feelings of trust or distrust about the practitioners or program may be related if families perceived early intervention as vital because they trusted the practitioners' assessment of their child and families' needs, or as intrusive because they distrusted the practitioners' motives. Families who viewed early intervention as intrusive reluctantly participated in early intervention services.

Undocumented families, especially, were concerned about how participation would impact their ability to stay in this country and their safety. One observer noted, "[The practitioner] tells me that the family doesn't really think anything is wrong with [their child]. They don't see her speech delay as a problem, but apparently they indulge these therapists who keep coming and working with the child." This family also refused to be interviewed for our study, perhaps because further involvement was viewed as another intrusion into their life.

#### *Practitioner Perceptions and Assumptions*

Practitioners developed perceptions or made assumptions about families based upon their own practitioner characteristics. Practitioner perceptions and assumptions are the practitioners' subjective viewpoint and expectations for how families will behave and what they want in early intervention. For example, we can conclude from the composite profile of challenged and typical families that practitioners made assumptions about the families they recruited as typical or challenged based upon their knowledge of the literature on risk and protective factors (See Table 3). From

the theoretical slant of constructivism in grounded theory, we recognized that the perceptions of those persons actively involved in the culture of early intervention influence the reality of practice (Charmaz, 2006). In this case, the practitioners had perceptions about challenged families that were evident in their professional philosophy and in their concerns about lifestyle differences, safety, and exploitation. Further, practitioners made assumptions about the strengths families possessed or they overlooked those strengths if other challenges stood in the way.

*Professional philosophy.* Practitioners' perceptions about challenged families were evident in their philosophy about early intervention, whether it was child-directed or family-focused. Some practitioners were very child-focused and felt that they needed to get in there and "fix the child" to do their job successfully. Other practitioners viewed early intervention as a process in which a partnership is developed to build upon the families' strengths to support their child. To illustrate this point, two different practitioners approached services to challenged families with different philosophies. The following were quotes from the practitioners.

Practitioner A: When I have a family that doesn't show up, I have to wonder what are they saying to me about the value of this in their life. Or are they at such a point that this is such a low priority in comparison to they're about to be kicked out of where they're living or they're running low on money, their electricity is shut off and so I don't really....I think about their challenges more than my challenges. Whether they show up or not, I'm still working. So, I don't think about them being challenged as the work being challenging. What do I need to do to get that connection going so that they'll be there for the visit; so that there is some value in having me come? So, it has to be valuable to them or they will tell us by not being there or not calling or canceling all the time that they're not getting much out of it.

Practitioner B: Well I think when I go out and I talk with the parents, I always explain to them you know my role is to come out every two weeks and I'm

here to do whatever I can to help you. I think for some of the [challenged] families we have a lot of it is it's not their primary concern. Their primary concern is getting food on the table. Their primary concern is, you know, having enough money to pay for groceries or, you know, or it's just a lack of education or a lack of really not doing....I think we just try by just telling the family you know the child's success depends on if you're going to carry these strategies over, you know. So you kind of make a difference, you can make a difference at this stage for your child, you know. And if the families really care, they will follow through with it. Like for example, [one child's] mother (a typical family), I made....and when I did the routine for them, and the next time I went she had it taped up on the back of the door. I mean she is very adamant on getting that child to talk. She wants that child to be right on, you know and then I have other families that that's not their primary....you know so it makes it hard and we have to stop and realize, like we have several families that don't show up for meetings and so we have to stop and realize that's not their primary concern, so I try to just let them know that you know we are here to help you know, we're here to help. If you don't want services, you don't have to have them but you know we're here to help.

If a family was not available or not responding to the services, Practitioner A reflected on her practice and made changes or adjusted the services to make it more valuable or appealing to the family to participate. Her approach to providing services was oriented towards the family's needs and priorities. In contrast, Practitioner B seemed aware of the multiple challenges that accompany poverty and acknowledged that compliance with home therapy programs was not a priority for families concerned with providing food or shelter. Despite this, she ultimately indicated that families who really wanted to help their children follow through on early intervention services. She did not describe a reflective process for changing her services or her approach to meet the families' needs. Her role was to provide early intervention services to their child and if the families couldn't see the benefits then she felt helpless.

Practitioners spoke about families needing to “value” early intervention services. The practitioners’ perceptions or assumptions about the importance of families valuing early intervention are directly linked to their professional philosophy. For example, Practitioner A previously expressed her philosophy as an approach to services which was adaptable to challenged families’ priorities. She explained that families may or may not value services,

Practitioner A: I think it is perfectly normal, it’s okay and whether they accept services or not, it is a choice. Most of them end up going for the services and yet they tell us by behaviors, much like children tell us with their behaviors, that this is right or not.

However, this perception was not common among practitioners. More likely, practitioners took the view of Practitioner B and expressed that families should value the services provided by early intervention in order to make a difference for their child.

Practitioner B: I think the role is one of primary practitioner of course, you know we provide them with strategies and they either choose to use those strategies or choose not to. They choose to value what's happening or not to value what's happening and the amount of progress their child makes I think is directly dependent on those variables.

*Safety or fear.* Practitioners also made assumptions about the safety of families’ home environments or neighborhoods. The practitioner’s fear became entangled into their perception of the family. Some practitioners visited families in pairs to increase their sense of safety. “There are some homes that some of us have been uncomfortable going to by ourselves. And, we’ve always been able to take care of that by just going with another person.” In two of the sites, our researchers wanted to interview the families that lived in public housing. The practitioners at both sites

insisted that the housing complexes were unsafe for us to visit alone. From our researcher's notes,

We had to stop by the Center to pick up some papers and I thought I would get my car so that I could stay after the visit and interview [the mom] . . . Then, it occurred to [the practitioner] that she could not leave me in the apartment alone! She said we never go alone . . . So I reluctantly rode to the interview with [the practitioner]. I later felt I could have stayed myself to do the interview. I felt safe.

However, incidents have occurred that cause practitioners to increase their measure of safety. One practitioner reported that she had been approached by a "creepy" neighbor who yelled at her; the encounter left her feeling uncomfortable. Sometimes, though, the fear does not come from the outside physical environment but from other family members. One mother had an estranged relationship with her husband because he had "intermittent explosion disorder, so . . . he can fly off in a second." The practitioners who visited that home went in groups or pairs because they were fearful of the father's behavior.

*Exploitation or need.* Practitioners felt that some challenged families were "system savvy," or able to work the system to their benefit. This perception undermined the practitioners' trust of the families whom they felt were exploiting the services of the Part C agency. One practitioner described a recent challenging situation, in which she felt taken advantage of by a family,

My most challenging family would be one that I felt sorry for them....mom did not work, the son has Down's Syndrome, mom had lost two previous children and husband was stepping out on her. She would call and say I have no money; I have no electricity, her house burnt down. . .So they had to stay at a hotel and so we were providing so much support, you know, with money but also trying to find appliances for this new home that she was going to get that she took advantage of it and felt that it was her right that we provide more



because she knew that we could do it . . . And by that time we realized that, we had lost our focus from the family, befriended the child really to make mom happy . . . my other team members felt that the only reason I had connections with this family was because she was using me and I thought, you know, okay if she's using me, that would be fine, but I would not let the child starve. So if there was a way, I could get food in there, I would for this child. It was really hard. It was just constantly every move that I made was thought through several times, you know, and it was you go to the house and she'd treated you real nice but you knew not to believe some of these words.

Practitioners struggle with balancing the families' needs with distrust that comes from exploitation. But the needs usually outweighed the practitioner's distrust of the families' motives. As one practitioner said, "We do it because we can't not do it." Several practitioners indicated that their agency provided families with concrete resources to enhance their physical well-being, however, these items were undocumented on IFSPs because the "higher ups wouldn't approve." One agency indicated that they had provided several challenged families with diapers on occasion, but, "We don't want to be known as the agency that gives away diapers . . . We'd have people lining up around the block. That's not what we are here for, but if a family is in dire need you just do it."

*Lifestyle differences or similarities.* Practitioners also made assumptions about families based upon the similarities or differences of the families' lifestyles in contrast to their own lifestyle. One factor is the climate of the home environment. Some of the challenged families lived in homes that the practitioners reported as unsafe to visit alone as previously noted. Practitioners talked about homes that were unclean and how uncomfortable those environments made them feel.

When you walk in and there's stuff on the floor . . . that you have no idea what it is and you still have to sit down and there are bugs crawling around, then

you know, it's so you know, it's not....it's not the lifestyle that we're used to and it can be very difficult. But by the same token, that's what their reality is and so you know I have to accept their reality as well and if I expect them to be able to accept what I'm doing with their child. . .It can be really hard. I think one of the things for myself, typical things don't bother me, I mean its okay, its okay but it's not okay, but it's their home. Sometimes it's the smell. Sometimes you know we all have little triggers that....and so that's something that I've really worked on because I have to set that stuff aside, that can't interfere with the work . . . So it's just....it's just a reality, so we kind of suck it up and go on and so it's okay if the dog pees on your shoe and....It's like, do you have a paper towel and you just go on.

*Family strengths or barriers.* Practitioner's assumptions and perceptions also clouded their ability to view strengths in the families with challenges. Because the families had so many concerns for practitioners to address, finding the family's strength from which to build their capacity may have been more difficult. One administrator worried that time stood in the way of practitioners truly finding families strengths. She elaborated to say that there was not enough time because of the "multitude of families they serve and the multitude of needs of the families." Two practitioners further explained the difficulty,

I mean you can get hung up on families not doing things, they're not doing things and you can really get into a negative cycle thinking about that family as opposed to as just realizing that my gosh, you know the fact is they got out of bed and they brushed their teeth today. Start looking at the things that they are doing and think about the positive, quit thinking about the negative so much, you know.

But I think that once they're already invited us into their home, there's already a plus. They've already accepted help.

Practitioners indicated that a strength of typical families was their consistency at providing support to their child between visits. Typical families were described as those families that follow through, or were "empowered to do what is necessary to

take care of their child and family's needs." Empower, empowering, and empowerment were terms used by practitioners to describe their assumptions about the underlying goal of early intervention. Empowerment was defined by practitioners as "helping families help their child through the use of informal supports."

Practitioners vocalized their perceptions and assumptions about empowerment,

And if we can help them understand, you know, if we can have them get right in there with us and have them practicing things and empower them to feel comfortable following through maybe they won't be needing us as frequently. They're feeling skilled enough to help their child.

Several of the mothers in challenged families were very outspoken about their child's needs and what services they would like to receive from the agency. When these services were not available or not provided by the Part C agency, many of these mothers were "empowered" and searched their community for supports. One mother developed a relationship with the librarian and had her child stay with at the public library so she had assistance with child care to run errands. Another mother wanted to find a parent support group or disability support group to understand her child's disability and prognosis better. She found support services through a local community church. "I do it because my kids need it. I do what I got to do. That's just how my mom raised me; if you have kids it's your job to do what you gotta." One practitioner referred to this mother as "tricky" and "system savvy." When challenged families were empowered to either decline early intervention services or pursue services from other agencies within the community, practitioners did not consider that a strength of the family. Instead of focusing on the skills these families had developed to advocate and to locate informal supports in the community, the

practitioners viewed their empowerment as not valuing early intervention services. The strengths that our researchers noted from our observations and interviews with challenged families were often elusive to the agency and practitioners.

### *Family-Practitioner Interaction*

The underlying perceptions or assumptions families and practitioners held about one another influenced the interaction between families and practitioners during home visits. Family and practitioner interaction is defined as the action and reactions between family members and practitioners during home visits which includes their verbal exchanges and body language. As noted by the framework in figure 1, this was not a linear relationship. The feedback loops indicate that the interaction practitioners and families had with one another could, in turn, affect their previous perceptions and assumptions. If practitioners had positive interactions with challenged families, they adjusted their assumptions and reported the family was “awesome” and “follows through” and “will do anything for their child.” On the other hand, if the interaction was challenging or negative either in the level of engagement of the family in services, the family’s follow through with service, or the practitioner’s ability to “get to the child,” the practitioner maintained their previous perceptions or assumptions about the family that was unfavorable.

Interactions between practitioners and families were impacted in several ways: (a) the practitioners’ ability to access the child, (b) the families’ level of engagement in the services, (c) the families’ commitment to follow through with

services, (d) the practitioners' boundaries in the relationship, and (d) how the practitioner balances the priorities of the family with their own expertise.

*Gaining access to the child.* One factor that impacted the practitioner and family interaction was the practitioner's ability to get access to the child. If the practitioner could not "get to the child" they spoke of not being able to give services or supports and expressed frustration. The practitioners, although family-focused, viewed their ultimate goal as getting services to the child. When families inhibited that process, for whatever reason, the family was viewed as challenging.

"Challenging families are those families that miss appointments. We can't help them because we can't get to them, so we are not meeting their needs. There is no way to know what their needs or their child needs really are." They were challenging because it was challenging to get services to the child in need.

Families that canceled appointments or were "no shows" were frustrating for practitioners to work with. Families with challenges often had snags in life that got in the way of keeping the appointments with practitioners. For one family, a custody battle became unpredictable. From time to time, appointments were not kept because the child was with her mother; therefore, the grandparents had to cancel appointments at the last minute. Practitioners often built their daily schedule around families that were more difficult to access or those families that needed more of the practitioner's time and attention. Appointments were scheduled at families' convenience and reminder calls were given to families the day prior to the visit. Still sometimes, despite these efforts, "you show up and they're just not there."

Access to the child was sometimes blocked by families who did not place the same "value" on early intervention services as the practitioner. One family did not see the need for services because they did not feel their child was delayed. Therefore, they often did not keep their appointments or the child was unavailable during home visits. Sometimes practitioners did not have access to the child because the child was napping during their visit. One practitioner discussed this frustration,

We should be in there, we should be the ones doing it, but as you saw today when we got to that house the baby's asleep...You know. Are you going to wake her up so you can do therapy and then have her fussy the whole time and not really doing anything anyway.

With families having multiple challenges, building rapport with an outsider could be difficult and time-consuming (Able-Boone, 1996). One practitioner talked about the frustration of not providing services to the child because the mother did not respond to her attempted contacts. But, as she noted, that was the families' priority or choice to not engage in early intervention services. Her strategy was consistent and repeated attempts to provide information and community resources to the mother to build rapport and trust. The practitioner was using community supports, in this case a bread ministry from a community church, as a basis to visit the mother and develop a relationship. Over time she hoped she would be able to forge a connection and work with the child or make referrals to other agencies on behalf of the mother in order to get services to the child.

*Engaging the family.* The interaction practitioners had with families was impacted based upon the families' level of engagement in the services. One practitioner shared her thoughts on family engagement,

We could convince parents that they are part of the solution. Sometimes we are not able to do that. It depends upon where the parents are coming from . . . ‘You’re here, you’re my child’s teacher, and I’m going to go into the bedroom and watch TV.’ We’ve all had that happen or something like that. If we can get them to understand that it is really important for them to be involved in it. That they have the power there . . . to empower them.

Most often the researchers in this study observed practitioners and family members working together during the home visit. Family members were usually engaged in the visit by either talking about their child or working with the practitioner to engage the child in an activity. However, there were cases in which the family member seemed uninterested in the activities or suggestions that practitioners had for their child. The following were cases from researcher’s field notes of home visit observations.

Case 1: [The practitioner] told Mom that [her child] had met her pivot goal – would she like to write a new goal? “What do you think Mom?” Mom responded to several probes with “I don’t know. What do you think is next? Whatever you think.” [The practitioner] said “Do you want to work or reaching for more toys or getting on hands and knees?” [Mom] replied, “Whatever you want.”

Case 2: Since the girls, who receive services, were asleep [the practitioner] offered to show [Mom] the video from their last visit. [She] had a portable DVD player and they sat on the floor and watched. [The practitioner] pointed out details from the video and asked [mom] what she thought about them. Although [the practitioner] was excited about [mom]’s response to the video after the home visit, [the mom] did not seem very engaged to me. Apparently they have had a hard time getting [the mom] to participate in the sessions. [The practitioner] said, “That was the first time she ever got on the floor with us.” Once the video was over; [the practitioner] sat with [mom] and went through the IFSPs for both girls. [The practitioner] asked several questions about whether [mom] was satisfied with the progress her daughters were making, what else she needed, and if she was working with them at home. [Mom]’s answers were monosyllabic for the most part but [the practitioner] was excited that [mom] sat through the review and responded to her questions. After they finished reviewing the IFSPs, [mom] moved over and sat with [practitioner] and her youngest daughter. [The practitioner] demonstrated a

few stretches and exercises to [mom] and then had her repeat them. [The practitioner] was excited about this saying that [mom] usually just sits on the couch during their visits and doesn't participate.

Practitioners struggled to engage families in the home visit activities. As noted above, one practitioner used a video recording of a previous home visit to draw the mother into a discussion of the child's progress. One practitioner described her strategy for engaging the families in an activity,

Asking them you know, to come in, be a part of whatever it is you're doing. A lot of times I'm very quiet when I go into the appointments and I just do a lot of things and demonstrate and whatever and let them kind of just observe . . . they become more interested because you're not forcing them, you're just kind of relaxing and letting them take whatever part they can and you know subtly drawing them in with things like well, here would you hold this for me while we're doing whatever. You know, try to get them to come to you.

In order to maximize the interactions between the practitioner and the family, one agency used research-based evidence regarding temperament and personality to match practitioners with families. Personality matching, as one practitioner described, was not based upon personal characteristics or socioeconomic status. She explained the benefits,

Well definitely you have to build a rapport first and you've got to be personable. You've got to....they've got to feel that you're an advocate for them and that you're someone that they can depend on. And then you can ask those tough questions . . . Sometimes, sometimes it takes time. Sometimes it's almost built into the personality. That you have a personality that you can just go in and sit down and say, what the heck is going on here? And you may not have known that family long enough, but they've got the kind of personality, you've got the kind of personality that you can just.... that you're a fit.

*Following through.* Additionally, the practitioners' interactions with the family were impacted by the family's follow through, or compliance, with intervention. Practitioners in our study defined follow through as the family



incorporating the early intervention strategies provided by the practitioners or therapists into their daily routines. For one practitioner, the criteria of follow through and accessibility is how she defined typical and challenged families,

I think the more difficult families are probably single parent families that maybe don't carry over the strategies that I teach them. So I don't see that much progress but they're still in there. They're also the families that you know aren't consistent with the...I usually have a hard time reaching them, I have a hard time you know getting out to see them. The families that are usually a little bit easier are typically families where you have both mom and dad that are following the strategies, you know, the parents are easy to get a hold of, they keep their visits. Those would probably be the easiest.

Some families placed a high priority on incorporating the strategies or activities provided during the home visit into their daily routine. However, other families, and oftentimes those families with multiple challenges, had other concerns that took precedence in their home life. These concerns included transportation, medical issues, employment, and legal issues. These families did not place as high a priority on the strategies practitioners suggested. Practitioners utilized the physical surroundings to optimize the likelihood that families would follow through with the activities or interventions for their child. Practitioners in one agency shared that they post daily routine activities on the families' refrigerators as a reminder tool. In a home observation, the practitioners designed the interventions around the mother's physical limitations and her easy chair. One of the practitioners described,

[The child] needed a lot of positioning help and it's not really something you can do from the chair. [Mom] just had a hard time getting on the floor and getting in those positions to hold [her child] so that was a big challenge for us . . . All of our planning has been around that chair. We've had a little table and a tote for her to sit on and it was right there so mom could work on fine motor stuff right in front of her.

Most of the practitioners acknowledged that families were trying their best to follow through with interventions. The practitioners' thoughts about follow through were usually enmeshed with their professional philosophy of early intervention services. When asked about follow through practitioners said,

[You have to] try and develop that relationship and make sure that they will follow through on the things that we're showing them to do. If there's no follow through, then you're not going to see progress.

It just doesn't happen. I mean I can go in . . . if I could go in every day, unless somebody else is following up on the things that I'm teaching or working on, it's not going to happen just because they're in therapy.

Because it gets to a point where parents don't want to hear it or maybe that idea is just not going to fit into their routine and we can provide suggestions but if it doesn't go into their routine, it's not going to get done.

If they're happy, they're content, then what's it my business that they're not doing all this stuff that I think that they need to be doing?

*Setting professional boundaries.* Practitioners defined both personal and professional boundaries when interacting with families. Boundaries in a relationship refer to the appropriate amount of closeness or distance with a family that is comfortable and safe for practitioners (Nelson et al., 2004). One practitioner explained her point of view,

I really enjoy having a relationship with the families. I enjoy the personal department, just getting to know them on a friendly basis. Just getting to know about their lives. I enjoy on visits asking how did something go or how's the wedding. I enjoy when they feel free to share life with me and not like we are just here to talk about my child and we are here just to do business.

The practitioners' boundaries were dependent, in part, upon finding similarities in their backgrounds with the families they serve. In relationships with some of the typical families, practitioners had a dual relationship with families and wore two hats,

one of the professional and one of a family friend. Dual relationships with families had blurred boundary lines in which practitioners felt comfortable sharing personal information with families. On the other hand, some practitioners felt most comfortable with rigid boundaries maintaining formal and business-like interactions.

In home visit observations, practitioners were business-like with some families while at the same time developing a “girlfriend” relationship with other mothers, all of which were typical. In these girlfriend relationships, we noticed that the practitioners often had contacted the mother or vice versa between home visits and these interactions appeared to be very warm and friendly. In these interactions, the practitioner was willing to share information about themselves and their family with the mothers they serve in a manner that one would treat a girlfriend. They giggled and shared private jokes during the home visits. One researcher observed a practitioner’s interaction with both a typical and challenged family in which the boundaries of the relationship were very different.

Typical family: After the home visit, the mother and [practitioner] made arrangements for their children to get together for a playgroup outside of school hours. There was a personal exchange between the two about [the practitioner’s] pregnancy and other topics. Later, this mother talked about [the practitioner], “She's the type of person that I would love to keep in touch with because now she's got a daughter who I think is maybe fourteen ...Fourteen months or something, so you know, I could see us this summer meeting at a park or something.”

Challenged family: At the home visit, the practitioner immediately began working with the child using a box of toys. She encouraged the child to play while explaining the concepts of “tempting” and “parallel talk” to the mom. The practitioner shared information with the mother about the developmental preschool and suggested further testing. As we left she handed a paper to the mother and said, “This is important.” The interaction was very focused on the child’s needs and goals.

From our observations, extra time was devoted by the practitioners to build a more intimate relationship with the “girlfriends” through extra phone calls and sharing of their personal life. Time was given to relationships with challenged families, but not in the same manner. The time spent with challenged families was business-like and problem solving oriented; it lacked the same energy or enthusiasm as the relationships that had developed into friendships. Practitioners were more likely to draw more rigid boundaries with challenged families. “I don't give out my cell phone number...and I know some people have. Some people do.”

I think, as you...as you start realizing the need to separate your personal life and your work life, and also to empower the families to understand that this is a service that's provided to you but you need to meet me in the middle, you know, I'm not going to make eight o'clock visits every week, you know.

Practitioners were, however, accessible and available to families by sharing common courtesies and maintained a high level of professional commitment to families by often going “above and beyond.” After losing his grandchildren in a custody hearing, a grandfather noted,

Not only did we talk about what was going on with [child's name], we also talked about what was going on with the other kids with the divorce and the personal stuff too. It was great to be able to have that outlet for me to talk a little bit with them. I like [our practitioner]; she just called me last week to ask me, she keeps in contact to see if [child's name] is coming back or how the kids are doing.

*Balancing priorities.* At times practitioners did not acknowledge the challenged families' requests for support during home visits. Sometimes the practitioner ignored the families' request because the families' needs did not mesh with the practitioners' goals for the child. When the challenged families vocalized

needs or desired goals for their children, practitioners did not recognize or prioritize the requests during the home visit. In a home visit, we observed a routines-based assessment in which the practitioner responded to a grandfather's comment that the child often ended up in bed with him and his wife. The practitioner suggested a goal to transition the child out of her grandparents' bed during naptime and bedtime. The grandfather, however, responded that it was not a priority and that he was satisfied with the bedtime and naptime routine. The practitioner persisted with the issue and promised to bring "more material about bedtime routines at the next visit." The following interaction between a teen mom and the interviewer explained the mother's frustration with having her requests ignored by her practitioner.

M: But I felt like I said, I've got two kids and I haven't heard the word mommy yet and I'm just waiting around for that. I mean, I had [his sister] and it was very hard, you know, and I still haven't heard the word momma said to me. Mommy, momma, anything.

I: But that's what you really want, you want to hear him say momma. Have you told [the speech pathologist] that?

M: Uh-huh.

I: And have they worked on him saying momma?

M: Not really, I haven't heard, I don't think she's working on that. I think she just wrote it down, but I don't think she is, but the next time she comes, I'm going to mention it

Several times during home visits or interviews, families indicated they were struggling with emotional stressors that practitioners ignored or missed in their interactions with families. Families spoke of being lonely or isolated because of being the primary caregiver of the child, though few services addressing this issue

were provided to families. Tough emotional issues were not addressed or were dismissed. One family requested the practitioner write a letter to a judge in a custody battle but was denied because it was “against the agency’s policy.” At another home observation, a researcher witnessed a mother detailing her and her children’s kidnapping, during which the practitioners continued on with their therapy with the child, unaffected by the recounting.

Perhaps though, practitioners didn’t necessarily ignore these comments from family members, but lacked the skills to address these harder issues. Many practitioners indicated the need for more training to learn how to talk to families about "bad news" and tough emotional issues. One practitioner stated, “I need more training on that. There are subjects that are brought up in home visits that I feel that ‘I’m not the right persons for this.’” It was beyond the practitioners’ expertise in helping challenged families with these issues. Currently, practitioners come into early intervention with training in child development and “are uncomfortable with the emotional family aspect of the job.” An administrator explained practitioners’ comfort levels rise with experience and “on the job” training.

Regardless of the reason for ignoring families’ needs or requests, the effect, as shown in Figure 1, may explain families’ continued reluctance to follow through on interventions and activities, which, in turn, provided continued reinforcement of the practitioners’ assumptions about the families.

### *Practices and Outcomes*

Professional practices were the specific strategies that were provided to the family to achieve outcomes for the family and/or child. The positive or negative impacts that families experienced as a result of early intervention supports and services for themselves and/or their children with disabilities were hypothesized as leading to family outcomes (Mannan, Summers, Turnbull, & Poston, 2006). The elements of the grounded theory framework detailed thus far, family and practitioner characteristics, perceptions and assumptions, and their interactions, influenced the practices practitioners exercised when working with challenged families and in turn, the outcomes challenge families experienced.

In our framework, practices and outcomes were intertwined. To parcel out the fine line between practices and family outcomes, we asked families about the outcomes they had experienced from their involvement with the early intervention program. Most families were ambivalent about how the program impacted the family or themselves directly. Families tended to focus on how their child was impacted by the services. “[My child] has grown leaps and bounds since they have been coming to the house.” Families were able to provide concrete examples about their child’s growth, “Once they started working with her, she learned like really quick . . . And now she's crawling, she's sitting up on her own; she's doing a lot of stuff.” This refers back to the families’ perceptions or assumptions for their expectations of the program. Most families assumed the program was to focus on their child’s needs and not the families, as one mother reasoned,

I don't think I really ask anything for me, other than something to do with [my son]. Always, I think it's always about [my child]. What he needs to do to help, or what we need to do for him to get better.

Although we asked families questions about outcomes and impacts they had experienced from participating in early intervention, the responses did not sufficiently differentiate the differences between the professional practices that were provided and the outcomes families experienced. Therefore, practices and outcomes are reported in tandem in this section. A better understanding of outcomes experienced by families would require more prolonged engagement and was noted as a limitation of this study (see Methods section).

Practices and outcomes included providing disability-related supports, enhancing parenting skills, providing emotional supports, and promoting physical well-being. Both typical and challenged families noted consistently that they were satisfied with the early intervention program. Interestingly, practices and supports were not always evenly distributed to typical and challenged families; however, the same outcomes were reported across the two groups. Some challenged families noted several unmet needs and made suggestions for the programs to improve their services for other families with multiple challenges.

*Resources for disability needs.* First, professional practices focused on providing disability-related supports for the child and family. These professional practices were provided to both typical and challenged families equally. As mentioned previously, several of the challenged families wanted information or referrals to support groups that were specific to their child's disability. Professional



practices and outcomes for disability needs included the following: (a) sign language skills, (b) behavior modification support, (c) disability specific information and interventions, (d) picture exchange systems, (e) occupational therapy, (f) speech therapy, (g) physical therapy, (h) early childhood special education, (i) assessments, (j) IFSP/goal writing, (k) transition program (nonrural agency), (l) audiology services, (m) assistive technology, and (n) service coordination (by the therapists or devoted personnel).

*Enhancing parenting skills.* Most of the families, both challenged and typical, felt their involvement in Part C improved their parenting skills and boosted their confidence. Parenting skills were enhanced by practitioners through parent education, encouragement, and emotional support. “They're kind of teaching me how to like be calm with him and stuff like that.” One mother explained that after working with the practitioner that she interacted better with her daughter,

I find that I can empathize with her frustration and I find that I take things, I look at things differently, like when I'm trying to explain and I also explain situations to her using smaller more direct words.

The professional practices that were most commonly utilized in home visits included: behavior management training and information, information on developmental milestones, routines-based interventions and assessments, and Parents as Teachers curriculum embedded into the services.

A new mother explained how the practitioners helped her parenting abilities,

Because you know, you know it's like my husband says they come without a set of instructions. . . And they told me, yeah leave him on his stomach, let him lay and play and let him cry, let him cry if he wants to and fall asleep. You're not being mean . . . it helped me a lot.

Other families said the following about themselves as parents as a result of their involvement in early intervention,

They are trying to educate us to become better parents while we're helping him be the best that he can be through everything that's gone on. . . They teach us how to be better parents. (Typical father)

I'm a little bit more of a confident mom; I'm able to be more self-assured on what I'm doing for my kids, and self confident of what I'm doing. (Challenged mother)

I learned how to be a better educated parent towards the kids. Being able to just be a better parent; to look at things a little differently. (Challenged father)

Just ways of working with [my child], that I probably wouldn't have thought. I mean I guess they just, you know, encourage me, you know, and tell me I'm doing a good job. (Typical mother)

An incidental outcome of enhanced parenting skills and confidence was improved family interaction. Both typical and challenged families acknowledged that being a better parent made the interactions with the entire family “happier” and “everyone just gets along easier.” Several of the challenged mothers felt their bond with their child had improved because they were more responsive to their child. “[Mom] said that they had taught her how to talk with [her son], games to play with him, and sign language. She had shared this information with her mother and grandmother and now they all incorporate it into their interactions with [the child]. She said this information has ‘made her happier’ because it has increased the bond she has with [her son]” (researcher field notes).

*Providing emotional supports.* While we as observers noted differences in rapport in the interactions between practitioners and typical versus challenged

families, the families themselves did not report a difference. From their perspective, practitioners gave emotional support to both typical and challenged families equally. Families in our study indicated practitioners were like “friends coming to visit” and their encouraging words and support led to confidence as parents. The families referred to them as a person to lean on and to tell problems. Interestingly, families noted the amount of emotional support that practitioners gave, however, the practitioners did not realize the impact of their relationship on the families’ emotional well-being. One practitioner said professionals don’t always remember that “we’re their second family.” Throughout the transcripts we found evidence of providing emotional support to families through the following practices: listening, hugs, friendship, encouragement, praise, emails or phone calls to families, attending appointments with families, and providing playgroups for interaction with other children and mothers. A challenged mother explained the emotional support she felt from the practitioners,

Just a lot of encouragement because I know when they first got involved that I realized just how far behind [my child] was and I was really overwhelmed and they just sat there and talked to me and they said don’t worry she’ll catch up she’s just going to do it her own time, you’ll see.

When working with challenged families, the practitioners’ values or judgments about the families’ circumstances or stresses influenced the supports that were offered. Practitioners at times withheld information about supports because they believed it would reduce emotional stress to the family. One practitioner indicated that the supports she referred families were based upon what she felt the family could handle at the time. She wanted to be careful not to burden the family further by

suggesting activities or resources that she felt the family would not follow through with either because they did not have the time or because they did not have the necessary informal supports to access the desired services. For example, she noted that if a family did not have transportation she might not tell them about a playgroup or if a family did not have a phone she may not give them a phone number for a community service organization.

*Promoting physical well-being.* Concrete resources were more likely provided to families with challenges than to typical families. These families had needs that were related to environmental risk factors associated with poverty (see Table 3). In one agency, practitioners helped a young challenged mother fill out a job application and then secure childcare for her children so she could be employed. Additionally, practitioners helped families complete paperwork to qualify for social benefits, such as Medicaid Waivers or Healthwave insurance or other community assistance programs. Transportation was a common problem for challenged families in accessing services. At times, practitioners arranged or provided transportation to and from IFSP meetings and appointments within the community. Several practitioners talked about providing material items, such as diapers or formula, to families “under the table” that went undocumented.

All the agencies and practitioners made referrals to community resources for both challenged and typical families as needed. The urban agency provided books to all their families through a literacy program with which they had partnered. The nonrural agency had a toy lending library that was available to all families they

served. One mother indicated that she wished that program would extend their library to include larger toy items that were more expensive to purchase.

*Unmet needs of challenged families.* Overall, both typical and challenged families were pleased with the supports they had received from their practitioner and the Part C agency. Typical families were satisfied and felt the program was “awesome.” One mother said, “It is a service that I am grateful for.” Families with challenges were also satisfied with the services they were receiving from the Part C agency. Sometimes they expressed satisfaction because they felt the agency had provided them all the services they had available. “I think they did a good job. I know they are not a social service.” Sometimes it was a matter that the families were not aware of the supports that the agency could provide. In interviewing a teen mother, the researcher questioned her about wanting to receive behavior modification supports from the early intervention agency. She said,

They explained to me why he qualified for certain things and why he didn't qualify. They didn't think he met the standards in behavior problems, they think it was just a typical toddler. . . Well they just gave me a lot of papers, a lot of information, I worked with the papers but they really didn't help.

Although challenged families expressed satisfaction with the Part C program; they also vocalized suggestions for improving the services to families. Challenge families were more likely than typical families to respond to the question - what services would you like the Part C program to provide? A few of the typical families mentioned wanting more intensive services or more home visits than they currently were receiving. One typical family said she would like to receive support from a parent group. The suggestions made by challenged families, however, were more

specific than those from typical families who were generally very satisfied with the program. One explanation may be that some of the challenged families had more extensive needs that could not entirely be met through Part C services.

Overall challenged families wished that programs would expand their programs to include emotional support for children through counseling services or links with Mental Health agencies. Two of the families in the study felt that this was so important for their child that they were willing to search out the services in the community without the aid of their practitioner. One family said,

If we had to we were going to pay for it financially out of our own pockets. Maybe the state would have taken care of it . . . whatever it would have taken. . . Education is important, but a kid's mental health and well-being is as important.

In addition to improved emotional health for their children, families also wanted to make connections with other families in the community to enhance their own emotional well-being. A teenage mother wanted to be connected with older mothers in the community to have a mentor for parenting skills. Another mother talked about finding a support group in her community so she could learn more about her child's specific disability.

Practitioners were either unaware of the emotional support services available to families in their community or they were trying to protect the family from "bad news." One practitioner explained that support groups were limited in availability and were more specific for families with specific conditions. She thought that practitioners were "leery" of telling families about formal support groups because of the age of the children (0-3 years) and that they wanted to protect families. She

elaborated to say that formal support groups sometimes provided information “too soon for families to hear,” i.e., she believed families of infants and toddlers were not ready to hear the prognosis or progression of the disability.

In addition to emotional support services, challenged families made other suggestions for the Part C agency. First, families wanted practitioners to offer resources for material items. Families suggested toy lending libraries for large ticket items and help acquiring cell phones. Both of these suggestions related directly to income. Families also requested parenting support for child behavioral concerns. Further, challenged families wished that services were more intense and more often, similar to typical families. One mother said,

I just want all that I can get for [my child] just to help her because it’s like the doctor said, we have no idea what this disability means for her, so I figure it’s better to have too many services than not enough, so I don’t care if I have to have people in here 24/7 if it helps her, I don’t care.

Last, and perhaps the most complicated, was the request for support during a custody hearing. Some families asked for help with custody issues. Sometimes that help involved just listening and preparing the child for the transition from the mother’s home to the father’s home. However, in one family the grandparents asked the practitioner to help them with a custody battle with their daughter, who was struggling with addictions, by writing a letter to the courts. The family wanted the court to know that they had been the primary caregiver and had been following through with early intervention services for the children. Policy issues within the agency kept the practitioner from writing the letter. Although family members

understood practitioners had their hands tied, it didn't ease the pain or frustration of their loss.

The one thing I would have liked or wished that would have been part of their thing was whenever they seen kids like our grandkids in a situation as to ours, that they would be able to have more rights to speak up and speak out. And get a hold of the necessary authorities because I think that we wouldn't have lost the kids then. I mean, it's not their fault. It would have helped. I did talk to [our practitioner] about it but she couldn't do it by law. She couldn't help.

### *Summary of Findings*

The purpose of this grounded theory framework was to understand how practitioners perceived families they believe to be challenged, and how their perceptions influenced the way they interacted with, and ultimately the practices they used to provide supports to those families. This framework illustrated the dynamic process between practitioners and families, hence, many elements of the framework overlapped. The overlap between elements was intentional to depict the complexity of an interactional process. The framework in Figure 1 illustrated that individual characteristics and experiences influenced both family and practitioner perceptions and assumptions, which in turn shaped their interactions with each other and finally, the specific practices practitioners used to achieve outcomes for the families and children. The data in this study confirmed many similar themes which emerged across different program sites, as well as from different community and geographic areas, which added to the validity of our conclusions.

The framework shown in Figure 1 depicts how family and practitioner characteristics and perceptions/assumptions influence their interactions and the resulting practices and outcomes. The figure helps to illustrate how the



characteristics, perceptions/assumptions, and interactions work together to influence the practices and outcomes provided in early intervention. For example, a challenged family characterized by previous negative experiences with other service agencies might react with initial distrust toward the practitioner. The practitioner, drawing on training about the purpose of early intervention, would in response be reinforced in her perceptions about the family's lack of engagement or "not caring" about her child. These perceptions would lead to further reductions in providing emotional supports because of the practitioner's own lack of engagement with the family, which in turn would reinforce the family's lack of trust. The missed cues and missed communications by both parties would in turn lead to a failure to provide practices that were a "best fit" to the family's needs and characteristics, and thus would reduce the effectiveness and level of the outcomes.

In contrast, when family and practitioner characteristics are more similar, their expectations and assumptions about early intervention would be more aligned and the resulting interaction more smooth, resulting, again, in reinforcing those assumptions. In that case, however, the supports provided would meet both the family's and practitioner's need and would increase both the relevance and the impact of the resulting practices.

The cumulative effect of family and practitioner characteristics, perceptions and assumptions, and their interactions impacted the practices practitioners exercised when working with challenged families and the outcomes families' experienced. Professional practices were those specific strategies provided to the family to achieve

outcomes for the family and/or child. Professional practices influenced family outcomes. Family outcomes were defined as either positive or negative impacts that families may have experienced as a result of supports and services for themselves and/or their children with disabilities (Mannan et al., 2006).

## CHAPTER 4: DISCUSSION

### *Key Findings*

Overall, this study develops a grounded theory explaining the relationships among family/practitioner characteristics, their assumptions and expectations, and the resulting interactions which lead to practitioners' decisions about practices and services and, ultimately, to outcomes for families. The data suggest that characteristics of the two partners (families and practitioners) may set up self-fulfilling prophecies, which, in the case of challenged families, create miscommunications and failure to establish a trusting relationship. This may lead to less effective professional practices and unmet needs for the family.

The practitioners in this study, like all populations, vary in their practices. Some are outstanding in their support to challenged families, whereas, others struggle with balancing family-centeredness while addressing the child's needs. Using this grounded theory framework to analyze the dynamics we observe, we find four key themes regarding family supports for challenged families: (a) the definition of challenged families based upon practitioners' perceptions, (b) the philosophy of early intervention practitioners to empower families, (c) the boundaries between practitioners and families, and (d) the mismatch between expressed satisfaction with services and unmet needs in the case of challenged families.

*Defining challenged families.* The first key theme is the definition of challenged families based upon practitioners' perceptions. Based on our analysis of the characteristics of families who practitioners recruited as challenged and typical,

we conclude that risk and protective factors appears to affect their perspectives. Although challenged families exhibit many of the risk factors associated with poverty, they also tend to be noncompliant, uncooperative, or unmotivated; in other words, they do not follow through with interventions, are not engaged in the home visit, or miss appointments (Atkins-Burnett & Allen-Meares, 2000; Shannon, 2004). Challenged families are perceived by practitioners as hard-to-reach (Landy & Menna, 2006). In a survey of multidisciplinary professionals in an urban area, practitioners indicated that family engagement during home visits needed to be improved in regard to follow through, responsibility to keep appointments, and accountability (Campbell & Halbert, 2002). Interestingly, the focus of the responses in this survey, as well as in our study, was on families changing their behaviors rather than practitioners changing their practices to improve the likelihood of follow through and enhance family involvement.

Perhaps a better description of the families recruited by practitioners is not challenged families, but families that are *challenging*. In this study, practitioners seem to view the challenges as foremost to the family and their strengths. Literature suggests that practitioners tend to make judgments about families and children based upon the families' status and structure (Amatea, Smith-Adcock, & Villares, 2006). Their beliefs about families come from their own personal background, experiences, professional literature, other professionals, the media at large, and from children (Grossman, 1999; Trivette & Dunst, 2005). The majority of early intervention practitioners come from a Euro-centric background (Baird & Peterson, 1997;

Hebbeler et al. 2007) which may be their perspective or standard for family “norms” (Baird & Peterson, 1997). Families have described a conflict with cultural values and practices between themselves and the practitioner (Park et al., 2001). Each of the practitioners in this study entered the partnership with perceptions or assumptions about how services should be provided. Embedded in these assumptions were notions about where and how families live, the families’ home environments, and their motives. When the interaction was difficult for any of the above reasons, the practitioners identified those families as challenged. Research indicates practitioners label families as unmotivated due to their own lack of training to establish trusting relationships or understand cultural or ethical differences and, instead, apply their own middle-class values to at-risk families (Shannon, 2004). There were several families in our sample who had many of the environmental risk factors in the literature but who also followed through with activities, kept appointments and were engaged in home visits; these families were identified by practitioners as typical families. We speculate early intervention practitioners perceive the families in our study as challenged due to environmental risks, but also as challenging because they are difficult to work with or considered hard- to-reach.

*The meaning of empowerment.* Second, some practitioners indicate that they believe an underlying philosophy of early intervention and family supports is to *empower* families. The definitions of the terms empower, empowerment, and empowering in the literature are vague (Ackerman & Harrison, 2000; DeMontigny & Lacharite, 2005). In a small qualitative study by Ackerman & Harrison (2000), the

participants use contradictory concepts regarding empowering their clients to be self-directed; empowerment is person and context specific. Empowerment is often used synonymously with parental efficacy, which is defined as “beliefs or judgments a parent holds of their capabilities to organize and execute a set of tasks related to parenting a child” (DeMontigny & Lacharite, 2005, p. 390). In this study, some practitioners tended to use the latter definition, i.e., referred to empowerment to express their beliefs that families should: (a) follow through on interventions, (b) do what is necessary to take care of their child and family’s needs, and (c) feel skilled enough to help their child through informal supports. The contrast between the literature definition of parental efficacy and the view practitioners in our study have regarding empowerment is the importance of the family viewpoint, rather than the practitioners’ perspective. The key of parental efficacy is how families view their capabilities, and this is promoted through experiences with parent training programs, verbal encouragement and persuasion, and lower stress levels (Bickman, Helfinger, Northrup, Sonnichsen, & Schilling, 1998; DeMontigny & Lacharite, 2005).

If practitioners believe the goal of early intervention is to empower families and families advocate and obtain services for their child or family in the community, then families must be empowered. However, in situations in which families obtain their own services or supports in the community, some practitioners seem suspicious and refer to families as “system savvy” and “tricky.” These families are empowered, but in the system they are considered challenged or challenging. Bailey (2001) and Carpenter (1997) suggest professional practices should encourage families to feel and

be competent in advocating for services to meet the needs of their child. Advocating for services or family empowerment is a protective factor which increases family resilience (Keogh, 2000; Wang, Haertel, & Walberg, 1997). Protective factors are shown to increase resilience in families in poverty which increases the likelihood of family sustainability (Juby & Rycraft, 2004; Vandergriff-Avery, Anderson, & Braun, 2004). Perhaps when working with challenged families, especially those families who live in poverty, we need to not only focus supports on building the family's capacity to care for their child, but enhance and develop the family's protective factors, i.e., empowerment and advocacy, to build their capacity for resilience (Vandergriff-Avery et al., 2004).

Empowerment, at times, is used by practitioners in this study as a way to describe enhancing family engagement in services, but this is a limited view of family strengths approach (Powell et al., 1997). Professionals must “understand the many contexts in which families live, work, and play--these different contexts are important components of the way we can work together with families. Differences can be strengths, and it is with this strengths perspective that [practitioners] can help diverse families become actively involved with their children” (Chavkin, 2003, para 4). We observe some practitioners using a “hit or miss” strategy to either promote involvement or blame the family for lack of engagement. Unfortunately, family strengths are not recognized explicitly by some practitioners in our study. Practitioners tend to tailor their services and supports around the child, and addressing the family's needs seems secondary to their purpose. Although

practitioners indicate they have adopted family-focused practices, comparing our observations with best practice recommendations provides insight into the extent to which their behaviors actually mirror their beliefs. Practitioners implement practices to encourage collaboration with families and address improved family functioning. In the study, practitioners promote parental confidence and emotional support through encouragement and verbal praise to families. We observe, however, that professional practices are not always individualized for families or built upon family's resources or strengths. During home visits, we notice services do not differ much from family to family. Research demonstrates utilizing a strengths-based model of services should enhance family engagement and family-practitioner partnerships, as well as improves parenting skills, parenting competence, and parental empowerment (Green, McAllister, & Tarte, 2004). Further, families perceive that strengths-based services become stronger over time, partially due to the increased duration of involvement in the program and stronger relationships with practitioners (Green et al., 2004; Powell et al., 1997).

*Relationship boundaries.* The third key theme is the boundaries between practitioners and families. Practitioners set boundaries in their work to protect their personal time and space (Nelson et al., 2004). However, family-centered practices focus on the interaction between families and practitioners, creating opportunities for more blurred boundaries (Nelson et al., 2004). In this study, we observe practitioners developing relationships with typical mothers that could be characterized as “girlfriends”; whereas, the relationships with challenged families were more business-



oriented. McWilliam, Tocci, and Harbin (1998) determine that effective family-centeredness includes six components to build reciprocal and trusting relationships, of which family orientation and friendliness refer to extending the boundaries of the practitioner relationship and taking the role of a curious and concerned family friend. Additionally, Schorr (1997) notes that successful programs have practitioners who extend their self to be included in the lives of the families and children with whom they work.

We suspect that several factors play into the comfort level of practitioners when developing girlfriend relationships with families. First, practitioners may feel more of a connection with families who are invested in the services they are providing to the child and family. Typical families are those families that follow through with suggestions and are accessible. These families place the same value on early intervention as the practitioner, and therefore, the practitioner feels a connection to follow through for the family. Psychologically, the practitioners may have been reinforced and so they continue to go “above and beyond” or broaden their breadth of responsibility for these families (Nelson et al., 2004). Second, practitioners cultivate connections with families who are most like them. The relationships and boundaries practitioners develop are conceptualized as a continuum that is fluid for each family (Nelson et al., 2004). In order to facilitate the development of trusting relationships, early intervention programs have utilized matching practitioner and families based upon personalities and personal history (Brookes et al., 2006; Lee et al., 2003). For smaller agencies, this may not be feasible, therefore, it is important that all staff are

well trained in relationship techniques to build connections with families over time (i.e., persistency and consistency) (Brookes et al., 2006; Landy & Menna, 2006).

Third, in developing relationships, we feel the issue of time is an influencing factor on the relationship that is built between the family and practitioner. “Trust involves time, effort and at times, setting aside our own deeply held convictions” (File, 2001, p. 71). In home visits with typical families, practitioners may have more time to develop friendships, chat about personal issues, and find common ground, because the family has fewer concerns or the family is only focused on the child (McBride & Peterson, 1997). With challenged families in this study, practitioners indicate they have only a limited amount of time to work with families; when there are many pressing issues to solve, practitioners feel pressure to jump in and fix things. This is consistent with literature indicating that practitioners report their time is spread so thinly that they don’t have time to develop a quality relationship with challenged families (Atkins-Burnett & Allen-Meares, 2000; Lee et al., 2003; Powell et al., 1997). Time and professional boundaries are barriers to developing quality relationships between challenged families and practitioners.

*Satisfaction and unmet needs.* The outcomes or impacts families experience from early intervention participation constitute the final theme. Both typical and challenged families express satisfaction with the supports they receive from the Part C program. However, when we asked families for suggestions for program improvement, typical families are unable to think of any, while challenged families indicate they have many unmet needs. The needs vary from a desire to connect with

other families and parenting programs to needing material items. Families expressing satisfaction with the program, despite having needs that are unmet; is consistent with current research. Research suggests that families of young children tend to be highly satisfied with family-practitioner partnerships and early intervention services (Hebbeler et al., 2007; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005).

There are several possible reasons for families to express satisfaction though continuing to need more support. First, this is the families' first exposure to the early intervention system, and they may not understand or realize the role of the Part C agency (McBride & Peterson, 1997; McWilliam et al., 1995; Summers et al., 2005). Families are happy with what they have received thus far, but still have needs. They may feel that the program is not a social service or the services are only for their child or they do not yet realize what would be helpful for their family (McWilliam et al., 1995; Turnbull et al., 2007). Second, family satisfaction is a self-report measure and may not accurately evaluate the impact of the supports provided by the program. Current program evaluations do not provide the information practitioners and researchers need to fully understand the families' and agencies' nuances and their interactions; multiple methods and documentation are needed to effectively evaluate the complexity of early intervention supports (Bailey, 2001; Peterson, 2002). Third, families may be expressing their needs, but practitioners' perceptions and assumptions may get in the way of hearing families' needs, which leads to negative family outcomes or unmet needs. Consistent with the literature, families believe that their desires are not always broached by the practitioners serving the family

(Carpenter, 1997). In this study, the practitioners tailor the services and supports they provide to challenged families based upon their priorities for the child and family and their perceptions of the family circumstances. For example, some practitioners inform families about play groups only if the families have transportation to get there, instead of working with the families' informal supports to find resources for transportation to and from activities. In practice, practitioners need to tailor services to the family's individual needs (Bailey, 2001; Middlemiss, 2005); however, early intervention continues to individualize primarily for the child's needs and disability (Campbell & Halbert, 2002; Hebbeler et al., 2007; McBride & Peterson, 1997; McWilliam et al., 1995; Wesley et al., 1997).

#### *Comparing Study Findings and Recommended Practices: Implications*

This study investigates the perceptions of early intervention practitioners in regard to challenged families. Further, we want to know if practitioners' perceptions of challenged families influence the practices they carry out in home visits. DEC recommends family-focused practices to guide practitioners about the important aspects of working with families (Trivette & Dunst, 2005). Family supports should include the *how*, *what*, and *where* of early intervention services. The *how* of services refers to the style of interaction and interpersonal dynamics; the *where* of services refers to the setting of the services; and the *what* of services refers to the specific types of family supports and services that are provided (Turnbull et al., 2007). As noted by Turnbull and colleagues (2007), the DEC family-focused recommended practices outlined in Table 4 focus more on the *how* and *where* of supports, rather

than on the what. In Table 4 we include data observations to demonstrate the alignment of practitioner behaviors in this study, as well as the mismatch, with the DEC family-focused recommended practices. McBride and Peterson (1997) report that there is a lack of congruence between professional practices and philosophy in early intervention. It appears that many of the practitioners in this study are focused primarily on the *how* of supports; they are most concerned with families engaging in services, being available, and following through with the interventions.

Table 4

*DEC Recommended Practices and Observations from Study Data: Family-based Practices*

DEC Recommended Practices	Data Observations
<p><b>Families and professionals share responsibility and work collaboratively</b></p> <ul style="list-style-type: none"> <li>• Family members and professionals jointly develop appropriate family-identified outcomes.</li> <li>• Family members and professionals work together and share information routinely and collaboratively to achieve family-identified outcomes.</li> <li>• Professionals fully and appropriately provide relevant information so parents can make informed choices and decisions.</li> <li>• Professional use helping styles that promote shared family/professional responsibility in achieving family-identified outcomes.</li> <li>• Family/professionals' relationship building is accomplished in ways that are responsive to cultural, language, and other family characteristics.</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Practitioners tried to engage families in joint decision making regarding outcomes but families usually took the practitioners lead in determining the goals for the child. Most of the goals were written based upon the child's needs.</i></li> <li>• <i>Practitioners gave families written information regarding the child's disability, activities, routines, and other community resources.</i></li> <li>• <i>Practitioners used videotaped sessions of families and children during home visits.</i></li> <li>• <i>All visits/activity settings were conducted in the home.</i></li> <li>• <i>Families requested connections with other families. This only occurred in the context of program sponsored playgroups.</i></li> <li>• <i>Practitioners provided emotional support to families through</i></li> </ul>

DEC Recommended Practices	Data Observations
	<p><i>encouragement, friendships, praise, and “just being there.”</i></p> <ul style="list-style-type: none"> <li>• <i>Agencies utilized interpreters to communicate effectively with ELL families.</i></li> </ul>
<p><b>Practices strengthen family functioning</b></p> <ul style="list-style-type: none"> <li>• Practices, supports, and resources provide families with participatory experiences and opportunities promoting choice and decision-making.</li> <li>• Practices, supports, and resources support family participation in obtaining desired resources and supports to strengthen parenting competence and confidence.</li> <li>• Intrafamily, informal, community, and formal supports and resources (e.g. respite care) are used to achieve desired outcomes.</li> <li>• Supports and resources provide families with information, competency-enhancing experiences, and participatory opportunities to strengthen family functioning and promote parenting knowledge and skills.</li> <li>• Supports and resources are mobilized in ways that are supportive and do not disrupt family and community life.</li> </ul>	<ul style="list-style-type: none"> <li>• <i>A few of the practitioners utilized strategies to promote family engagement in services. Some simply scheduled appointments conveniently for families, whereas others actively reflected on ways to involve families in home visits.</i></li> <li>• <i>Two of the agencies embedded PAT curricula into their routine-based interventions.</i></li> <li>• <i>Two of the agencies hired a parent liaison devoted to connecting families with services in the community.</i></li> <li>• <i>Practitioners promoted parenting confidence through emotional support and verbal encouragement.</i></li> <li>• <i>The families reported an increased competence in their parenting and confidence from early intervention services and as a result felt their family interaction was improved.</i></li> </ul>
<p><b>Practices are individualized and flexible</b></p> <ul style="list-style-type: none"> <li>• Resources and supports are provided in ways that are flexible, individualized, and tailored to the child’s and family’s preferences and styles, and promote well-being.</li> <li>• Resources and supports match each family member’s identified priorities and preferences (e.g., mother’s and father’s priorities and preferences might be different).</li> <li>• Practices, supports, and resources are</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Services did not seem to differ much from one family to the next. Services tended to be once or twice a week for one hour. Families expressed a desire for more visits.</i></li> <li>• <i>Families also expressed a desire to connect with other families or support groups, however, these needs or desires were unmet.</i></li> <li>• <i>Most of the families were from low SES, and practitioners seemed to have preconceived notions about</i></li> </ul>

DEC Recommended Practices	Data Observations
<p>responsive to the cultural ethnic, racial, language, and socioeconomic characteristics and preferences of families and their communities.</p> <ul style="list-style-type: none"> <li>Practices, supports, and resources incorporate family beliefs and values into decisions, intervention plans, and resources and support mobilization.</li> </ul>	<p><i>families and their homes and surroundings.</i></p> <ul style="list-style-type: none"> <li><i>There seemed to be a mismatch of the practitioner and family's values regarding the purpose of early intervention and the needs of the family.</i></li> </ul>
<p><b>Practices are strengths- and assets- based</b></p> <ul style="list-style-type: none"> <li>Family and child strengths and assets are used as a basis for engaging families in participatory experiences supporting parenting competence and confidence.</li> <li>Practices, supports, and resources build on existing parenting competence and confidence.</li> <li>Practices, supports and resources promote the family's and professional's acquisition of new knowledge and skills to strength competence and confidence.</li> </ul>	<ul style="list-style-type: none"> <li><i>Practitioners did not recognize family strengths.</i></li> <li><i>Although families reported becoming more competent and confident as parents, we did not observe utilizing family strengths as a foundation to build families' skills and capabilities.</i></li> <li><i>All agencies provided practitioner development training for staff to increase their knowledge and skills in routines-based interventions, relationship-focused approaches, and transition planning, as well as other topics.</i></li> </ul>

Note. From Trivette, C.M. & Dunst, C.J. (2005). DEC recommended practices: Family-focused practices. In S. Sandall, M.L. Hemmeter, B.J. Smith, & M.E. McLean (Eds.), *DEC recommended practices: A comprehensive guide for practical application* (pp 107-126). Longmont, CO: Sopris West.

### *Implications for Research*

This grounded theory framework contributes to the field of early childhood special education by supplementing the research which focuses on professional practices for working with challenged families (i.e., Campbell & Halbert, 2002; Darling & Gallagher, 2004; Mahoney & Filer, 1996; McWilliam et al., 1998; Shannon, 2004). It begins to fill the gap in research by demonstrating the effectiveness of family supports related to families in poverty (Turnbull et al., 2007).

The DEC family-focused recommended practices (Trivette & Dunst, 2005) and research by McWilliam and colleagues (1998) identify key components and practices that result in effective family-centeredness in early intervention. This grounded theory study provides a framework for understanding the dynamic process of how practitioners choose and exercise practices when working with challenged families and how that interaction leads to family outcomes.

This study needs to be replicated to determine if the framework and factors are transferable to other agencies and practitioners. Additionally, research should determine the extent to which family supports are consistent with recommended practices (Bailey, 2001). For future research, we suggest using an observational checklist during home visits to empirically measure practitioners' behaviors towards challenged families (McBride & Peterson, 1997; Peterson, 2002). Observation checklists should include the factors we identify in our framework that impact interactions with challenged families, such as practices which engage families in services, promote family empowerment, are sensitive to families' culture and values, and assess and build on families' strengths and assets. Given the complexity of the interactions that occur during home visits, observational measures, as a complement to other measurements, would accurately detail the professional practices employed during home visits (McBride & Peterson, 1997).

In our framework, practices and outcomes mesh because our findings do not substantially delineate the differences between the two factors. Further research needs to parcel out outcomes and practices and uncover the relationship between



which professional practices led to specific family outcomes (Bailey, 2001; Peterson, 2002; Turnbull et al., 2007). Understanding the relationship between practices and outcomes would benefit practitioners in choosing interventions, strategies, and settings to match individual family strengths, needs, and cultural expectations (Bailey, 2001; Peterson, 2002). In addition, we suggest using the theories of resiliency and protective factors to measure outcomes for families in poverty. Mannan and colleagues (2006) propose a framework to measure both the *how* and *what* of service delivery using multiple measures. They recommend measuring family satisfaction, family empowerment, family social supports, parenting skills and competency, and overall family quality of life to understand the relationship between practices and outcomes. This framework incorporates three key protective factors for promoting family resilience: empowerment, social supports, and parenting skills (Amatea et al., 2006; Carpenter, 1997; Juby & Rycraft, 2004; Keogh, 2000; Middlemiss, 2005; Vandergriff et al., 2004; Zeece & Wang, 1998).

#### *Implications for Policy*

Cultural responsiveness in disability policy is defined as the services and supports that are provided in a culturally sensitive manner which respond to the family's individual needs and, thus, increases the likelihood of the family receiving benefit from the early intervention program (Turnbull, Beegle, & Stowe, 2001). Recent policy analyses of IDEA Part C indicate that although cultural responsiveness is supported in the findings of the policy, there are neither provisions within the statute to mandate resources nor requirements of accountability (Epley, 2006; Friend,

2006). The analysts refer to the lack of specificity of the policy in (a) defining culturally sensitive services, (b) addressing recruitment of minorities, (c) outlining requirements for personnel preparation, (d) addressing needs of families from linguistically diverse backgrounds, and (e) maintaining a narrow concept of culture as referring to persons' ethnicity (Friend, 2006). IDEA Part C warrants stronger language in regard to cultural responsiveness for families to match the ideals and findings of IDEA with specifically outlined provisions for resources and outcomes.

Additionally, the Office of Special Education Programs (OSEP) has adopted outcomes specifically for families in early intervention. Although these indicators are a starting point for family policy, they do not incorporate outcomes to promote resiliency for families with multiple challenges. The Early Childhood Outcome (ECO) Center initially recommended OSEP incorporate five outcomes, which included (a) families know their rights and advocate effectively for their children and (b) families have support systems (Bailey et al., 2006). The literature indicates that both of these outcomes, advocacy and social supports, are linked to increased family resilience (Amatea et al., 2006; Carpenter, 1997; Juby & Rycraft, 2004; Keogh, 2000; Vandergriff-Avery et al., 2004; Wang et al., 1997). Although literature suggests the importance of families attaining these goals, OSEP has not yet adopted these outcomes into the accountability standards for early childhood special education programs. We recommend that OSEP require the outcomes for family advocacy and support networks in the future to assure that early intervention programs will

implement practices to promote family efficacy and sustainability for challenged families.

### *Implications for Practice*

In order to improve supports for challenged families, practitioners must expand their strategies with the intention of enhancing their interaction with families. From this research, our recommended practices for working with challenged families include: (a) clarifying values and differences through cultural reciprocity, (b) enhancing family engagement using reflective practices, (c) developing trusting relationships by matching practitioners and families, and (d) promoting resilience through parent training and mentoring programs.

*Cultural reciprocity.* Our research indicates that practitioners need more training or coursework in cultural awareness. Practitioners identify challenged families as those with environmental risk factors and noncompliant behaviors. Although we observe practitioners using strategies for cultural sensitivity (i.e. interpreters, flexible scheduling, transportation), cultural reciprocity goes beyond these standard strategies (Kalyanpur & Harry, 1997). Cultural responsiveness and reciprocity needs to be adopted to understand challenged families and to put into perspective practitioners' values and how they impact service delivery (Baird & Peterson, 1997; Harry 2002; Mahoney, Boyce, Fewell, Spiker, & Wheeden, 1998; Powell et al., 1997; Turnbull, Blue-Banning, Turbiville, & Park, 1999).

Cultural reciprocity is an understanding of the practitioners' underlying values and norms and then comparing, reflecting, and collaborating with families to provide

services and set goals which build on the families' strengths and values (Atkins-Burnett & Allen-Meares, 2000; Harry et al., 1999). The practitioners' values and priorities may not always coincide with the families, and understanding what the differences are will open up lines of communication to shared decision-making (Atkins-Burnett & Allen-Meares, 2000). In order to connect with families with multiple challenges, practitioners must give up their preconceived notions of how families must function, especially when the family differs from their own cultural values (Powell et al., 1997). Instead, practitioners need to understand families' beliefs, values, and interactional patterns to be more effective (Amatea et al., 2006; Harry et al., 1999; Lava, Recchia, & Giovacco-Johnson, 2004; Powell et al., 1997). Practitioners could improve their interaction with challenged families by spending extended time in the families' home to become familiar with the routines and lifestyle (Turnbull et al., 1999).

Consequently, practitioners' own values, biases, training, and experiences influence how they view their role in the family interaction and the decisions they make in providing supports to challenged families (Gilkerson & Stott, 2000; Kalyanpur & Harry, 1997; Lee et al., 2003). In a reflective practice, practitioners must articulate their differing beliefs and values to families (Kalyanpur et al., 2000). Cultural reciprocity contributes to the foundation for building a collaborative relationship with challenged families (Kalyanpur & Harry, 1997).

*Reflective practices.* A key concern of practitioners is engaging families in early intervention services, so much that it influences their perception challenged

families. When their service delivery approach does not mesh with families, most practitioners have an attitude that they are helpless to get families involved. A few of the practitioners do reflect on their practices to individual families and adjust or try different strategies to enhance the likelihood that families engage or follow through with interventions. One component of practitioner training and resources that is needed for practitioners is the ability to reflect on their practices and make critical decisions regarding how or if a change is needed in their approach (Harry et al., 1999). Reflective practice is as an ongoing process of critically examining current and past practices to facilitate future action or intervention (Wesley & Buysse, 2001) and further examining the congruence of one's actions and practices with their underlying philosophy or belief of service delivery (Corcoran & Leahy, 2003).

We observe in our home visits practitioners utilizing DVD video taping of the family-practitioner interaction. Watching the video as partners in the child's development, the practitioner and family are able to converse about the observed intervention and target areas for improvement or change. Additionally, close bonds with practitioners encourages family engagement in the early intervention; this is facilitated by consistency and persistence by the practitioners (Brookes et al., 2006; Summers, McMann, & Fuger, 1997). In interviews with practitioners, some indicate they have invented reasons to visit homes in order to interact with the families, hopeful that the continued contact could result in services to the child and family engagement in early intervention. Gilkerson (2004) recommends that practitioners have opportunities to critically reflect on families and their needs with peers and

supervisors to share ideas and brainstorm solutions. In this study, all practitioners participate in staff and team meetings, but without more observation of those activities it is difficult to know whether they are using reflective practices.

*Practitioner/family matching.* Families with multiple risks need programs to provide interventions of high intensity and over a long period of time, during which time the practitioner/family relationship becomes the focus (Landy & Menna, 2006). Schorr (1997) states successful programs encourage practitioners to build strong, trusting relationships with families. Extending professional boundaries may enhance the relationship with challenged families, but the boundaries of the relationship are determined by both the practitioners' and the families' desires and preferences (Nelson et al., 2004). One strategy utilized by agencies is matching practitioners and families. Matching practitioner and family involves attending to subtle similarities between the two, such as personal history and personality (Brookes et al., 2006). Some agencies, however, attempt to match the practitioners' ethnicity with those of the families they serve (Lee et al., 2003). For example, if the families the agency serves are primarily African American, the agency purposefully sought out to hire practitioners that were also African American. The hope of matching practitioner and family is to develop a closer bond between the two which will lead to enhanced family engagement (Brookes et al., 2006).

We realize matching may not be feasible for all early intervention programs, given the varying sizes and staff of agencies. One way to encourage matching is to recruit more diverse personnel in the field of early intervention. Currently, the field is

dominated by white female practitioners (Baird & Peterson, 1997; Hebbeler et al, 2007). Literature about matching focuses on drawing home visitors from the community or similar cultural backgrounds (Brookes et al., 2006; Lee et al., 2003). For example, one practitioner in the study is a member from the community and strongly believes that she needs to represent her culture. She serves as a bridge for Latino families across her agency and as a knowledge base about Latino culture for the staff.

*Training and mentoring for resiliency.* Empowering families to work with their child and utilize their informal supports to build their capacity is a goal of early intervention services. Identifying strengths in challenged families eludes some practitioners in our study. What we observe as an asset in challenged families, such as finding a support group at a local church in the community, many practitioners view as a challenge. Perhaps the key to working with challenged families is turning the perceived challenges into resources to draw upon in practice. A family-strengths perspective should include building resilience in families living in poverty through skills and resources for advocacy and empowerment.

Similar to a family-strengths perspective, resiliency theory is based on identifying and enhancing the presence of protective factors (i.e., family strengths, informal support resources) that can assist families and children to avoid negative trajectories from early risk to later problems and circumstances (Middlemiss, 2005). Resiliency-based interventions consider different potential sources of risk and then build skills around the protective factors. To increase the likelihood of building

resilience in challenged families, literature recommends early intervention practitioners receive training to learn how to identify family's protective factors and use those resources to build the families' capacity and resiliency (Middlemiss, 2005; Vandergriff-Avery et al., 2004). Additionally, practitioners would benefit from more awareness about poverty factors and how they impact families' functioning (Fujiura & Yamaki, 2000).

Early intervention home visiting programs are ideally set up to promote resiliency in families. Like Part C programs, successful resiliency intervention programs work with families, children, and practitioners concurrently (Middlemiss, 2005). To maximize change and resiliency in challenged families, families need modeling and mentoring to learn new skills, such as advocacy, empowerment, communication, and parenting (Keogh, 2000). Several authors suggest the use of parent mentoring programs or Parent to Parent connections for challenged families to encourage parental self-efficacy (DesJardin, 2006; Singer et al., 1999; Thompson et al., 1997; Wall et al. 2005;). In a six-year study of Early Head Start and Part C services, researchers found that mentoring programs for families helped them advocate for services and become more effective problem solvers (Wall et al., 2005). Further, literature supports training in empowerment skills and strategies to increase knowledge about available services and enhance the families' confidence in their ability to negotiate the system (Bickman et al., 1998; Cooper & Christie, 2005; Vandergriff-Avery et al., 2004; Zeece & Wang, 1998).



Parent mentors can help families negotiate systems and truly become more empowered by learning how to be “system savvy.” Further, parent mentoring or Parent to Parent programs can help alleviate some pressure from practitioners. One practitioner states at times she feels like a “social worker.” Practitioners in follow-up interviews report they need more training to learn skills to address the families’ more difficult emotional issues. They also question whether this is part of their job. Emotional support for practitioners is an area to investigate further in research. Parent mentoring programs could be beneficial to assist practitioners in dealing with families’ tough emotional issues and provide resources, while encouraging family empowerment.

## CONCLUSION

Working with families having multiple challenges presents unique challenges for practitioners. Families with environmental risk factors need programs to provide interventions with broad-based formal and informal supports in which the family and practitioner interaction guides the process (Landy & Menna, 2006; Powell et al., 1997). Problems in practice do not center around the child's learning and development, but on the dynamics of the family-practitioner partnership (Gilkerson, 2004). Early intervention practitioners must examine their values, attitudes and beliefs and how it influences their practices and family supports. "How parents come to view themselves as parents, their child, and their circumstances will depend, in part, on the attitudes of those who work with them and on the approaches taken to the intervention process" (Gilkerson & Stott, 2000, p. 460).

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