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How Do Administrators of New York City Early Intervention Programs Conceptualize and Implement Family-Centered Care?

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HOW DO ADMINISTRATORS OF NEW YORK CITY EARLY INTERVENTION
PROGRAMS CONCEPTUALIZE AND IMPLEMENT FAMILY-CENTERED CARE?

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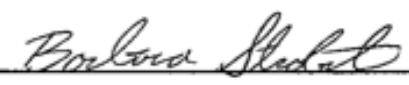
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submit a copy with your final dissertation to be bound as page number two.

ABSTRACT

Family-centered care, the mandated delivery approach outlined under the Individuals with Disabilities Education Act, Part C, is considered best practice in providing services to families with children under three with special needs. It has been shown to benefit children and families through numerous positive outcomes. Yet, family-centered care is not implemented in all programs universally, and significant variation exists in how programs deliver family-centered services, to the detriment of families. Much of that variation can be attributed to programmatic leadership, as administrators establish the philosophy, policies, practices, and organizational climate of an agency.

This project intended to build on the limited research regarding the role administrators have in delivering family-centered Part C services by exploring administrators' definition and viewed purpose of family-centered care, identified challenges to providing family-centered services, ways the obstacles were negotiated, and how those factors impacted the implementation of family-centered programming. In this qualitative case study, 21 administrators of New York City Part C programs anonymously completed a web-based questionnaire that was used to elicit narrative and demographic data. The data were examined using Creswell's (2003, 2008) six stages of qualitative data analysis and descriptive statistics.

The results reaffirmed previous research (Mandell & Murray, 2009), which found that how administrators conceptualize family-centered care reflects how it is implemented in programs. This demonstrates the influential role administrators have in the delivery of family-centered services. The data revealed New York City Part C

administrators conceptualized family-centered care as a means of including and engaging families in programming to teach families intervention strategies to carry over into the child's natural environment for the benefit of the child. The categories of practices that were least frequently implemented in programs involved supporting and partnering with families, which are the fundamental elements of a family-centered service delivery approach. The results implied programs operated under a family-allied or family-focused, family-oriented program model as outlined by Dunst and his colleagues (1991), which is consistent with previous research on programs that provide services to families with young children who have special needs. The data suggested potential contradictions regarding how administrators perceived families, how staff were viewed, between rhetoric and practice, and in practices that could support staff to provide family-centered programming. Characteristics of administrators and programs were identified that appeared to influence the delivery of family-centered services. These factors deserve attention in practice as well as in further research. The data suggested there is room for growth in the delivery of family-centered care in New York City Part C programs and in policies that would facilitate programs to provide family-centered Early Intervention services. Last, although this study was focused on Part C programs, family-centered care can be beneficial to the educational community beyond the early childhood years by serving as a platform for education personnel to use to develop collaborative partnerships with families, thus improving academic achievement.

It is very easy to overestimate the importance of our own achievements in comparison with what we owe others. — *Dietrich Bonhoeffer*

ACKNOWLEDGMENTS

am today. You gave me the strength, determination, and passion that enabled me to achieve this goal.

Thank you all very much!

DEDICATION

Other things may change us, but we start and end with the family.
—Anthony Brandt

Hey,

Pop^2 & Mom^2

Daddy & Mom

Chris & Sam

& Amy

This is for you!

waving

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

INTRODUCTION

With his signature, President Gerald R. Ford changed the face of education on

November 29, 1975, when he signed the Education for All Handicapped Children Act

(EAHCA), by legitimizing and formalizing the role parents play in the education of their

children ages 3 to 21 with special needs. Until the EAHCA, also known as Public Law

94-142, was passed, parents of a child with special needs were granted neither rights nor

specified roles in their child's education (Valle, 2011; Wehman, 1998). The intent of

EAHCA's legislative mandate was to incorporate parental input and participation into a

child's educational programming as well as ensure equal and respectful partnerships

between families and members of the child's educational team (Dunst & Dempsey, 2007;

Spann, Kohler, & Soenksen, 2003; Osher & Osher, 2002; McCoy & Glazzard, 1978;

Wehman, 1998) on behalf of and for the benefit of the child with special needs.

However, those intended partnerships have not often materialized as envisioned

by lawmakers (Coots, 2007; Howland, Anderson, Smiley, & Abbot, 2006; McCoy &

Glazzard, 1978; Spann, Kohler, & Soenksen; 2003; Valle, 2011; Valle & Aponte, 2002).

In many instances, adversarial and acrimonious relationships develop. Yet, the consensus

is that parental involvement is vital to educational success for a child with special needs

(Al-Shammari & Yawkey, 2008; Edwards & da Fonte, 2012; Howland et al., 2006;

Jeynes, 2005, 2012; Spann, Kohler, & Soenksen, 2003; Tucker & Schwartz 2013).

Collaborating with families has been determined to be even more essential for the

educational outcomes of young children with special needs (Bailey, Raspa, & Fox, 2012;

Bronfenbrenner, 1975; Campbell & Sawyer, 2007; Dempsey & Keen, 2008; Dunst,

Trivette & Hamby, 2007; Dunst, Trivette, Hamby, & Bruder, 2006; Mahoney & Wiggers, 2007).

When Congress reauthorized EAHCA in 1986, Part H was added. Part H, also known as Public Law 99-457, established Early Intervention programs that would deliver services to facilitate the development of children under the age of three with special needs. However, there was a unique facet to this legislative act. Recognizing the central role of the family in the development and functioning of a child under the age of three (Bailey, Raspa, & Fox, 2012; Thomas, 1998), the law mandated that services be provided to the family as opposed to the child in isolation. Under Part H, assessment, planning, and services centered on the entire family, even though the child presented an identified need (Allen & Petr, 1996). Therefore, the needs of the family, family support systems, and resources have to be evaluated and addressed.

Consequently, this new legislation and its requirements necessitated momentous modifications in relationships with families, paradigms, and practices from the traditional educational model. With the enactment of Part H, the balance of power and locus of control between families and personnel of the educational system shifted. The legislation stipulated families were to hold decision-making power over the assessment, intervention, and planning of services. This meant that members of the educational community and families were, at the least, equal partners. Others deemed that because families had sole decision-making power regarding goals and priorities, as well as the planning and implementation of services, families were the leaders of the service teams; and the personnel of the educational system were working in service of, or as agents of,

families (Allen & Petr, 1996; Crais, Roy, & Free, 2006; Dunst, 2000; Dunst, Hamby, Johanson, & Trivette, 1991).

With Part H, the pendulum swung so that the nature of the relationships between families and the personnel of the educational system were intended to become more collaborative. The treatment model of focusing on families is considered best practice in the field of working with infants and toddlers with special needs (Bailey, Raspa, & Fox 2012; Campbell & Sawyer, 2007; Crais, Roy, & Free, 2006; Dempsey & Keen, 2008; Duwa, Wells, & Lalinde, 1993; Dunst, Trivette, & Hamby, 2007; Law, Hanna, King, Hurley, King, Ketroy, & Rosenbaum, 2003). The personnel of the educational system, many of whom often experienced difficulty establishing basic working alliances with families as outlined under the EAHCA, now had to adapt to the mandates outlined in Part H.

The term "family-centered care" has been used to describe the family-inclusive treatment methodology outlined under Part H, later reauthorized as the Individuals with Disabilities Education (IDEA) Act, Part C. However, more than 28 years after the law was passed, there remains no concise definition of family-centered care (Allen & Petr, 1996; Bamm & Rosenbaum, 2008: Chong, Goh, Tang, Chan, & Choo, 2012; Duwa, Wells, & Lalinde, 1993; Epley, Summers, & Turnbull, 2010; McWilliam et al., 2000; Murphy, Lee, Turnbull, & Turbiville, 1995) or standard set of practices that constitute the delivery of family-centered services. Family-centered care is understood to be the philosophical set of beliefs that governs behaviors and practices provided by practitioners and organizations. The behaviors and practices of a family-centered service delivery approach are based on the collaborative relationship between families and practitioners.

Because of a lack of consensus, there is no uniformity in how, or what, family-centered

practices are implemented and utilized (Bailey, McWilliam, & Winton, 1992; Dempsey

& Dunst, 2004; Epley, Summers, & Turnbull, 2010).

Although IDEA, Part C, commonly referred to as Early Intervention, defined

minimal directives of what is to occur in providing services to families, as with all laws,

its implementation is open to interpretation. There are federal guidelines that must be

followed by all programs, but the degree to which families are incorporated beyond the

federal mandates is left to each program's discretion. Delivering true family-centered

care is difficult (Bailey, Palsha, & Simeonsson, 1991; Brinker, 1992; Doll & Bolger,

2000; Edwards, Millard, Praskac, & Wisniewski, 2003; Ingber & Dromi, 2010; Minke &

Scott, 1995; Trivette, Dunst, & Hamby, 1996b) and requires significant administrative

and programmatic commitment to accomplish. Providing family-centered care is a

continuous process, as opposed to a cumulative event (Chong et al., 2012; King, Kertoy,

King, Law, Rosenbaum, & Hurley, 2003; Mandell & Murray, 2009).

An agency's practices, policies, organizational climate, and structure affect the

family-centered services offered by that program (Epley, Grotto, Summers, Brotherson,

Turnbull, & Friend, 2010; Law et al, 2003; Mandell & Murray, 2009). Those factors are

dictated by the administrator of the institution. Specifically, an administrator's

understanding of family-centered care influences the agency's organizational

characteristics as well as the organization's policies and practices, which impact the

delivery of family-centered services (Epley et al., 2010; Mandell & Murray, 2010).

Additionally, the barriers administrators identify to implementing family-centered care

and, more importantly, how the administrator handles those identified barriers, affects the

characteristics of the organization, as well as program policies and practices which impact the family-centered care delivered by that agency. According to the framework provided by classical management theory, as developed by Henri Fayol (1916/1949), an administrator is responsible for establishing, maintaining, and ensuring adherence to the policies, practices, and organizational climate in an agency.

Theoretical Framework

Fayol's (1916/1949) classical management theory identifies the importance of management to an institution, recognizes how a skilled and effective administrator influences the success of an agency, and defines the role of a leader in an institution (English, 1994; Pugh & Hickson, 1994; Smith & Boyns, 2005; Urwick, 1949). Fayol's (1916/1949) five functions of management are: (a) planning, (b) organizing, (c) commanding, (d) coordinating, and (e) controlling. The administrator of an organization influences the agency's events, activities, choices, objectives, strategic movements, structure, morale, culture, professional development, fostering of relationships, self-assuredness of staff, as well as recruitment of resources from outside the institution (Yukl, 1998). This premise is indicative of the power-influence dynamic, where leaders act and followers react (Yukl, 1998), which is the paradigm used for this study.

Hypothesized Conceptual Framework

Figure 1 displays the hypothesized conceptual framework of this project.
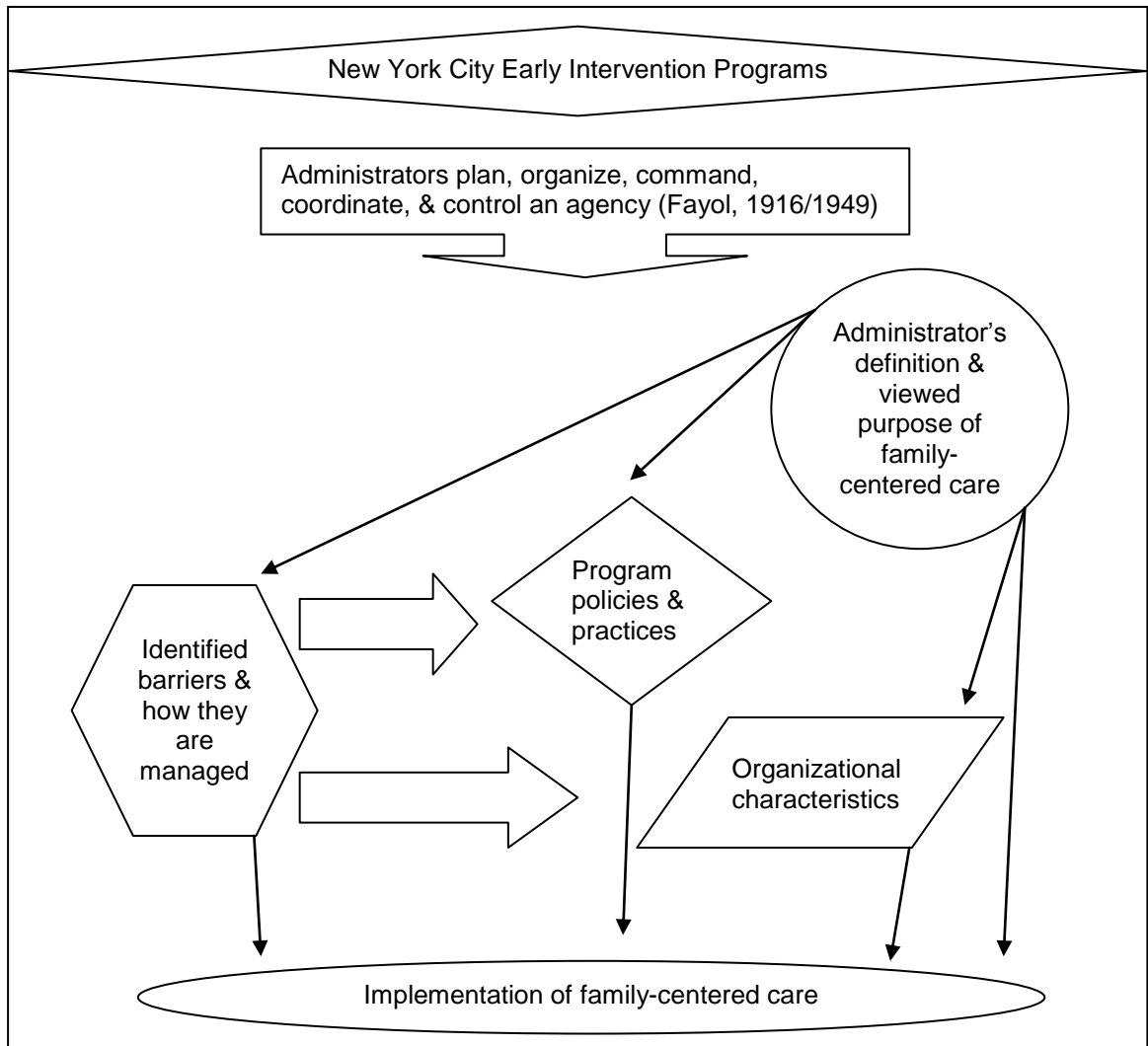
Figure 1. Hypothesized conceptual framework of the study.

Research Problem

Administrators impact the delivery of family-centered care provided by the

organizations they oversee (Epley et al., 2010; Mandell & Murray, 2009; Dinnebeil,

Hale, & Rule, 1999). Utilizing a family-centered service delivery model with families

who have infants and toddlers with special needs positively impacts the outcomes for

children and families receiving Early Intervention services (Dempsey & Keen, 2008;

Dunst, Trivette, & Hamby, 2007; Dunst et al., 2006; Law et al., 2003).   Despite

consistent research supporting its use, and overwhelming recommendations that a family-centered service delivery approach is best practice in the field of Early Intervention, it is not being implemented in all programs (Bailey, Raspa, & Fox, 2012; Campbell & Sawyer, 2007; Crais, Roy, & Free, 2006; Dempsey & Dunst, 2004; Dunst, Trivette, & Hamby, 2007; Law et al., 2003; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007), even with programmatic and staff claims to the contrary (Crais & Wilson, 1996; Dunst, 2002; Epley et al., 2010; Mandell & Murray, 2009; McBride & Peterson, 1997; McBride, Brotherson, Joanning, Whiddon, & Demmit, 1993). When a family-centered approach is utilized, implementation varies greatly from setting to setting (Epley, Summers, & Turnbull, 2010; Dunst, Humphries, & Trivette, 2002). Consequently, there is a need to further examine the factors that influence the implementation of family-centered programming, including how administrators impact the delivery of family-centered services, to improve the quality of services provided to families and outcomes for children and families.

Purpose of the Study

There is limited research concerning the role administrators have in the delivery of family-centered Early Intervention services (Epley et al., 2010). There is a lack of qualitative research from the perspective of Early Intervention program administrators regarding how they conceptualize and implement family-centered care. Specifically, there is a lack of qualitative research examining how Early Intervention program administrators define family-centered care, view the purpose of family-centered care, what barriers they identify to delivering family-centered services, and the ways they navigate the obstacles, as well as how those factors impact the implementation of family-

7

centered programming. The existing literature regarding the role administrators have in the delivery of family-centered programming determined that an administrator's understanding of family-centered care impacts the level of family-centered services provided by their organization (Mandell & Murray, 2009) and that an Early Intervention program administrator's knowledge and vision, decisions regarding the allocation of resources, and climate created in the organization influence the family-centered care provided by the agency (Epley et al., 2010).

The purpose of this study was to explore how administrators of New York City Early Intervention programs conceptualized and implemented family-centered care by examining the administrators' definition and purpose of family-centered care, identified challenges to delivering family-centered services, ways the obstacles were negotiated, and how those factors impacted the implementation of family-centered programming.

Research Questions

1. How did administrators of New York City Early Intervention programs define family-centered care and its purpose in the delivery of services to families who have children under three with special needs?

2. What barriers did administrators of New York City Early Intervention programs identify to delivering family-centered services, and how did they respond to those challenges?

3. How did an administrator's definition of family-centered care and its purpose impact the implementation of family-centered programming?

Methodology

The nature of this project was qualitative, using a case study strategy of inquiry. Leedy (1998) contends that qualitative research "is used to answer questions about the nature of phenomena with the purpose of describing and understanding the phenomena from the participant's perspective" (p. 104). Krawthwohl (1998) asserts case studies provide the opportunity to "seek explanations that provide the best understanding of what was observed" (p. 26) from the individual(s), group(s), situation(s), or event(s) being studied because the researcher is able to develop an in-depth understanding of the case (Creswell, 2008). Employing a case study methodology allowed for descriptions to be elicited from the participants, which facilitated inferences to be drawn regarding how administrators of New York City Early Intervention programs conceptualize and implement family-centered care. In this project, narrative data were collected, using a questionnaire consisting of eight open-ended and multiple-choice questions, as well as a series of demographic questions, which was emailed to 100 site administrators of the 93 New York City Early Intervention programs in operation in July 2013. Questionnaire completion was anonymous.

The data were scrutinized utilizing the six stages of qualitative data analysis as identified by Creswell (2003, 2008). This involved segmenting the raw material into meaningful and usable formats, coding the data by identifying repetitious concepts, grouping related codes into categories and identifying relationships between categories, creating generalizations from the categories, preparing the material for presentation, and comparing conclusions to existing literature in the field. All the while, memos or graphic displays were created to illustrate the insights garnered as well as to document and reflect

on the process. Qualitative data analysis is a comparative process in which the researcher is continuously evaluating data to develop hypotheses, as well as an interpretative process where the researcher delves deeper and deeper into the data for meaning and understanding (Corbin & Strauss, 1998; Creswell, 2003). Descriptive statistics were also used in this project.

Significance of the Study

Administrators of Early Intervention programs are what Weatherly and Lipsky (1977) refer to as "street level bureaucrats" (p. 172), as they are responsible for interpreting federal and regional legislative mandates, implementing and overseeing the services directly provided to families, and making discretionary decisions regarding services, including developing policies and practices that govern the distribution of services. The decisions made by program administrators form the program that becomes and embodies Early Intervention, as it is the program delivered to the families, the program the families receive. This includes the family-centered care a family receives through Early Intervention.

Bailey, Raspa, and Fox (2012) have called for improvement in the quality of family-centered care provided by programs. Examining the role of administrators is one avenue to achieve that goal that has been, thus far, underexplored. Investigating how administrators define and view the purpose of family-centered care, how administrators identify and manage barriers to providing family-centered services, and how those factors influence the delivery of family-centered programming may offer additional insights regarding the implementation of quality family-centered services. Consequently, this study has the potential to be of merit to various local and state governing bodies that

oversee Early Intervention agencies, professional development planners for Early

Intervention program administrators, training programs and educational institutions

offering preparation programs for Early Intervention administrators, policy makers,

researchers examining family-centered care and practices, as well as to administrators of

Early Intervention agencies or other programs that offer family-centered programming

that are looking to reflect on their own practice.

Limitations of the Study

There were several limitations to this research project. Most importantly, all of

the data collected were self-reported by Early Intervention program administrators

regarding the programs they oversee. The halo effect, in which the participants may

report themselves or their programs in the best possible manner, may have clouded

responses. In addition, there is the possibility that the questions posed may have been

misinterpreted by participants. Last, researcher bias is an inherent limitation of

qualitative research.

The accuracy of the data was based upon the self-evaluation of the respondents'

practices. In this study, there was no direct measure of behaviors of the respondents and

their programs; consequently, there may be a discrepancy between responses and actual

practices and policies. The results only reflect the participants' perceptions. Programs

and their administrators implementing a family-centered service delivery approach, rarely

provide the level of family-centered care they report (Dunst 2002; Crais, Roy, & Free,

2006; Crais & Wilson, 1996; Fingerhut, Piro, Sutton, Campbell, Lewis, Lawji, &

Martinez, 2013; Mandell & Murray, 2009; McBride & Peterson, 1997).

The questionnaire used in this study was pilot tested for clarity; however, that does not diminish the possibility that the questions were misinterpreted by the respondents. The context, semantics, and intent of the questions, as well as the options for the multiple choice answers, could have been misconstrued by participants of the study.

In constructivist research, such as in this study, a researcher is creating meaning from the responses of others. Accordingly, because the researcher is being inserted into the data analysis process, a degree of researcher bias is expected (Creswell, 2003, 2008; Leedy, 1998; Krathwohl, 1998; Yin, 2009).

Delimitations

There were several delimitations to this project. The delimitations focused primarily on the cases used in this study and methodology choices regarding data collection.

Family-centered care is currently only mandated in Early Intervention; thus, this study was confined to administrators of Early Intervention programs. In addition, this project focused solely on administrators' conceptualizations of family centered-care and how it is reflected in the implementation of family-centered services in the Early Intervention agencies they oversee. Obviously, the insights of families and direct service providers are of vital importance in analyzing the implementation of family-centered programming offered by Early Intervention agencies. However, incorporating feedback from practitioners and families regarding the implementation of family-centered service was beyond the scope of this work.

This project was limited to Early Intervention programs that provide services to families who reside within New York City. For a variety of reasons, New York City is a unique setting. It is the most populated city in the United States. In 2010, 60,800 children under three received Early Intervention services within the five boroughs of New York City at a cost of $482.283 million (Fiorentini, 2012). By comparison, the state of Nevada provided Early Intervention services to 3,805 children for fiscal year 2010, utilizing a budget of $21,988,778 (Nevada State Health Division, 2011). Because each state determines its eligibility requirements and delivery system for Early Intervention services, as defined by Public Law 99-457, effectively comparing two states or municipalities may be challenging. Unfortunately, as Hebbeler (1997) explains, "State of residence has a great deal to do with whether a family receives Early Intervention services" (p. 32); also, variation occurs within a state based upon the geographic region or municipality where a family resides.

Questionnaires offer respondents the opportunity to edit and filter their responses. Additionally, collecting data anonymously precludes in-depth analysis and exploring the reasoning behind the participants' answers. Providing multiple-choice options to questions also may have skewed the feedback provided by respondents.

Successful case studies have been conducted using one source of evidence (Yin, 2009), although most use multiple sources. This project used a self-reporting questionnaire as the sole source of evidence and data collection tool.

Definition of Terms

Administrator – For the purpose of this study, an administrator is defined as the director of an Early Intervention program who is responsible for day-to-day operation of

a program. "Administrator" is an occupational title. That person may or may not have the final decision-making powers in an organization. However, it was assumed that the person was responsible for the general daily operation of the program.

Early Intervention – For the purpose of this study, Early Intervention is defined as the services provided to families with children under the age of three with special needs as specified in Public Law 99-457, or EAHCA, Part H, and later reauthorized as IDEA, Part C. Bailey, Aytch, Odom, Symons, and Wolery (1999) explain as follows:

> Early intervention is not a discrete event but rather a complex series of interactions and transactions centered on the accomplishment of 2 basic tasks: nurturing and enhancing the development and behavior of the infant or toddler with a disability, and supporting and sustaining their families" (p. 12).

Family – For the purpose of this study, family is defined as the constellation of people responsible for the day-to-day care of a child. That may be a child's parents, non-biological caregivers, biologically related caretakers, single parent, blended families, or any other group of people who have a vested interest in the health, safety, welfare, and daily responsibilities of rearing that child. When the term "parents" is used, reference to biological parents is not solely implied.

Practitioner or Provider – For the purpose of this study, practitioner or provider is defined as the person who provides direct service to families enrolled in Early Intervention or a family-centered program. In Early Intervention, that would be the people mandated to provide services listed on the Individualized Family Service Plan, which can include a special instructor, physical therapist, speech therapist, vision therapist, occupational therapist, social worker, service coordinator (similar to a case

manager), nurse, nutritionist, psychologist, or medical provider such as an audiologist or physician. In other programs offering family-centered services, it may be a home visitor.

Program – For the purpose of this study, a program is defined as an agency or organization that is authorized and/or contracted by the local municipality or governing body to provide Early Intervention services within a geographic location.

Organization of the Study

This project is laid out in five chapters, with Chapter 1 being the introduction. Chapter 2 provides a review of literature covering an overview of family-centered care, family-centered care beyond Early Intervention, definitions of family-centered care, the role of administrators in the delivery of family-centered services, the outcomes of using a family-centered service delivery approach, barriers to providing family-centered care, program practices and features that reflect family-centered care, and Fayol's (1916/1949) classical administrative theory. In Chapter 3, the methodology and research design used for this study are detailed. The results of the data gathered in this project are presented in Chapter 4. Chapter 5 outlines the conclusions, recommendations for practice and future research, and addresses the limitations of this project.

CHAPTER 2

REVIEW OF THE LITERATURE

Early childhood and special education legislation has formalized the role of

parents in the education of their children with the passage of Head Start and Handicapped

Children's Early Education Program (HCEEP) in the 1960s, as well as the Education for

All Handicapped Children Act (EAHCA) in 1975. In 1986, Public Law 99-457 was

enacted, which changed the focus of providing educational services from a child to a

family. In a twenty-year time span, the role of families in their child's education shifted

from having no legal recognition to being the focus of service delivery as well as the

primary decision makers regarding the needs, priorities, and goals for planning and

intervention. This required changes in practice and paradigm for practitioners working

with infants and toddlers with special needs and their families.

The term "family-centered care" is used to describe the paradigm in service

delivery that encompasses the family unit as a whole, as opposed to treating only the

child in isolation. Various positive outcomes for families, which in turn benefit the child,

have been connected to the use of practices that are considered family-centered. The

basis of these practices involves the support given to providers and families, which

enables practitioners to provide family-centered services and for families to receive

family-centered care. Although utilizing a family-centered approach is considered best

practice to providing services to families with children under the age of three with special

needs (Bailey, Buysse, Edmundson, & Smith, 1992; Dempsey & Carruthers, 1997; Dunst

et al., 2002, 2006; Dunst, Trivette, & Hamby, 2007; Mandell & Murray, 2009; McBride

et al., 1993), no universal description exists as to what constitutes family-centered care

and services (Allen & Petr, 1996; Bamm & Rosenbaum, 2008; Epley, Summers, & Turnbull, 2010; McWilliam et al., 2000; Murphy et al., 1995).

The support that families and practitioners receive that facilitates the delivery of family-centered services begins with the administrator of the program. Administrators of Early Intervention programs are responsible for the policies, practices, philosophy, and culture of the organization as well as decisions regarding resource management, program operations, and organizational characteristics. The administrator determines how the program will address the numerous challenges that confront the agency, staff, and families in the delivery of family-centered care. These factors impact how the practitioners of the agency are able to deliver family-centered services, as well as how families are able to receive the care offered to them.

Parameters of the Literature Review

This review of literature examined the following topics: (a) an historical overview of family-centered care in Early Intervention, (b) the potential impact a family-centered service delivery model can have on the educational community beyond Early Intervention, (c) the enigma of the term "family-centered care," (d) the role of administrators in the delivery of family-centered services, (e) outcomes identified when using a family-centered approach, (f) barriers to providing family-centered care, (g) family-centered program features and practices, and (h) Fayol's (1916/1949) classical administrative theory. A search of literature was conducted in an effort to locate relevant studies, books, and conceptual articles that pertained to these topics. The literature reviewed used many empirical studies, both qualitative and quantitative. International studies and articles were examined as applicable.

17

Literature Review Methods

   This literature review was carried out primarily through the libraries of Seton Hall University and Bank Street College of Education. Searches for sources were conducted both in person and remotely. Information was collected mainly from electronic data-bases, such as Academic Search Complete, CINAHL, EBSCO, ERIC, JSTOR, PsychINFO, and ProQuest Education Journals. The conceptual framework for analyzing each piece of literature was based on the following questions:

1. What did the literature contribute to the knowledge dynamic for this project?

2. How did the literature align with previous or current literature on the subject?

3. What type(s) of references did the author(s) use?

4. For research studies examined:

  a. What was the quality of the study, including sample size, design, methodology, data analysis, results, and conclusions?

  b. How did the results fit with the accepted theoretical framework?

Criteria for Inclusion

   Guidelines for inclusion of material were established for this project. To be included in this literature review, material had to meet the following two criteria:

1. Literature that examined one of the aforementioned topics outlined in this literature review

2. Literature published after 1975, with the exception of original theoretical texts (e.g., Fayol, 1916/1949)

  a. Journal articles that were published in peer-reviewed periodicals. Peer review is the accepted method for ensuring that information is of the

highest quality, strength, and academic integrity, as the peer-review

process requires articles to be critically analyzed by other scholars in the

author's field prior to acceptance for publication.

b. Books or chapters in texts that involved seminal works or underlying

theories.

c. Qualitative studies that used ethnographic, case study, literature review

and synthesis, meta-analysis, grounded theory, narrative research,

naturalistic inquiry, or phenomenological strategies of inquiry.

d. Quantitative studies.

e. Mixed-method studies.

f. Conceptual articles published in peer-reviewed journals that provided

insight into the scope of the problem or context of the subject.

Overview of Family-Centered Care

Family-centered care was born out of early childhood and special education

legislation, which were the first governmental initiatives to formally incorporate families

into the education of their children (Allen & Petr, 1996; Gallagher, 2000; Hebbeler, 1997;

Mahoney, 2007; Mahoney et al., 1999). Although the goal of the initial special education

protocols was to unify families and the members of a child's educational team on behalf

of the child, the opposite often occurred for families with children enrolled in special

education programs. Another dimension of parental involvement was mandated by

Congress when the provision of services to infants and toddlers with special needs was

added to the arena of special education. Services to this population introduced the

concept of family-centered care, which required professionals to change their interactions with families and service delivery methods.

During the 1960s, President Johnson developed Head Start and HCEEP, both which included roles for parents. Head Start integrated family involvement in program governance while HCEEP created model demonstration programs for preschool children with special needs throughout the country, many which incorporated parent-training opportunities (Duwa, Wells, & Lalinde, 1993; Gallagher, 2000; Hebbeler, 1997; Keogh, 2007; Mahoney et al., 1999; Richmond & Ayoub, 1993; Wehman, 1998). The civil rights and social justice movements were gaining momentum. Out of this climate of societal transformation grew a grassroots movement of families advocating for the educational rights of their children with special needs (deFur, 2012; Keogh, 2007; Leafstedt, Itkonen, Arner-Costello, Hardy, Kornstein, Medina, Medina, Murray, & Regester, 2007; McCoy & Glazzard, 1978; Mead & Paige, 2008; Milligan, Singleton, & Neal, 2012; Valle, 2011; Valle & Aponte, 2002: Rosenbaum et al., 1998).

Families who had children with special needs had been repeatedly denied educational opportunities. Around the country, families won local lawsuits because, at the time, legal recourse was the only option families had to demand their children with special needs be afforded access to a public education (Itkonen, 2007; Keogh, 2007; Mead & Page, 2008; Milligan, Singleton, & Neal, 2012; Valle, 2011). However, there were no uniform policies or standard guidelines as to how special education programs should be implemented and organized once the lawsuits were won; hence, the call for federal protocols (Itkonen, 2007). The contentious negotiations between associations representing parent groups and various educational organizations over the extent of rights

afforded to parents nearly derailed what was to become the Education for All

Handicapped Children Act, perhaps predicting the nature of future relationships between

the staff of the educational system and parents (Itkonen, 2007).

A majority of members of Congress and parents' rights groups believed that to

ensure children with special needs had access to a free, appropriate, public education,

parents would need to advocate for their children, and the means for advocacy would

have to be clearly specified in the law (Mead & Page, 2008; Itkonen, 2007). Parents'

rights under EAHCA are divided into four categories: (a) the right to be informed of the

process and all information; (b) the right to grant permission for evaluations and services;

(c) the right to be involved in all aspects of the process; and (d) the right to challenge

decisions made regarding their child's education (Mead & Paige, 2008). The intent of

these provisions was to facilitate parental participation in educational planning for a child

with special needs so the members of the child's educational team and families could

partner in educating the child. Instead, special education evolved into a system fraught

with legal mandates that revolve around the compliance with timelines, creating formal

meetings, and legal documents, all of which require a tremendous amount of time and

effort (deFur, 2012; Howland et al., 2006; Leafstedt et al., 2007; Milligan, Neal, &

Singleton, 2012; Tucker & Schwartz, 2013).

The detailed due process and parental rights statutes outlined in EAHCA often

create a launching point for adversarial relationships that negate the intent of

collaboration between parents and the members of the child's educational team, as well

as the positive effects those partnerships can have on a child's educational outcomes.

Special education policy is the most litigated policy type in the country (Katsiyannis &

Herbst, 2004). Between 1982 and 2009, 11 cases were heard before the United States

Supreme Court regarding parental rights and the EAHCA (Conroy, Yell, Katsiyannis, &

Collins, 2010), which have clarified the definition and scope of parental rights provided

under EAHCA (Mead & Paige, 2008). In advocating for services for their children,

many families were forced into battles with the members of the educational system that

left them feeling stressed, exhausted, overwhelmed, frustrated, and humiliated (Blue-

Banning et al., 2004; Jackson, Traub, & Turnbull, 2008; McCoy & Glazzard, 1978;

Osher & Osher, 2002; Summers et al., 2005) and led to division, mistrust, strained

relationships, and communication breakdown.

Public Law 99-457

In 1986, as part of the reauthorization of the EAHCA, Congress added Part H,

also known as Public Law 99-457, which specified the framework for the provision of

services to children under the age of three with special needs. The field of special

education recognized that the earlier special education and therapeutic interventions were

provided to a child with special needs, the greater the benefit to the child, which would

result in a reduction in special education and related costs over time (Belcher, Hairston-

Fuller, & McFadden, 2011; Florian, 1995; Hebbeler, 1997). Providing services to

children so young, however, created unique challenges and required special

considerations.

With input from practitioners, families, and advocacy groups (Garrett, Thorp,

Behrmann, & Denham, 1998), the legislation for Part H was drafted, which contained

three significant aspects. The first identified development as overlapping, requiring

service delivery to be multidisciplinary and integrated (Duby, 2007; Farrell, 2009;

Florian, 1995; Garrett et al., 1998; Hebbeler, 1997; Richmond & Ayoub, 1993). Second, the law established that services could be provided as a form of prevention of developmental risk or potential delay at the discretion of each state (Bailey et al., 1997; Belcher, Hairston-Fuller, & McFadden, 2011; Duby, 2007; Florian, 1995; Hebbeler, 1997; Ramey & Ramey, 1998). Last, the focus of service delivery was to be the family as a whole, not solely or primarily to the child (Florian, 1995; Mahoney et al., 1998; Park & Roth, 2011). This last facet of the law is the most profound.

Changes in Paradigm and Practice

Developing practices for families who had children under the age of three with special needs that encompassed the new legal mandates outlined in Part H necessitated a significant change in paradigm, service delivery methods, and treatment protocols from programs and practitioners alike, which represented a considerable deviation from the traditional educational model. The rationale for a family-based service delivery model is rooted in the belief that because infants and toddlers function primarily as members of a family constellation, families have an inimitable and significant impact on the development of children under three (Bailey et al., 1999; Bruder, 2010; Mannan et al., 2006; Mahoney & Bella, 1998; Mahoney & O'Sullivan, 1990; Mahoney & Wiggers, 2007; Odom & Wolery, 2003; Ozdemir, 2008). Part H, later reauthorized as IDEA, Part C, specified that a program for infants and toddlers with disabilities must be designed to support and strengthen the abilities of families to recognize, cope with, and meet the unique needs of their infants and toddlers with special needs (Bailey 2001; Bailey et al., 1999; Bruder, 2010; Dinnebeil, 1999; Epley, Summers, & Turnbull, 2011; Mahoney et al., 1998; Mahoney & Filer, 1996; McWilliam et al., 1995). This also involves

supporting the interaction between the parent and child in order to facilitate the child's

development (Dinnebeil, 1999; Guralnick, 2001, 2005; Mahoney et al., 1998; Odom &

Wolery, 2003; Woods, Wilcox, Friedman, & Murch, 2011).

As stipulated in the EAHCA of 1975, each child aged 3 to 21 with special needs

was afforded educational services under the scope of an Individualized Educational Plan

(IEP). An IEP mandates a unique educational program, with services, supports, and

accompanying goals for each child. With Part C, services were to be provided through an

Individualized Family Service Plan (IFSP), as opposed to an IEP. Belcher, Hairston-

Fuller, and McFadden, (2011) explain an IFSP as follows:

> The IFSP is a family-directed process that outlines the services based on the
>
> child's and family's needs. The parent is viewed as a professional about his/her
>
> child, one who is able to provide the best insight into what the child needs and
>
> what will or will not work in their household (p. 37).

In other words, in the IFSP, "intervention is based on the family's vision and values . . .

[and] . . . services are designed to meet the needs of the family," as opposed to the family

" . . . fitting into the services or interventions that are already in place" (King, Law, King,

& Rosenbaum, 1998, p. 23). The IFSP cements the family's role in service planning, and

as the focus of programming, in Early Intervention. Campbell, Strickland, and La Forme

(1992) declare, "The IFSP process and plan are central to the delivery of family-centered

(rather than child-centered) services" (p. 113).

Through Part C, commonly referred to as Early Intervention, the family is viewed

as the vehicle for intervention. The premise of service is that families will carry over

intervention strategies into their child's daily routine (Kummerer, 2012). Conventionally,

school personnel created school sponsored opportunities that were deemed appropriate for parent involvement, (Burton, 1992; Chao, Bryan, Burstein, & Etgul, 2006; Duwa, Wells, & Lalinde, 1993; Jeynes, 2005, 2012; Mandell & Murray, 2009; Osher & Osher, 2002), including conferences between the parents and teachers, parent organizations, specific volunteer opportunities, IEP meetings, open houses, and parent education workshops. The aim was to educate the child with school personnel perceiving and utilizing the family as a tool to assist in meeting that goal (Burton, 1992; McWilliam, Maxwell, & Sloper, 1999; Osher & Osher; 2002). Educational personnel focused on developing relationships with parents to facilitate communication as well as to offer families meaningful opportunities to be involved in their children's education.

The concept of sending a child off to a brick and mortar school for educational programming was also changed under Early Intervention. Because Early Intervention professionals recognized the importance of an infant and toddler's natural environment on his or her development and learning, services would have to be integrated into and delivered in the child's and family's home and community (Campbell & Sawyer, 2007; Childress, 2004; Dunst, 2000; Dunst et al., 2006; Odom & Wolery, 2003; Rapport, McWilliam, & Smith, 2004; Sylva, 2005). This is in contrast to the traditional practice of children leaving home to go to a school with other children, where each morning a child says goodbye to his or her family, goes to school, and spends the day with his or her peers and educational staff, then returns home at the end of the day.

In addition to where services were provided, how services were provided was modified under Part C. In the traditional educational model, services were based on a deficit, or medical, model. Traditionally, a provider, who focused exclusively on the

25

child, implemented a structured intervention that involved a planned skill or strategy

taught to address a specific objective that was aimed at the child's developmental needs,

utilized a method to measure progress toward the goal, and then gave the child

opportunities to practice the skill (Campbell & Sawyer, 2007). Part C recognized that

because routines, activities, rituals, experiences, and opportunities are the basis of

learning and development for a child under three, intervention was to be embedded in the

daily life of an infant or toddler (Campbell & Sawyer, 2007; Childress, 2004; Coots,

2007; Dunst, 2012; Dunst et al., 2000, 2006; Guralnick, 2001; Kummerer, 2012; Odom &

Wolery, 2003; Sylva, 2005). Additionally, services provided for one or two hours per

week would be ineffective to elicit growth and change in the context of the life of a child

under the age of three. Learning and developmental growth may not occur during those

sessions, which amounted to such a small part of a child's life, but would happen

between the sessions, with the child's family (Kummerer, 2012; McWilliam & Scott,

2001, Mahoney & Wiggers, 2007; Rapport, McWilliam, & Smith, 2004). This was a

departure from the traditional educational model in which instruction took place during a

specific time frame in a structured environment.

Over the past 50 years, the members of the educational system and legislative

bodies have recognized the importance of partnerships with families for the benefit of

children with special needs. In turn, the roles of parents in the education of their young

children have evolved, due to legislative initiatives, from involvement in program policy

formation and implementers of therapeutic interventions in the 1960s, to partners with

educational professionals in the 1970s, to primary decision makers regarding service

planning and intervention in the 1980s and beyond. These changes introduced the

paradigm of family-centered care, which deviated from the traditional educational model.

Family-Centered Care Beyond Early Intervention

Currently, personnel in the education system, primarily in elementary and

secondary schools, devote a substantial amount of time, effort, and resources trying to

engage and develop partnerships with families (Blue-Banning et al., 2004; Coots, 2007;

deFur, 2012; Edwards & da Fonte, 2012; Howland et al., 2006; Osher & Osher, 2002;

Staples & Diliberto, 2010; Valle, 2011). This would indicate that an effective model for

school-dictated parent involvement programs has yet to be developed or identified.

Could a family-centered approach be the answer to engaging families in collaborative

partnerships with educators and school personnel? Creating collaborative partnerships,

based in a family-centered paradigm, could elicit increased levels of parental involvement

beyond what is found in the current models of school sponsored programs, which has the

potential to significantly impact academic achievement.

If the foundation is laid for a family to engage in collaborative relationships with

educational professionals from the onset of a child's educational career, based on a

family-centered approach while the family is enrolled in Early Intervention (Dinnebeil &

Rule, 1994; Doll & Bolger, 2000; Blue-Banning et al., 2004; McBride et al., 1993;

Summers et al., 1990), then the groundwork for ongoing collaboration with educational

professionals has been established. Thompson and his colleagues (1997) assert that a

function of Early Intervention is to assist families in developing advocacy skills as well

as the ability to "better cope with the complexities of human service bureaucracy" (p.

100), which can include the school system. Research attests to the importance of

partnerships between families and schools (Edwards & da Fonte, 2012; Howland et al., 2006; Jeynes, 2005, 2012). School personnel have the onus and position of leadership to engage and develop partnerships with families as well as to cultivate and sustain those relationships (deFur, 2012; Dinnebeil & Rule, 1994; Staples & Diliberto, 2010; Tucker & Schwartz, 2013). This is, in part, related to the default position of power that professionals hold, which as Farrell (2009) asserts, may impede families from forming partnerships with professionals. A collaborative relationship requires substantial time and effort to develop (deFur, 2012; Ingber & Dromi, 2010; Spann, Kohler, & Soenksen, 2003; Tucker & Schwartz, 2013).

At this time, family-centered planning and collaboration is only mandated in the early education years, despite evidence that demonstrates its benefits (Dunst, 2002; Richmond & Ayoub, 1993). The degree of family-centered services declines with each stage as a child and family progress through the educational system (Burton, 1992; Dunst, 2002; Dunst, Humphries, & Trivette, 2002; Fingerhut, et al., 2013; McWilliam et al., 1995; Mahoney, O'Sullivan, & Dennebaum, 1990; Podvey, Hinojosa, & Koenig, 2013; Raghavendra et al., 2007; Spann, Kohler, & Soenksen 2003). Early Intervention programs provide the highest level of family-centered care; preschool programs provide fewer family-centered services than Early Intervention programs (Dunst, 2002). A family faces drastic changes in service delivery methods, program philosophical orientation, and intervention approaches at the time of their child's third birthday, when the family transitions out of Early Intervention and into preschool programs (Branson & Bingham, 2009; Hebbeler, 1997; Podvey, Hinjosa, & Koenig, 2013). Elementary schools offer less family-centered care than preschool programs (Chao et al., 2006;

28

Dunst, 2002), and family-centered services are virtually non-existent in secondary schools (deFur, 2012; Dunst, 2002; Spann, Kohler, & Soenksen 2003; Tucker & Schwartz 2013).

Developing collaborative relationships with families should be a priority for all schools (Al-Shammari & Yawkey, 2008; Blue-Banning et al., 2004; Coots, 2007; Edwards & Da Fonte, 2012; Howland et al., 2006; Spann, Kohler, & Soenksen; 2003; Staples & Diliberto, 2010; Tucker & Schwartz, 2013; Valle, 2011). Chao (2006) and his colleagues, deFur (2012), and Dunst (2002) question the potential impact on the educational outcomes for children if family-centered services are provided throughout the span of children's education. According to McWilliam, Maxwell, and Sloper (1999), offering family-centered practices in a school setting simply involve providing "a framework for professionals to establish a partnership with families to empower families and to attend to some family-level needs" (p. 391). This could be similar to what Caulfield (1989) describes when he declares that early childhood programs have the potential to provide families with an occasion "to identify with the school as an extension of the home, a place to meet, a cause to celebrate and to rally around" by offering programs such as "parenting, stress management, study skills, and computer literacy" that "help to galvanize" families as well as "to provide opportunities for mutual support" (p. 62) from other families, the school community, and its personnel.

Many of the families who were enrolled in Early Intervention established and enjoyed collaborative relationships with professionals based on a family-centered model. However, it appears that over time, as their child has transitioned through the educational system, and the educational system has become less family-centered and more

professionally driven, the nature of those relationships changed. As Podvey, Hinojosa, and Koenig (2013) explain, because "schools are education-centered . . . in the school setting, families did not have frequent opportunities to establish similar relationships (as they had experienced with Early Intervention professionals) because of the nature of the parental role in schools" (p, 219).   The collaborative partnerships developed between families and providers during Early Intervention have often morphed into bitter, acrimonies relationships, especially for families with children who continue to receive services under IDEA. Interestingly, McWilliam, Maxwell, and Sloper (1999) found that families with children in kindergarten to third grade who receive special education services reported receiving less family-centered services from school personnel than families with children of the same age who do not receive special education services.

The history of parental involvement in education, specifically special education, is tumultuous and most relationships between school officials and families continue to be adversarial rather than collaborative. Although the intent of the EAHCA was to unify families and educators on behalf of children with special needs, the opposite often occurred. Introducing a new paradigm, service delivery, and treatment model as outlined under Part C that placed the family as the focus of intervention, required a momentous shift in perspective and practice by the professionals in the field of special education. As a model to developing collaborative partnerships with families, family-centered care may hold the key to engaging families with the staff of elementary and secondary schools, thus enhancing student academic achievement.

Importance of Defining Family-Centered Care

There is an enigma to the paradigm of providing family-centered services to families with children under the age of three who have special needs. On the most fundamental level, a clear, mutually agreed upon definition of family-centered care does not exist (Allen & Petr, 1996; Bamm & Rosenbaum, 2008; Chong et al., 2012; Epley, Summers, & Turnbull, 2010; McWilliam et al., 2000; Murphy et al., 1995). Consequently, how the term has been used and which elements of the definitions have been emphasized has fluctuated over time. The conceptualizations of family-centered care have matured from a fundamental foundation focused on how to perceive the family to a framework of how to partner and collaborate with families. Themes that emerge from more recent definitions of family-centered care include collaborating with families, respecting families as decision makers and the decisions they make, as well as empowering families. The development of the definition of family-centered care signifies the progression of thinking, insights, and terminology regarding the conceptualization of family-centered care.

There had been references to practice focusing on the family as the center of care, or "family-centered care," beginning in the 1950s (Allen & Petr, 1996; Espe-Sherwindt, 2008; Pereira & Serrano, 2014). The terms family-centered care, family-centered services, family-centered approach, family-centered practices, and family-centered help giving (Dunst, Trivette, & Hamby, 2007), as well as family-inclusive, family-driven, family-friendly, and family-responsive care or services (Duwa, Wells, & Lalinde, 1993) have been used interchangeably. The basis for the concept of family-centered care appears to be derived from family systems theory, empowerment of patients, and help

giving models of treatment practices (Dempsey & Keen, 2008; Dunst & Trivette, 2009a), as well as child development theory and psychiatry (Bamm & Rosenbaum, 2008). The concept and terminology gained widespread use regarding children and families with special needs in the 1980s (Dunst & Trivette, 1994a; Espe-Sherwindt, 2008). The lack of a clear definition of family-centered care, or family-centered practices, is detrimental to the field of Early Intervention (Epley, Summers, Turnbull, 2010; McWilliam et al., 2000; Murphy et al., 1995).

Without a concise, operationalized definition of family-centered care, there is ambiguity, inconsistency, and discontinuity. A clear reference point for joint understanding of the term family-centered care and a framework from which to develop practice do not exist. Bamm and Rosenbaum (2008) attest that for an ideal to become standard practice, the following is necessary:

> [It is] accepted and implemented in a field, it has to be clearly defined, and its main principles [have to] be outlined. Explicit definition of the concepts provides common ground for interprofessional communication and proper interpretation of the ideas by service providers (p. 1619).

However, they added that "family-centered theory is continuing to develop, is yet to be fully understood, implemented, and effectively evaluated, so it can be universally adopted as best practice" (Bamm & Rosenbaum, 2008, p. 1623). Having a transdisciplinary definition of family-centered care and practices has the potential to influence personnel preparation, assessment, and continuing education, as well as the development, administrative functioning, and evaluation of programs (Epley, Summers, & Turnbull 2010; Perrin et al., 2007).

As the field of Early Intervention has evolved, so have the working

understandings of family-centered care. Instead of specifying which behaviors denote

family-centered care, there has been a trend towards postulating that family-centered care

is a value system that governs actions. McWilliam, Tocci, and Harbin (1998) consider

family-centered care to be a mindset that is "complex and accommodates many different

styles of service provision . . . [that] encompasses both philosophy (i.e., attitudes and

beliefs) and behavior (i.e., practices)" (p. 219). A family-centered approach "is a

philosophy and a set of practices that characterize service delivery" (Bailey, Raspa, &

Fox, 2012, p. 217) founded upon a "complex construct reflecting diverse beliefs,

dispositions and practices" (Mandell & Murray, 2009, p. 18). Bailey, McWilliam, and

Winton (1992) indicate family-centered care is "a concept based on basic values and

philosophic assumptions . . . rather than a fixed set of services or a step-by-step

procedure" (p. 74). Belcher, Hairston-Fuller, and McFadden (2011) suggest family-

centered principles are "integrated attitudes and beliefs that foster service delivery

strategies that respect the family's culture (p. 39). Mandell and Murray (2009)

encapsulate the breadth of the construct in their following definition:

> We consider family-centered service delivery as a complex social phenomenon
>
> that involves much more than merely providing an array of services and
>
> traditional involvement opportunities for families in their children's educational
>
> programs. Moreover, we believe that high-quality family-centered practices are
>
> continuous, rather than culminating, processes that require as a foundation a
>
> shared vision among all participants (e.g., administrators, teachers, family
>
> members, consultants) (p. 33).

Initially, after Part H was passed and in the process of being implemented, the emphasis in defining family-centered care was to offer rudimentary guidelines for practitioners to begin to shift their theoretical constructs from a traditionally child-focused treatment approach to a family-centered paradigm. This is demonstrated in definitions such as those of Bailey (1992) and his colleagues, Duwa, Wells, and Lalinde (1993), Dunst, Trivette, and Deal (1994a), Shelton, Jeppson, and Johnson (1987) as well as Allen and Petr (1996). As the field of Early Intervention was in its conceptual phase during this time, these guiding principles provided a framework for establishing practices for programs interested in offering quality family-centered programming. Shelton, Jeppson, and Johnson (1987) developed the following eight principles of family-centered care: (1) recognizing the family is the constant in a child's life, (2) facilitating collaboration between parents and professionals throughout the care process, (3) sharing unbiased and complete information with parents continuously in a manner that is supportive and appropriate, (4) implementing comprehensive and appropriate programs and policies that provide emotional and financial support to meet the needs of families, (5) identifying family strengths and individuality and respecting various methods of coping, (6) understanding and incorporating the holistic needs of family members into plans of care, (7) encouraging and creating opportunities for parent-to-parent support, and (8) assuring that the design of delivery systems are flexible, accessible, and responsive to family needs (p. 71).

Duwa, Wells, and Lalinde (1996) define a family-centered approach as a manner of "working with families that supports and builds on family strengths and resources and deals with family issues and concerns in a holistic, culturally appropriate manner" in an

environment "that promotes the growth, development, and health of the family" and "that focuses its energy on strengths, resources, and solutions, not weaknesses, deficits, and problems" (p. 96). Allen and Petr (1996) contend that family-centered care "views the families as the unit of attention. This model organizes assistance in a collaborative fashion and in accordance with each individual family's wishes, strengths, and needs" (p. 64), while enabling and respecting the "fully informed choices made by the family and focuses on the strength and capacities of the family" (p. 68).

According to Dunst, Trivette, and Deal (1994a), family-centered care involves services that "are responsive to the needs of all family members as well as the family unit; are provided in an individualized, flexible, and culturally sensitive manner; and place families in pivotal roles as decision makers concerning all aspects of the provision of services and mobilization of supports and resources" (p. 222). Bailey and his colleagues (1992) identified four guiding assumptions regarding family-centered care. These assumptions are as follows:

> (1) children and families are inextricably intertwined. Intentional or not, intervention with children almost invariably influences families; likewise, intervention with and support of families almost invariably influence children; (2) involving and supporting families is likely to be a more powerful intervention than one that focuses exclusively on the child; (3) family members should be able to choose their level of involvement in program planning, decision making, and service delivery; and professionals should attend to family priorities for goals and services, even when those priorities differ substantially from professional priorities (p. 299).

These definitions provide an elementary framework for how the family should be viewed in the context of a family-centered approach, which coincides with the passage of the law and creation of programs under Part H to provide services to families with infants and toddlers who have special needs.

Over time, the focus on building relationships, establishing collaborative bonds, and partnering with families emerged as the focus of conceptualizations of family-centered care in Early Intervention. These features are expressed in the definitions of Chong, Goh, Tang, Chan, and Choo (2012); Crais, Roy, and Free (2006); Dirks, Blauw-Hospers, Hulshof, and Hadders-Algra (2011); Dunst (2002); Dunst, Humphries, and Trivette (2002); Kuo, Houtrow, Arango, Kuhlthau, Simmons, and Neff, (2012), as well as Raghavendra, Murchland, Bentley, Wake-Dyster, and Lyons (2007). Dirks and his team suggest "a crucial element of family-centered services" is "family autonomy" (p. 1305) which is grounded in the partnerships between families and practitioners. Crais, Free, and Roy (2006) contend that "the key to providing family-centered service is not to identify the perfect set of practices but to recognize the family's role in helping to decide on those practices" (p. 375). A family-centered approach, according to Dunst (2002), utilizes the following:

> individualized, flexible and responsive practices; information sharing so that families can make informed decisions; family choice regarding any number of program practices and intervention options; parent-professional collaboration and partnership for family-program relations; and the provision of and mobilization of resources and supports necessary for families to care for and rear their children in ways that produce optimal child, parent, and family outcomes (p. 139).

Dunst, Humphries, and Trivette (2002) describe family-centered principles and

practices as those "that treat families with dignity and respect, recognize and build upon

family capabilities, promote informed family choice and decision making, and support

family participation in achieving desired goals and outcomes" (p. 3). Raghavendra and

her colleagues (2007) propose family-centered care is a philosophy that "emphasizes the

partnership between families and service providers . . . [and] . . . recognizes that parents

are the 'experts' in their child's care, are equal partners in the rehabilitation process, and

have the right to determine what is most important for their child" (p. 587). Kuo and his

team (2012) describe family-centered care "as a partnership approach to decision

making" (p. 297) that involves "information sharing, partnering, respect, and negotiation"

(p. 298).

The emphasis on decision making and the locus of control regarding decisions

residing with families is evident in many definitions of family-centered care. For

example, Rosenbaum and his team (1998) contend that the premise of family-centered

care is "encouraging parental decision-making based upon appropriately presented

information, in the context of clearly defined child and family needs, and built upon child

and family strengths" (p. 5). Dunst (2000) echoes this by stating that "family-centered

practices place families in central and pivotal roles in decisions and actions involving

child, parent, and family priorities and preferences" (p. 102). According to Crais, Roy,

and Free (2006), the focus of family-centered care provided through Early Intervention

"is on enhancing the ability of parents to become informed decision makers as well as

advocates for their children through active collaboration with professionals" (p. 366).

Chong and his team (2012) echo this when they state that "family-centered practices

37

work to promote the family's capacity to make decisions about their needs and preferences through facilitating collaborations and partnerships between them and professionals" (p, 284). These definitions emphasize the theme of empowering and respecting families in the decision making process, which seem to have emerged after programs were established and operational under the guidelines outlined by Part C.

Use of the Term in the Literature

With no clear meaning established, research teams Allen and Petr (1996) and Epley, Summers, and Turnbull (2010) began to explore how the term family-centered care was used in the literature. In 1995, Allen and Petr (1996) analyzed 120 articles for definitions and usage of the term. From the literature reviewed, their efforts identified the following 10 key concepts and the frequency with which concepts were mentioned in the construct of family-centered care: the family as the target of intervention (100%), the family-professional relationship (36%), the needs of the family (32%), specific service delivery methods (32%), the family's right to exercise decision making power and choices (29%), emphasizing the family's strengths (25%), maintaining the child at home as opposed to in a institutional setting (18%), responding to the cultural background of the family (7%), empowering the family (7%), and supporting the family to live life as they otherwise would (7%). The 10 components were condensed into the following six categories: (1) family as the focus of service, (2) family-professional partnerships, (3) family choice, (4) family strengths, (5) family needs and priorities, and (6) individualized services.

A decade later, another team decided to examine if any shifts had occurred in regard to the term family-centered care and its usage. Epley, Summers, and Turnbull

(2010) reviewed 63 articles published from 1996 to 2007, following Allen and Petr's

(1996) framework. Instead of the original six categories, however, the categories of

family needs and individualized services were collapsed into one category entitled

"individualized family services." Analyzing the literature utilizing their five categories

demonstrated that family-professional relationship was referenced in 90% of the articles,

family choice was mentioned in about 75% of the definitions, approximately 66% of the

works discussed the family as the focus of intervention, with strengths of the family

referred to in a little more than half of the literature examined, and individualized family

services cited in approximately 50% of the articles (Epley, Summers, & Turnbull. 2010).

The findings of Epley, Summers, and Turnbull (2010) provide an example of the

significant impediment caused by the lack of a clear, commonly held definition of family-

centered care. Of great concern to Epley, Summers, and Turnbull (2010) was that

individualized family services was referred to in only approximately 50% of the

definitions of family-centered care reviewed. In true family-centered care, services that

are individualized to meet the needs of a particular family are a fundamental requirement

and an essential element of the concept and practice of family-centered care. Therefore,

any definition of family-centered care must include the tenet that services are

individualized to meet the unique needs of a family (Epley, Summers, & Turnbull, 2010).

Shifts in Terminology

In comparing the results of Allen and Petr (1996) to the efforts of Epley,

Summers, and Turnbull (2010), several themes emerge. Clearly, the trend shifted from

emphasizing the family as the unit of care in the definitions. It may simply be that as the

field has grown more established, the concept of family-centered care has become more

grounded, and the notion that families are the center of intervention may be an assumed component of the process. Or it may be that the lack of a concise definition has left this essential element of the definition of family-centered care as a forgotten aspect of the construct. The shift in emphasis of family choice may be attributed to the plethora of options that have now been conceived and can be offered to families that were not available or had not been thought of at the time Allen and Petr (1996) conducted their investigation, which occurred soon after the full implementation of Part H. The increase in focusing on a family's strengths could be related to the influx of research and techniques regarding how to operationalize this term (Dunst, Boyd, Trivette, & Hamby, 2002; Dunst & Trivette, 1994a, 1994b, 1996; Dunst, Trivette, & Hamby, 1996, 1997; Dunst, Trivette & Mott, 1994; Trivette, Dunst, & Hamby, 1996a).

Initially, as Early Intervention was in its infancy, definitions of family-centered care focused on how to implement this new service delivery methodology. These definitions were appropriate for the time, considering the novel treatment approach and paradigm that was being introduced. As time progressed, how to partner and collaborate with families became the focus of explanations of family-centered care, and an emphasis of empowering and respecting the decisions of families emerged. These factors reflect the evolution from the basic, elemental nature of the concepts originally proposed to more refined aspects of family-centered care. The emphases on the different facets of the term have shifted over time. This can be attributed to the lack of consensus as to the meaning of family-centered care.

Administrator's Role

Although there is no consensus as to how to define family-centered care, there appears to be agreement in the field that administrators influence the delivery of family-centered services. Even though only limited research exists, the results indicate administrators significantly impact the provision of family-centered services in the programs they oversee. The work of Mandell and Murray (2009), as well as Epley and her team (2009), demonstrate the nature of the top-down affect program administrators have on the delivery of family-centered care. The administrator implicitly or explicitly establishes the philosophy and vision of the institution, climate and culture of the organization, design and structure of the agency, as well as the policies and procedures instituted within the program, all of which impacts the delivery of family-centered care (Epley et al., 2010). An administrator's impact on the delivery of family-centered services permeates an agency and trickles down throughout an organization.

Although the work of Mandell and Murray (2009) and Epley and her team (2010) were significant in that they were the first studies to formally examine the role administrators have in the delivery of family-centered programming, both had limitations. Both studies had small samples. Mandell and Murray (2009) used a purposive sample of only 11 administrators, all of whom had been the supervisors of the participants for a previous study they conducted (Murray & Mandell, 2006). Epley and her colleagues (2010) observed two sites in their ethnographic study; but, one site was only observed for a total of 20 hours and the second site for a total of 37 hours. Despite these limitations, these studies offer important insights into the role administrators have in the delivery of family-centered services.

Administrator's Understanding

An administrator's understanding of family-centered care permeates an agency. Mandell & Murray (2009) found that an administrator's "values, beliefs, and attitudes" determines how an administrator understands family-centered care (p. 17). An administrator's understanding of family-centered care determines how family-centered care will be implemented in that organization by dictating the level of support and assistance provided to families and practitioners through the policies and practices developed by the administrator. Mandell and Murray (2009) found administrators to have either a comprehensive or limited understanding of family-centered care. Administrators with a comprehensive understanding of family-centered care facilitated practitioners in providing and enabled families to receive family-centered care with the policies and practices instituted in their programs, while those with a limited understanding did not (Mandell & Murray, 2009).

Professional experience is important in shaping an administrator's concept of family-centered care. Mandell and Murray (2009) found that experiences early in an administrator's career influence their beliefs and practices regarding family-centered service delivery. Educational training programs and field work experiences, professional development opportunities, personal events, supervisors or mentors, and work history all affected an administrator's understanding of family-centered care (Mandell & Murray, 2009). This coincides with the work of Sawyer and Campbell (2009), who determined that work experiences were more influential than pre-service training on the development of professional practice involving the delivery of family-centered services.

It can be surmised, therefore, that the cycle of limited understanding of family-centered care may be perpetuated through early work experiences. Employees who may become administrators later in their careers, whose initial work experiences are in programs with administrators who have a limited understanding of family-centered care, may develop a limited understanding of family-centered care themselves. Consequently, as they become administrators, the programs they oversee may not offer the same level of support to families and staff as programs with administrators who have a more comprehensive view of family-centered care. Additionally, providers who begin their careers in those programs, under the direction of this second generation of administrators with a limited understanding of family-centered care, may also develop a limited understanding of family-centered care. Thus, when those practitioners become administrators, they potentially become the third generation of administrators with a limited understanding of family-centered care.

Programmatic Framework

The programmatic framework of an organization, also under the direction of the administrator of the agency, influences the program's delivery of family-centered services. Leadership, organizational climate, and the allocation of resources, which are determined by the administrator of a program, affect the services delivered by a provider (Epley et al., 2010). These factors, identified as administrative structures, are the "general operating processes that enable staff to deliver services in a way that embodies recommended practice" (Epley et al., 2010, p. 20). Epley and her colleagues (2010) determined that the delivery of family-centered Early Intervention is impacted by the vision and knowledge of the program administrator, an organizational climate that fosters

peer support regarding implementing and evaluating practices, an environment that respects the independence and integrity of professionals while holding staff accountable, as well as thoughtful decisions regarding the use and management of resources. Administrators communicate their priorities and mind-set through the allocation of resources (Garland & Linder, 1994; Stoneman, 1993), and "a budget is merely the translation of the agency's goals, priorities, and action plan into fiscal terms" (Garland & Linder, 1994, p. 160).

Cohesive and adequate infrastructure within a program facilitates the use of best practice (McLean, Sandall, & Smith, 2000), which in an Early Intervention is family-centered care. McLean, Sandall, and Smith (2000) identify the elements of infrastructure as organizational structure, use of resources, policies, and procedures, which are at the discretion of the program's administrator. The policies and procedures require the use of family-centered practices, while organizational structures and resources enable staff to deliver family-centered services in Early Intervention programs (McLean, Sandall, & Smith, 2000).

In addition to the explicit aspects of an organization, there are many implicit factors that an administrator influences. Administrators establish the philosophy and climate of a program, which determines the program's operations. The agency's philosophy and principles dictates how the program is organized and operated and, in turn, how personnel behave and what they believe (Dinnebeil, Hale, & Rule, 1999; Dunst et al., 1991; Law et al., 2003; McWilliam et al., 2000). The climate of an organization impacts the quality of services provided by the agency (Dennis & O'Connor, 2013; Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Law et al., 2003). Law and his team

(2003) found a link between the level of a family-centered culture perceived by the families of a program and outcomes of children and families of that program. The culture of the program was influenced by the administrator providing staff training in family-centered service delivery methodology (Law et al., 2003). Administrators are responsible for creating an organizational climate that facilitates and mandates the use of family-centered practices.

Administrators are responsible for ensuring a family-centered philosophy is adopted and adhered to by the staff of an agency. A program's philosophy is established or promulgated by the program's administrator. Effective family-centered care involves a shared philosophy that addresses how to interact with families at every level of service delivery (Bailey, McWilliam, & Winton, 1992; Murray & Mandell, 2006), with all staff, from the administrator to security personnel (Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002; Mandell & Murray, 2009). King and her colleagues (1998) suggest that the degree to which a program operates under a family-centered paradigm is influenced more by the organizational climate of a program than the characteristics of the individual staff. Bruder (2000) contends that "attitudes don't just permeate individuals, but they are embraced and reflected by agencies, organizations, communities, and constituents of communities . . . if one part of the system does not demonstrate family-centered attitudes, it is hard for the others in the system to override the damage this causes" (p. 110). Therefore, a philosophy of family-centered care must be infused throughout the agency (Piper, 2011), both horizontally and vertically (Walter & Petr, 2000).

The basis of an administrator's influence over the delivery of family-centered care resides in the administrator's conceptualization, knowledge, and beliefs of family-

45

centered care, as well as the administrator's actions regarding the delivery of family-centered services (Mandell & Murray, 2009, Epley et al., 2010). An administrator's beliefs concerning family-centered care are shaped through his or her early professional experiences and training (Mandell & Murray, 2009). The actions regarding the delivery of family-centered programming specifically involve the policies and practices the administrator establishes, enforces, or does not enforce (Mandell & Murray, 2009; Dinnebeil, Hale, & Rule, 1999); the administrator's use of fiscal and personnel resources (Epley et al., 2010; Dinnebeil, Hale, & Rule, 1999); and the expressed or implied vision and philosophy the administrator instills in the organization (Law et al., 2003; Epley et al., 2010).

Outcomes

Family-centered service delivery models implemented by programs and providers have been linked to various benefits for children and families (Bailey, Raspa, & Fox, 2012; Bruder, 2010; Dunst & Trivette, 2009a; Epse-Sherwindt, 2008; Mahoney, O'Sullivan, & Dennebaum, 1990; Guralnick, 2005, 2011; Kingsley & Mailloux, 2013; Rosenbaum et al., 1998). However, the processes of how these positive outcomes occur are complex and not fully understood (Bailey, Raspa, & Fox, 2012; Dempsey & Keen, 2008). Because there is not a clearly defined set of practices upon which to assess family-centered care, measuring family-centered services and outcomes creates significant challenges. There is a lack of consensus as to what should be measured when assessing family outcomes (Bailey, 2001; Bailey et al., 2011; Epley, Summers, & Turnbull, 2011; Mannon et al., 2006; Wang, Summers, Little, Turnbull, Poston, & Mannan, 2006; Warfield et al., 2000). Additionally, the assessments that have indicated

the effectiveness of family-centered care have evaluated a range of behaviors. Although this validates the efficacy of family-centered care, this simultaneously creates difficulty developing a universal standard benchmark as to how to evaluate family-centered care.

Measuring Outcomes

Measuring the outcomes of family-centered care begets a distinctive set of complex issues. By their nature, family-centered services are intended to be individualized. A standardized measure may not encompass how a family has benefited from the services provided by Early Intervention practitioners. Because every family enters Early Intervention with unique challenges and needs, comparing the progress and outcomes of families is complicated. Also, some families have children who are identified at birth as being eligible for Early Intervention and begin receiving services shortly after their child is discharged from the hospital, or while in the hospital. However, other families have children who may not be identified as eligible for Early Intervention until the child is age two or older. Consequently, the outcomes of family-centered care for a family enrolled in Early Intervention since their child was born will be quite different from those of a family who has been enrolled in the program for a matter of months.

Additionally, some families, due to their child's diagnosis or special needs, receive very intensive, frequent services provided by a large team of interventionists. Other families may only receive services from one provider on a less frequent basis. The impact of the frequency and intensity of services provided, as well as interfacing with a large number of providers which creates multiple opportunities for support, may influence outcomes. The results and benefits of Early Intervention services for a family

with a child who has complex medical needs and profound developmental concerns and will require lifelong care and services will most likely be very different than those from a family who has a child with a mild developmental delay, who will not require services beyond Early Intervention.

There are also cultural considerations that may influence outcomes. For example, Bailey and his team (2005) consider a family's ability to advocate for the needs of their family and child as an outcome of family-centered care. However, in some cultures, it may be deemed disrespectful to question or disagree with a person who is considered an authority figure. Also, some families experience significant life events while enrolled in Early Intervention, which influences the outcome the family experiences. Finally, most of the studies regarding outcomes of family-centered care are based on self-reports from families or staff. Although the perceptions of practitioners and families provide tremendous insight regarding evaluating the outcomes of family-centered services, they offer no standard of measure that is quantifiable. The above stated reasons would make creating such a tool, as well as a suitable measure of accountability in Early Intervention, a herculean, albeit much needed, task.

Benefits of Family-Centered Service Delivery

The focus has shifted from child outcomes to family outcomes regarding accountability measures in Early Intervention (Bailey, Raspa, & Fox 2012; Epley, Summers, & Turnbull, 2011) and family outcomes related to family-centered practices (Dempsey & Keen 2008). The following benefits have been identified for families receiving a family-centered service delivery approach:

- Reduced levels of stress (Dempsey et al., 2009; Dunst & Trivette, 2009b; Thompson et al., 1997)

- Increased sense of competency to interact with, care for, and parent a child with special needs (Broggi & Sabatelli, 2010; McWilliam & Scott, 2001; Romski, Sevcik, Adamson, Smith, Cheslock, & Bakeman, 2011)

- Increased sense of empowerment (Chao et al., 2006; Dempsey & Dunst, 2004; Dunst & Dempsey, 2007; Dunst & Trivette, 1996; Fordham, Gibson & Bowes, 2011)

- Ability to access and utilize formal and informal support systems (Dunst & Trivette, 2009a; Raspa et al., 2010; Warfield et al., 2000)

- Increased sense of optimism regarding the future (Bailey et al., 2005; Dunst & Trivette, 2009b)

- Sense of control over events in their life and resources (Dunst, Trivette, & Hamby, 1996; Judge, 1997; Trivette, Dunst, & Hamby, 1996a, 1996b)

- Increased family cohesiveness and functioning (Broggi & Sabatelli, 2010; Dunst, Hamby, & Brookfield, 2007; McBride et al., 1993)

- Increased confidence in ability to partner with professionals (Bailey et al., 2005; Peterander, 2000)

- Increased ability to advocate for the needs of their child and family (Bailey et al., 2005)

- Enhanced sense of ability to cope (Bailey et al., 2006; Dempsey & Keen, 2008; Dunst, Hamby, & Brookfield, 2007)

- Satisfaction with services received (Applequist & Bailey, 2000; Peterander, 2000; Trute & Hiebert-Murphy, 2007; Ziviani, Feeney, & Khan, 2011)

- Improved sense of emotional well-being (Dunst, Trivette, & Hamby, 2007; Faramarzi & Afrooz, 2009; McBride et al., 1993; Trivette, Dunst, & Hamby, 2010)

- An overall sense of having benefited from receiving services from Early Intervention (Bailey et al., 2005; McBride et al., 1993; Raspa et al., 2010)

- Improved family quality of life (Davis & Gavida-Payne, 2009; Summers et al., 2007; Wang et al., 2006)

All of these benefits to families affect the child (Bailey et al., 2007; Odom & Wolery, 2003; McWilliam & Scott, 2001; Dunst et al., 2007; Dunst & Trivette, 2009b).

When measuring outcomes related to families, factors such as the family's well-being, satisfaction, sense of empowerment, sense of optimism, and ability to access informal support systems have been shown to significantly impact a parent, which then benefits their child (Bailey et al., 2005, 2006, 2007). The emotional well being of a parent is positively related to the parent's perceived sense of control (Trivette, Dunst, & Hamby, 1996a). Parents who experience a greater sense of emotional well-being are less depressed as well as able to be more responsive to, more interactive with, and more supportive of their child (Trivette, Dunst, & Hamby, 2010), which positively impacts their child (Dunst & Trivette, 2009c). Families who are satisfied with services are more likely to engage in programmatic activities and follow through or carry over prescribed intervention strategies (McNaughton, 1994; Peterander, 2000). Empowerment involves taking control of one's life (Thompson et al., 1997; Mannan et al., 2006), which includes

decision making and managing resources (Dunst, 1985). When a person is empowered

and solicits support and mobilizes resources, those actions beget a greater sense of

empowerment to acquire additional supports and mobilize further resources (Dempsey &

Dunst, 2004; Dunst & Trivette, 1996; Dunst, Trivette, & Hamby, 1996). Families who

identified themselves as being more involved in decision making, thus empowered,

expressed less need than families who considered themselves to be less involved in the

Early Intervention decision-making process (Garshelis & McConnell, 1993). Families

who were able to access informal support systems, such as family, friends, and

community resources, indicated greater feelings of empowerment, more adaptive coping

skills, an increased sense of overall well-being, a greater sense of emotional support, and

increased positive interactions between parent and child (Bailey et al., 2005, 2007; Dunst,

Leet, & Trivette, 1988; Dunst & Trivette, 2009a; McWiliam & Scott, 2001). Kyzar,

Turnbull, and Summers (2012) found that support enhances a family's quality of life,

functioning, and satisfaction, and provides a buffer against stress. Families with a greater

sense of well being, as well as adequate support systems, are able to focus their attention

on carrying over prescribed intervention strategies (Dunst, Leet, & Trivette, 1988).

The resounding impact of using a family-centered service delivery approach was

solidified in a study conducted by Dunst, Trivette, and Hamby in 2007. In a meta-

analysis of 47 studies across seven countries with more than 11,000 participants, Dunst,

Trivette, and Hamby (2007) determined that the delivery of family-centered services

increased a family's satisfaction with the program and services, program resources and

supports, sense of confidence and competence in parenting abilities, resources and

support offered by the program, sense of personal and family well-being, as well as with

51

their child's behavior. Conducting a meta-analysis of this magnitude makes "the findings particularly robust" because "replication of the results across measures, across countries, across helpgivers, across populations of participants, and across settings strengthens the conclusion that family-centered helpgiving matters in terms of program participant benefits" (Dunst, Trivette, & Hamby, 2007, p. 377).

How services are provided is more influential on the outcomes for families and children than what services are provided (Dunst, 1999; Dunst, Hamby, & Brookfield, 2007; Dunst, Trivette, & Hamby, 1996, 2007; McWilliam, Maxwell, & Sloper, 1999; Summers et al., 2007; Thompson et al., 1997; Ziviani, Feeney, & Khan, 2011). Because family-centered care is based on the relationships between providers and families, the nature of the working partnerships between the practitioner and family appears to directly influence the outcomes related to family-centered service delivery (Broggi & Sabatelli, 2010; Dempsey et al., 2009; Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 1996, 2007; Keen, 2007; Odom & Wolery, 2003; Ziviani, Feeney, & Khan, 2011). The type of relationship a family has with a provider impacts the maternal level of stress, sense of competence, and maternal perception of the program's provision family-centered services (Broggi & Sabatelli, 2010), as well as perceived sense of control over resources, supports, and services (Trivette, Dunst, & Hamby, 1996a). For increased positive outcomes, a practitioner needs to develop a relationship that is more than just respectful and empathetic with a family (Dempsey & Dunst, 2004; Dempsey & Keen, 2008; Dunst, Boyd, Trivette, & Hamby, 2002; Dunst & Dempsey, 2007; Dunst, Trivette, & Snyder, 2000; Trivette, Dunst, & Hamby, 1996a). Relationships that shift the locus of power and control to families and allow families to become the agents of change are correlated to

better outcomes (Dempsey & Dunst, 2004; Dunst et al., 2002; Dunst & Trivette, 2009; Dunst, Trivette, & Hamby, 2007). Kelly, Ghalaieny, and Devitt linked the relationships between provider and parent to continued participation and compliance in Early Intervention programming. Dunst, Trivette, and Hamby (2007) also discovered that when services were provided in a manner that was not consistent with family-centered practices, the results demonstrated no positive benefits or even negative outcomes. Therefore, when Early Intervention services are not provided in collaboration with the family, utilizing an approach that supports the abilities, backgrounds, decisions, and strengths of the family, it can have detrimental consequences.

The delivery of services utilizing a family-centered model has demonstrated multiple benefits for families (Dunst, Trivette, & Hamby, 2007; Bailey et al., 2005, 2006, 2007). However, there is no standard measure of outcomes, instrument to gauge family-centered care, or tool to assess the quality of services provided. Research indicates that the manner in which services are delivered is more influential on the outcomes for families and children than what services are provided (Dunst et al., 2006; Dunst, Hamby, & Brookfield, 2007; Dunst, Hamby, & Trivette, 1996; Dunst, Trivette, & Hamby, 2007; Thompson et al., 1997). Consequently, the relationship between providers and families impacts the outcomes of families (Broggi & Sabatelli, 2010; Dempsey et al., 2009; Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 1996, 2007; Keen, 2007; Odom & Wolery, 2003).

Barriers

Despite the demonstrated benefits of family-centered practices, there are many barriers to its implementation. The factors that impede the implementation of family-

centered care can be attributed to two broad categories: (a) barriers internal to an agency, and (b) barriers external to an agency. Barriers internal to a program are hindrances that occur within an organization that impact a practitioner's ability to provide and/or a family's ability to receive family-centered care. Within an organization, the obstacles to delivering family-centered services are divided into the subcategories of programmatic barriers, provider barriers, and family barriers. Programmatic barriers are general features of an agency that inhibit the delivery of family-centered care. Provider barriers are characteristics of direct service practitioners that interfere with the delivery of family-centered programming. Family barriers are the attributes of families that impede the delivery of family-centered services. External barriers are factors that occur outside of the organization, often beyond the control or influence of the administrators and program staff, which impede the delivery of family-centered care.

Internal Barriers

When examining programmatic barriers to the delivery of family-centered care, it can be conceived that every aspect of an organization can hinder the delivery of family-centered services, and all of these aspects are under the influence of the program's administration. The following factors have been cited as impediments to the provision of family-centered programming that are internal to an organization:

- Poor programmatic leadership and administrative support (Epley et al., 2010; Mandell & Murray, 2009; Murray & Mandell, 2006)

- Lack of staff training (Mahoney & O'Sullivan, 1990; McBride & Peterson, 1997; McBride et al., 1993)

- Organizational characteristics of an agency, such as the infrastructure, history, and/or bureaucracy of the agency (Kuo et al., 2012; Pereira & Serrano, 2014; Roush, Harrison, & Palsha, 1991; Shannon, 2004)

- Limits of budgets and funding resources (Bailey et al., 1992; Crais, Roy, & Free, 2006; Jolley & Shields, 2009; Perrin et al., 2008)

- Administrative practices, procedures, and operations (Crais & Wilson, 1996; Dinnebeil, Hale, & Rule, 1996, 1999; Fleming, Sawyer, & Campbell, 2011)

- Organizational climate and philosophy of the agency (Bellin et al., 2011; Dennis & O'Connor, 2013; Law et al., 2003)

- Difficulty changing established organizational behavior patterns (Bailey, McWilliam, & Winton, 1992; Bamm & Rosenbaum, 2008; Bruder, 2000)

- Conflicting philosophical perspectives between staff and administrators (Epley et al., 2010; Bailey et al., 1992)

- Service delivery options and program settings offered (Humphry & Geissinger, 1993; Iverson et al., 2003; Judge, 1997; McWilliam, Tocci, & Harbin, 1998)

- Fear of litigation (Tucker & Schwartz, 2013)

- The perceived difficulty in implementing family-centered care (McWilliam, 1999)

- Lack of time and opportunity (Campbell & Halbert, 2002; Crais & Belardi, 1999; Crais & Wilson, 1996; Fingerhut et al., 2013)

- The attitudes, beliefs, values, and characteristics of the staff of the agency (Brotherson et al., 2010; Henneman & Cardin, 2002; Howland et al., 2006)

55

There are impediments to creating partnerships and delivering family-centered care that reside within practitioners. Barriers that can be attributed to providers include the following:

- Lack of understanding and valuing of family-centered care (Dinnebeil & Rule, 1994; Iverson et al., 2003; Mandell & Murray, 2009)

- Lack of skills or knowledge as to how to develop partnerships and collaborative relationships with families (Bamm & Rosenbaum, 2008; Howland et al., 2006; Mahoney & Wiggers, 2007; Shannon, 2004)

- Discomfort working with families, or preference to work with children, as opposed to families (Bruder, 2000; Crais, Roy, & Free, 2006; Dinnebeil, Hale, & Rule, 1999)

- Reluctance to change professional practices (Campbell & Halbert, 2002; Campbell & Sawyer, 2007; Epley et al., 2010; Humphry & Geissinger, 1993)

- Staff attitudes, including those regarding families (Bailey et al., 1992; Dinnebeil, Hale, & Rule, 1996; McBride & Peterson, 1997; Pereira & Serrano, 2014)

The mind-set and traits of providers can be barriers that impact the delivery of family-centered care as well. For example, studies indicate that providers can be reluctant to change their practices because they are comfortable with the status quo (Dunst, Trivette, & Deal, 2011; Epley et al., 2010; Bailey et al., 1992) and are averse, uninterested, or not invested in implementing new family-centered initiatives (Mahoney, O'Sullivan, & Fors, 1989). Practitioners are not willing to engage in the practices, including the delivery of family-centered care, that do not match their personal belief set

(Campbell & Halbert, 2002; Mandell & Murray, 2009; Murray & Mandell, 2006).

Additionally, other studies found that the more years of experience the provider had, the less likely they were to adopt, use, or want to use family-centered practices (Epley et al., 2010; Campbell & Sawyer, 2007; Campbell & Halbert, 2002).

Families as Barriers

Of greatest concern are staff attitudes that perceive families as barriers to the delivery of family-centered care. Several studies found that providers report families obstruct the delivery of family-centered services (Bellin et al., 2011; Crais & Wilson, 1996; Pereira & Serrano, 2014; Roush, Harrison, & Palsha, 1991; Shannon, 2004). However, considering a family an obstacle to the delivery of family-centered programming is antithetical to the philosophy of family-centered service delivery. Practitioners have reported that families create the following obstructions to the delivery of family-centered care:

- Lack of participation (Campbell & Halbert, 2002; Childress, 2004; Mahoney & O'Sullivan, 1990; Shannon, 2004)

- Attitudes (Dinnebeil & Rule, 1994; Mahoney, O'Sullivan, & Fors, 1989; Tomasella, Manning, & Dulmus, 2010)

- Lack of skills and knowledge regarding how to develop partnerships with professionals (Crais, Roy, & Free, 2006; Howland et al., 2006; McBride & Peterson, 1997)

- Cultural barriers (Dinnebeil, Hale, & Rule, 1996; Iverson et al., 2003; McWilliam, Tocci, & Harbin, 1998)

- Family's resources and functioning (Bailey et al., 1992; Crais & Belardi,

  1999; Crais & Wilson, 1996; Edwards et al., 2003; Fingerhut et al., 2013)

Under the auspices of a family-centered service delivery model, families guide the assessment, planning, and implementation process. Providers are agents of the families and the decisions families make. Family-centered care is based on the premise of enhancing a family's strengths and recognizes that all families are competent and capable but that some families are unable to display their competencies and capabilities because of a failure of the social service system, not because the family does not have capabilities and competencies (Dunst, Trivette, Davis, & Cornwell, 1994). Therefore, if practitioners are truly providing family-centered care, families cannot be barriers to service delivery. The conclusion that families impede the delivery of family-centered care by practitioners confirms the impact provider attitudes, beliefs, and perceptions have on the delivery of family-centered services. Provider perceptions of families affect the interactions between provider and family (Sewell, 2012). Cultural differences, including socioeconomic disparity, between providers and families have been shown to influence the relationships providers have with families as well (Brinker, 1992; Dinnebeil & Rule, 1994; Fleming, Sawyer, & Campbell, 2011; Nelson, Summers, & Turnbull, 2004). Those differences and perceptions may be part of the reason that providers view families as barriers to the delivery of family-centered care.

External Barriers

Many of the barriers external to the agency are often outside the locus of control of the administrator and cannot be changed. Although they cannot be remedied, structures and adaptations to program operations can be made to accommodate the

impediments interfering with the delivery of family-centered services. The obstacles outside the walls of the agency that can hinder the implementation of family-centered programming can include the following:

- Not having a clearly defined set of practices that constitute family-centered care (Epley, Summers, & Turnbull, 2010; Guralnick, 2005; Kuo et al., 2012)

- The larger community outside of the agency, including the culture of the community and the geographic location, size, and features of the area in which services are provided (Bailey, McWilliam, & Winton, 1992; Crais & Wilson, 1996; Dinnebeil, Hale, & Rule, 1996; Epley et al., 2010)

- The limitations of budgets and funding (Bamm & Rosenbaum, 2008; Jolley & Shields, 2009; Perrin et al., 2007; Tomasello, Manning, & Dulmus, 2010)

- Interagency relationships and coordination (Guralnick, 2001; McWilliam, Tocci, & Harbin, 1998; Shannon, 2004)

- Constraints of the bureaucracy of the Early Intervention system and its requirements (Bailey et al., 1992; Crais & Belardi, 1999; Dinnebeil, Hale, & Rule 1999; Fingerhut et al, 2013; O'Neil & Palisano, 2000)

- The lack of quality training materials available (Bruder, 2000; Campbell & Halbert, 2002)

- The paucity of quality research that providers believe is directly related to their practice (Bruder, 2000; McWilliam, 1999)

- Billing and reimbursement regulations (Dunst, 2012; Perrin et al., 2007; Shannon, 2004)

- Pre-service undergraduate and graduate training programs which do not prepare practitioners to work with families (Crais, Roy, & Free, 2006; Fleming, Sawyer, & Campbell, 2011; Mandell & Murray, 2009; Pereira & Serrano, 2014)

- The philosophy of treatment disciplines, services, and methods (Bruder, 2000; McWilliam, 1999)

- The complexity of local, state, and federal service delivery and compliance policies (Dunst, 2012; Humphry & Geissinger, 1993; O'Neil & Palisano, 2000)

- The nature of federal, state, and local structures regarding the Early Intervention system (Dunst, 2012)

Multiple barriers to delivering family-centered care have been identified. Those barriers can be categorized as internal or external to an organization. Within the context of barriers internal to an agency, staff are often cited as hindrances to the delivery of family-centered care (Crais, Roy, & Free, 2006; Dinnebeil, Hale, & Rule, 1996, 1999; Dinnebeil & Rule, 1994; Epley et al., 2010; Howland et al., 2006; Mandell & Murray, 2009), as are families (Bailey et al., 1992; Crais & Belardi, 1999; Crais, Roy, & Free, 2006; Crais & Wilson, 1996; Fleming, Sawyer, & Campbell, 2011; Howland et al., 2006; McBride & Peterson, 1997; Roush, Harrison, & Palsha, 1991). However, citing families as barriers to the delivery of family-centered services negates the purpose and intent of family-centered care.

Program Features/Family-Centered Practice

The basis of family-centered care lies in the relationship between providers and families. Because there is no consensus as to what constitutes family-centered care, there is no consistency as to how family-centered practices are implemented between programs (Dempsey & Dunst, 2004; Dunst, Humphries, & Trivette, 2002; Mahoney & Bella, 1998; McBride et al., 1993; McWilliam et al., 2000; Murphy et al., 1995). Yet, practitioners consistently report a discrepancy between their conceptualization of ideal family-centered care and the actual family-centered services they deliver. The implicit or explicit philosophical orientation of a program, as well as the program's policies and practices, affect the family-centered services provided by an organization. Those policies and practices can be grouped into the categories of professionally focused, family-focused, and family-professional practices (Mandell & Murray, 2009).

Relationships with Families

The relationship between families and practitioners is the foundation of family-centered care. Relationships with families should be the primary emphasis of the delivery of family-centered services in Early Intervention (Broggi & Sabatelli, 2010; Bruder, 2000; Dinnebeil, Hale, & Rule, 1996; Duwa, Wells, & Lalinde, 1993; McWilliam, Tocci, & Harbin, 1998; Murray & Mandell, 2006; Odom & Wolery, 2003). Mannan (2006) and his colleagues contend that partnership is the process of service delivery of Early Intervention, whereas Dunst, Trivette, and Deal (1994b) assert that a partnership "creates the medium for effective work with families" (p. 10). Family-centered care emphasizes the partnerships between the provider and families (Dunst, Trivette, & Deal 1994b; Law et al., 2003; Mannan et al., 2006; Summers et al., 2007),

61

which is founded on reciprocal relationships (Bruder, 2000; Woods et al., 2011).

According to Trute and Hiebert-Murphy (2007), the relationship between providers and families begins as a working alliance, which involves mutual caring and effort towards a common goal by all parties. Working alliances build into partnerships (Dunst, Trivette, & Deal, 1994b; Trute & Hiebert-Murphy, 2007), then collaborations (Dinnebeil, Hale, & Rule, 1996).

A partnership is a reciprocal, complementary, and jointly beneficial relationship between professionals and families (Brotherson et al., 2010; Dunst & Dempsey, 2007; Dunst, Trivette, & Johanson, 1994; Judge, 2002) that requires release of control on the part of the professional (Garland & Linder, 1994). Keen (2007) identified the components of effective partnerships as mutual respect, trust, honesty, jointly agreed upon goals, shared planning, and decision making Both partnerships and collaborations promote cooperation (Dunst, Trivette, & Johanson, 1994), acknowledge that the parties involved are accomplishing more in their unified effort than if working in isolation (Dunst, Trivette, & Johanson, 1994; Dunst, Trivette, & Snyder, 2000), and consists of transactional as well as interactional exchanges (Dunst, Trivette, & Snyder, 2000). A collaboration is a closer relationship that involves cooperation, requires time and effort to develop (Dinnebeil and Rule, 1994), is based on equality and mutuality, entails all parties sharing their expertise, knowledge, and skills, while respecting, accepting, and understanding the investment the other has in assisting the family to achieve their goals (Allen & Petr 1996; Dinnebeil, Hale, & Rule, 1996; Duwa, Wells, & Lalinde, 1993). According to Duwa, Wells, and Lalinde (1993), collaborations are dependent on the delineation of roles, respect, and communication. Staff who develop collaborative

relationships with families employ participatory help-giving behaviors which involve

empowering and enhancing the competencies of families (Judge, 1997; Trivette, Dunst,

& Hamby, 1996a). The efforts of Early Intervention programs should be directed toward

developing collaborative partnerships with families that are empowering and capability

enriching.

Program Orientation

Family-centered care falls along a continuum of family oriented program models

developed by Dunst, Johanson, Trivette, and Hamby, (1991). The difference in program

models is based upon the program's and staff's assumptions regarding the family's level

of competence and control in service planning and delivery. The orientation of the

program impacts the services provided by the agency and, in turn, the outcomes of

families. The framework of a program, as determined by the program's administration,

can be expressed or implied. All of the program models focus on the family as the unit of

intervention, but differences lie in the intervention practices used, as well as the

perceptions of the roles of family and providers by each program model (Trivette, Dunst,

& Hamby, 1996a). Table 1 depicts the continuum of family-oriented program models

(Dunst et al., 1991) the philosophical underpinnings of each program, the suppositions

regarding families, and the roles of staff.

Table 1

Family-Oriented Program Models (Dunst et al., 1991)

Program Model	Professionally-Centered	Family-Allied	Family-Focused	Family-Centered
Philosophy	All expertise & decision-making capabilities rest with professionals Deficit-based premise of family functioning Paternalistic mindset Low expectations of outcomes to protect image of agency (Osher & Osher, 2002)	Family agent of professional by delivering intervention techniques practitioner deems necessary to support child's development (Trivette et al., 1995) Value strengths of family	Respect family's choices & actions Collaborate with families to define goals & needs	Expertise & decision-making capabilities reside with family Providers flexible & responsive to individual needs of families High expectations & continuous evaluations (Osher & Osher, 2002)
Assumptions About Families	Must have assistance from professionals to improve functioning	Require advice & guidance from professionals to improve functioning, incapable of doing so without professional assistance	Need advice & guidance of professionals	Decide all aspects of services & resource procurement based on their needs & desires Holistic view of family (Osher & Osher, 2002)
Staff Roles	Determine services, needs, & goals for families Implement interventions	Prescribe intervention strategies for family to implement Directly teach family skills to carry over between sessions	Assist families to choose from options professionals select & present that will best meet needs of child & family (Trivette et al., 1995; Trivette, Dunst, & Hamby, 1996a) Encourage families to use formal support network of professional services, as opposed to informal support network of family, friends, & community	Viewed as agents of families Aim to strengthen family's capacities, decision-making capabilities, & competencies

Because of their values and practices, family-centered programs have a unique structure. A theoretical framework for family-centered programs was created by Dunst and Trivette (1994a). The basis for family-centered programs is a philosophy that emphasizes family empowerment as well as principles that focus on supporting families. Programming is based on family-identified needs and priorities, which determines the various child, adult, and family services available for families. Dunst and Trivette (1994a) explain that under this model programs will "employ needs-based practices, strength-based practices, resources-based intervention practices, and competency enhancing help-giving practices as part of promoting the flow of resources to families that are competency enhancing and supportive" (p. 44). In addition to the often limited and scarce formal sources of support provided by professionals, family-centered programs would draw from the informal resources of support found within the larger community the family is a part of, which are renewable and expandable (Dunst, Trivette, & Deal, 1994c). The intended outcomes of family-centered programs include the family's increased satisfaction with the program, well being, stability, integrity, empowerment, and quality of life (Dunst & Trivette, 1994a) as well as the value-added benefit of enhancing a child's development (Chong et al., 2012; Sandall, McLean, & Smith, 2000).

The family-oriented program model and paradigm of the program affects the practices of the program (Trivette et al., 1995), which in turn influences the behaviors of staff (Dunst et al., 2002; Dunst, Trivette, Boyd, & Brookfield, 1994; Dunst, Trivette, & Hamby, 1996; Tang, Chong, Goh, Chan, & Choo, 2011; Trivette et al., 1995). Program

practices, and staff behavior are connected to outcomes of service delivery (Dunst et al., 2002; Dunst, Trivette, Boyd, & Brookfield, 1994; Judge, 1997; Tang et al., 2011; Trivette, Dunst, & Hamby, 1996a; Trivette et al., 1995). Many programs do not provide the level of family-centered care they claim to (Dempsey & Carruthers, 1997; Dunst, 2002; Dunst et al., 1991; Mahoney & Filer, 1996; Mandell & Murray, 2009; Minke & Scott, 1995; Roush, Harrison, & Palsha, 1991), with most Early Intervention programs employing family-focused or family-allied service delivery models (Dunst, 2002; Mahoney & Filer, 1996; Mahoney & O'Sullivan, 1990; McBride et al., 1993).

Policies and Practices

The basis of policies and practices of Early Intervention programs should be to facilitate providers to develop collaborative partnerships with families. The policies and practices of programs should be designed to enable providers to meet the needs of and support families (Dinnebeil Hale, & Rule, 1999; Epley et al., 2010; Henneman & Cardin, 2002; Sandall, McLean, & Smith, 2000), as the policies of programs impact the quality of services provided (Sandall, McLean, & Smith, 2000; Zhang, Bennett, & Dahl, 1999). Duwa, Wells, and Lalinde (1993) contend that family-centeredness should be "manifested in the way policy is developed, programs are designed, and services are delivered" (p. 120). Dinnebeil, Hale, and Rule (1999) echo that by proclaiming that program practices and policies "need to reflect the needs of families and support the work of Early Intervention professionals" (p. 234). "Policies that advocate family-centered practices place families at the core of the service delivery process" (p. 347), as providers serve as the link between families and policies (Zhang, Bennett, & Dahl, 1994). Those practices fall into three categories: (a) family-focused practices; (b) practices that support

the family-professional partnerships; and (c) professional-focused practices (Mandell & Murray 2009).

Facilitating family collaboration and involvement in Early Intervention is at the heart of family-focused activities. Family-focused practices that support the implementation of family-centered care are considered activities and opportunities that enable family participation as well as prepare families to be involved in their child's future education (Mandell & Murray, 2009). Several family-focused practices identified are as follows:

- Accompanying and preparing families to participate in meetings and appointments (Jackson, Traub, & Turnbull, 2008; King et al., 1998; Murphy et al., 1992; Staples & Diliberto, 2010)

- Providing parent-to-parent mentoring opportunities (Fordham, Gibson, & Bowes, 2011; Guralnick, 2001, 2011; James & Chard, 2010; Summers et al., 2007)

- Offering program-sponsored social events for families (Mandell & Murray, 2009; Tomasello, Manning, & Dulmus, 2010)

- Addressing the emotional needs of families, especially during periods of major transitions (Brotherson et al., 2010; Chong et al., 2012; Guralnick, 1998, 2001)

- Supplying resources from within the program to families with socioeconomic needs, such as diapers, vouchers to a food program, or maintaining an emergency assistance fund (Epley et al., 2010; Guralnick, 2011; McWilliam & Scott, 2001)

- Respecting families from diverse cultural, ethnic, and linguistic backgrounds (Kuo et al., 2012; Odom & Wolery, 2004; Paul & Roth, 2011; Walter & Petr, 2000)

- Presenting informative workshops on specific educational topics for families (Gooding et al., 2011; McWilliam & Scott, 2001; Shannon, 2004)

- Maintaining an open visitation policy in center-based programs (Gooding et al., 2011; Henneman & Cardin, 2002; Kuo et al., 2012)

- Utilizing daily communication notebooks and publishing regular program newsletters to facilitate communication between home and school (Mandell & Murray, 2009; Staples & Diliberto, 2010)

- Encouraging families to volunteer in their child's program (Bronfenbrenner, 1975; Mandell & Murray, 2009; Staples & Diliberto, 2010)

- Granting a stipend to families to cover expenses related to participating in events, such as transportation costs (Gooding et al., 2011; Mandell & Murray, 2009; Walter & Petr, 2000)

- Having, and ensuring program staff representation at, parent-teacher organization (PTO/PTA) meetings (Mandell & Murray, 2009)

- Using flexible practices to meet the individual needs of families to support family participation in the program (Dinnebeil, Hale, & Rule, 1999; Fay & Carr, 2010; Guralnick, 2005; Judge, 1997)

- Distributing a handbook to families of the program's philosophy regarding family-centered care, as well as the program's policies and practices (Edwards & DaFonte, 2012; Henneman & Cardin, 2002; Law et al., 2005)

- Ensuring flexible and varied service delivery options are available for families (Brown & Remine, 2008; Garland & Linder, 1994; Iverson et al., 2003; McBride et al., 1993)

- Offering training to families on how to collaborate or partner with Early Intervention practitioners and professionals (Law et al., 2003; Park & Turnbull, 2003; Shannon, 2004)

- Incorporating opportunities for all family members to be involved in the program, such as fathers, siblings, grandparents, extended family members (King, et al., 1998; Peterander, 2000; Summers, et al., 2007)

- Respecting the decisions of families, even if they differ from those of the providers (Judge, 1997; King, Rosenbaum, & King, 1995; Murphy et al., 1992)

- Viewing families as collaborators and equal partners in the team (Garshelis & McConnell, 1993; King, Rosenbaum, & King, 1995; Zhang, Bennett, & Dahl, 1999)

- Empowering families (Iverson et al., 2003; Shannon, 2004; Tomasello, Manning, & Dulmus, 2010)

- Having resources available for families to borrow and use, such as books, DVD's, equipment, specialized toys (Garshelis & McConnell, 1993; Guralnick, 2005; Law et al., 2003)

- Connecting families with social service resources (Guralnick, 1998; Haring & Lovett, 2001; Mandell & Murray, 2009)

The second category of practices include those that require collaborative efforts between families and staff. Practices that focus on supporting family-professional partnerships are considered activities or opportunities that require joint participation by families, as well as professionals, or policies that facilitate the relationship between families and providers (Mandell & Murray, 2009). Such activities include the following:

- Having family, as well as staff members, hold membership positions on program governance and policy formation committees (Bailey, McWilliam, & Winton, 1992; Garland & Linder, 1994; James & Chard, 2010; Ozdemir, 2008; Piper, 2011; Walter & Petr, 2000)

- Developing or adapting program practices based upon the needs of the families and practitioners (Dinnebeil, Hale, & Rule, 1999; Mandell & Murray, 2009)

- Having families and staff participate in system-wide program development and evaluation efforts (Kuo et al., 2012; Mandell & Murray, 2009; Moeller, Carr, Seaver, Stredler, Brown, & Holzinger, 2013)

- Matching providers to families based on the needs and characteristics of the family and practitioner, as opposed to assigning staff to families (Dinnebeil, Hale, & Rule, 1999)

- Working to maintain the consistency of the relationship between practitioners and families (Dinnebeil, Hale, & Rule, 1999; Peterander, 2000; Summers et al., 2001)

- Offering professional development opportunities for staff and families jointly, including on topics related to developing collaborative partnerships (Mandell & Murray, 2009; Law et al., 2003; Shelton, Jeppson & Johnson, 1987)

Professional-focused practices are activities and opportunities that support or prepare staff to work with families (Mandell & Murray, 2009). Examples of these program practices are as follows:

- Recognizing and emphasizing the attitudes, skills, and abilities of staff (Dinnebeil, Hale, & Rule, 1999)

- Planning staff development based on staff competencies, preferences, and input (Bailey, McWilliam, & Winton, 1992; Garland & Linder, 1994; Walter & Petr, 2000)

- Maintaining confidence in the staff as skilled and capable professionals (Dinnebeil, Hale, & Rule, 1999)

- Creating an environment that emphasizes and enables collaboration in all practices and policies, including between staff as well as between providers and families (Dinnebeil, Hale, & Rule 1999; Epley et al., 2010; Garland & Linder, 1994; Moeller et al., 2013)

- Having a policy for classroom staff to make home visits and enabling staff to do so by offering flexible work schedules or providing paid substitutes for classroom teachers (Mandell & Murray, 2009)

- Offering professional development opportunities for staff on collaborating with families, family-centered care, and how to implement effective parent-

teacher conferences (Guralnick, 2005; Iverson et al., 2003; Pickering &
Busse, 2010)

- Carefully screening staff to be hired based on personality traits and beliefs
  that lend themselves to providing family-centered care (Dinnebeil, Hale, &
  Rule, 1999; Dinnebeil & Rule, 1994; Epley et al., 2010)

- Developing systems and policies to support staff in providing family-
  centered services (Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, &
  Rule, 1999)

- Offering staff flexible work schedules to meet the needs of families
  (Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Mandell &
  Murray, 2009)

- Creating opportunities for team meetings and informal exchanges of
  information between staff (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010;
  Sandall, McLean, & Smith, 2000)

- Providing mentoring and supervision for staff and administrators (Bailey,
  McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Walter & Petr,
  2000)

- Emphasizing family outcomes and progress as opposed to child development
  and achievement (Garland & Linder, 1994; Mandell & Murray, 2009)

- Providing ongoing staff development activities, such as supervision or
  mentoring, rather than individual workshops on various topics (Campbell &
  Sawyer, 2007; Dunst, Trivette, & Deal, 2011; King et al., 2011)

- Establishing a steering committee to ensure a family-centered focus in the program (Henneman & Cardin, 2002; Walter & Petr, 2000)

- Addressing the emotional needs of practitioners with training and support so the providers can be available to families (Brotherson et al., 2010; Walter & Petr, 2000)

- Emphasizing family-centered care throughout the organization, with all staff, including security personnel (Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002)

Although the support practitioners provide to families is paramount to the delivery of family-centered services, the support that an organization provides to staff influences the provision of family-centered care as well (Dinnebeil, Hale, & Rule, 1999; Mandell & Murray, 2009; Walter & Petr, 2000). Many of the recommended practices that providers use to deliver family-centered services to families mirror the suggested practices programs are to employ to support providers in the delivery of family-centered care. For example, evidence-based practice indicates that providers should view families as competent decision makers (Crais, Roy, & Free, 2006; Judge, 1997; Raghavendra et al., 2007), address the emotional needs of families (Brotherson et al., 2010; Guralnick, 2001; Mandell & Murray, 2009), and provide training to families regarding how to develop collaborative relationships with professionals (Law et al., 2003; Mandell & Murray, 2009). Research regarding practices programs should implement to support staff to deliver family-centered care include respecting staff as competent decision makers (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010), addressing the emotional needs of practitioners and supporting providers so they can be available to families (Brotherson et

al., 2010; Walter & Petr, 2000), as well as offering professional development to staff on how to work collaboratively with families (Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Mandell & Murray, 2009; Moeller et al., 2013; Sandall, McLean, & Smith, 2000). In other words, practices that providers utilize with families that are considered family-centered mimic the same practices that programs and administrators are to use to support practitioners in order to facilitate the delivery of family-centered programming. It is not a different set of practices, but the same practices applied to a different group of people. This gives credence to how the culture of family-centered care should permeate and be infused in an organization's policies and practices, from supports offered to staff from administrators, to supports offered to families by practitioners. It also supports the hypothesis that family-centered care has a trickle-down effect that originates with the administrator of the organization; if the administrator creates program policies and policies that support practitioners in providing family-centered services, then providers can deliver family-centered care.

Ideal Practice

Although family-centered care is considered best practice in Early Intervention, there is a discrepancy between the actual family-centered services provided to families by practitioners and the family-centered practices providers consider ideal. Despite the lack of clearly defined attributes that determine what constitutes ideal family-centered care, many studies indicate providers recognize the family-centered services they provide differ from best practice (Crais & Belardi, 1999; Crais & Wilson, 1996; Dempsey & Carruthers, 1997; Fleming, Sawyer, & Campbell, 2011; Ingber & Dromi, 2010; King et al., 1998; Mahoney, O'Sullivan, & Fors, 1989; McBride et al., 1993; McWilliam,

Maxwell, & Sloper, 1999). King and her team (1998) contend that the difference lies in the notion of what practitioners want to provide families versus what they are able to provide families. Inadequate staff training and administrative support is the crux of the issue and cause of incongruity (Crais & Wilson, 1996; Dempsey & Carruthers, 1997; King et al., 1998; Mahoney, O'Sullivan, & Fors, 1989; McBride et al., 1993; McBride & Peterson, 1997; McWilliam, Maxwell, & Sloper, 1999). Rupiper and Marvin (2004) assert that the gap between actual and recommended practice may lie with the curriculum of pre-service training programs, where faculty value the importance of teamwork and communication skills less than other components of family-centered care, which means that practitioners are not adequately trained to provide services to families. In the study conducted by McBride and Peterson (1997), practitioners were surprised to discover services they were providing were not considered to be as family-centered as they had perceived and indicated they needed additional training and support from their administrators to increase their skill set. Another explanation for the discrepancy in actual versus ideal practice could be that when providers read the practices listed on the self-response forms provided in studies, the practitioners recognize they are not utilizing specific practices, but should be.

The family-oriented paradigm and practices of a program dictate the type of services provided by the agency (Dunst et al., 1991; Trivette et al., 1995). Those services can be professionally-centered, family-allied, family-focused, or family-centered. The basis of family-centered care is the relationship between practitioners and families. Therefore, the policies and practices of a program should be designed to support the delivery of family-centered care, and the focus of the organization should be on

enhancing the relationships between families and practitioners. The policies and practices of programs can be classified into three categories: (1) those implemented to support staff, (2) those designed to support families, and (3) those created to support professional-provider partnerships. Although there is no defined set of practices that constitute family-centered care, providers recognize the distinction between actual practice and ideal family-centered service delivery.

Administrative Theory

The Frenchman Henri Fayol, author of *Administration Industrielle et Generale* (1916/1949), is credited with the development of classical administrative theory as well as designating management as a profession to be studied (Parker & Ritson, 2005; Pryor & Taneja, 2012; Urwick, 1949). Fayol, originally an engineer, rose to Managing Director of a major metallurgical corporation, a company that he rescued from the brink of bankruptcy (English, 1994; Parker & Ritson, 2005; Urwick, 1949). Fayol recognized the significance of management to an organization and the vital role competent administrators have in an organization's success (Parker & Ritson, 2005; Pryor & Taneja, 2012; Smith & Boyns, 2005), which spurred him to write about his experiences and insights as an administrator. Fayol (1916/1949) identified and defined the role and functions of managers in companies and is acknowledged as the first to formally do so (Parker & Ritson, 2005, Pryor & Taneja, 2012; Smith & Boyns, 2005; Urwick, 1949). He explains that administrators need a special skill set and training to be effective, which until his time had been unexamined. Fayol (1916/1949) also proposed that although his experience and writing were from a business perspective, he believed that his insights could be applied to all types of organizations and companies. Because his book was

originally written in French, there has been much debate regarding the translation of the

text into English, such as the French word "administration" translated as "management"

(Pugh & Hickson, 1997; Pryor & Taneja, 2012; Smith & Boyns, 2005; Urwick, 1949).

Fayol (1916/1949) concluded that six types of activities are essential and present

in all work in all organizations to varying degrees. These functions are as follows: (1)

technical undertakings, (2) commercial endeavors, (3) financial duties, (4) security

actions, (5) accounting tasks, and (6) managerial activities. The technical skills are task-

specific and may require specific expertise or training to perform. Commercial

operations are related to purchasing goods and materials. Financial activities entail

deciding how to allocate monetary resources. Security tasks comprise protecting

resources, property, and personnel. Accounting functions are those associated with

bookkeeping and statistics. The managerial activities, or the functions of an

administrator, are the main focus of Fayol's interest, and the basis of classical

administrative theory.

Functions of Management

Managerial or administrative functions, according to Fayol (1916/1949), are

comprised of five components. Those tasks are as follows: (1) to forecast and plan, (2) to

organize, (3) to command, (4) to coordinate, and (5) to control. To forecast is to look

ahead to the future and anticipate. It requires the administrator to be flexible, assess

situations as accurately as possible, make provisions, develop a clear vision for the

agency, establish short-term and long-term goals, and use resources wisely and

responsibly. For Early Intervention program administrators, forecasting necessitates

keeping abreast of policy and practice changes, current research, the changing

demographics of families and their needs, and updated professional requirements for providers and programs. Administrators must also create an overarching mission as a guide for the future of the organization, which includes resource allocation.

Early Intervention, as a whole, has not been able to forecast the role of research and evidence-based practices. Dunst (2012) notes that state agencies have not incorporated current research into their models and paradigm of Early Intervention, which is a significant hindrance to the field. Providers report a lack of quality research as a barrier to implementing family-centered care (Bruder, 2000; McWilliam, 1999). Fayol (1916/1949) espoused employing a long-term plan that is adjusted annually to reflect current data. This could easily be applied to Early Intervention by examining methods based on the latest research and evidence-based practice, as well as by initiating a program evaluation that includes family input. Using the data collected, or projected, to adjust practices based on the changing needs of families and providers (Dinnebeil, Hale, & Rule, 1999; Mandell & Murray, 2009) would fall under the auspices of planning and forecasting also.

Organizing, commanding, and coordinating all focus on a clear sense of vision within the agency. Organizing is creating order for the materials and personnel of the organization (Fayol, 1916/1949). It enables the efficient, smooth operation of the institution. A clear vision that unifies the agency, defines responsibilities, identifies structure for the work that needs to be accomplished, as well as specifies expectations, policies, and procedures, are part of an administrator's role in organizing an institution. Managers command by ensuring that staff are performing the tasks assigned to them, according to Fayol (1916/1949). Delineating goals, developing a clear plan of action,

providing leadership, instilling a sense of purpose, and ensuring the organizational

structure matches the efforts of the agency and staff, are all tasks associated with

commanding. To coordinate is the administrator's role of bringing together the actions

and labor of the organization by orchestrating all staff so everyone is united in a common,

shared effort that is recognized by all facets of the institution (Fayol, 1916/1949).

Within an Early Intervention program, organizing, commanding, and coordinating

are overlapping functions in many respects. All involve a unified focus, clear mission,

and an operational emphasis that is governed by a philosophy of family-centered care that

is infused throughout the agency (Dinnebeil, Hale, & Rule, 1999, Walter & Petr, 2000).

Creating policies and practices that support practitioners in providing family-centered

services to families (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Henneman &

Cardin, 2002) would be an example of Fayol's (1916/1949) principles of organizing,

commanding, and coordinating. An organizational culture that exudes family-centered

care is created when systems that permeate the agency are in place to support

practitioners in delivering family-centered programming, with the focus and sole mission

of the agency being to provide quality family-centered care. It is also analogous to the

sense of clear vision that Epley (2010) and her colleagues, Bailey, McWilliam, and

Winton (1992), and Sandall, McLean, and Smith, (2000) emphasize as important to the

delivery of family-centered care in Early Intervention.

Control is the managerial role of maintaining order (Fayol, 1916/1951).

Conformity and following established rules are necessary for the smooth operation of an

agency. Therefore, it is the administrator's responsibility to oversee and inspect the daily

work of staff. The hope would be that with effective leadership, or command, less

control would be needed. An example of implementing control, under Fayol's (1916/1949) model, would be creating a personnel policy manual with clear expectations for staff and just sanctions that are equally applied. Control could be viewed, in essence, as the culminating task of forecasting, organizing, commanding, and coordinating. If a leader were effective in those areas, then controlling would, ideally, be a minimal part of the work responsibilities of an Early Intervention program administrator.

Principles of Management

Based on his personal experience, Fayol (1916/1949) identified 14 general principles of management. He did not believe the principles were permanent, universal, or finite. The 14 principles are as follows: (1) division of work, (2) authority, (3) discipline, (4) unity of command, (5) unity of direction, (6) subordination of individual interests to general interests, (7) remuneration, (8) centralization or decentralization of power, (9) scalar or hierarchical chain of communication, (10) order, 11) equity, (12) stability of tenure, (13) initiative, and (14) morale. In Early Intervention, many of these principles are related and consequently can be grouped together.

Division of labor is simply specialization of tasks and roles. That occurs naturally in Early Intervention with each practitioner, such as a special educator providing the tasks required of special education or a physical therapist providing the services specific to physical therapy. This principle applies to the role of an administrator as well. The basis of Fayol's (1916/1949) philosophy is that the job of a manager requires a unique skill set and training, a notion that Johnson and his team (1992) echo by proclaiming that administrators of Early Intervention programs require specialized training due to the technical rules and regulations associated with Early Intervention, interpersonal skills

involved in the position, as well as the need to keep abreast of best practice standards in the field. These proficiencies are in addition to the responsibilities associated with the daily operation of organizations, as well as ongoing programmatic leadership of the agencies they oversee (Johnson et al., 1992). Specialized training allows for administrators to perform the unique tasks prescribed by their roles and demonstrates the need for division of labor under Fayol's (1916/1949) framework.

Authority, discipline, equity, and order are elements of effective managers, regardless of the company type. Authority means that the administrator accepts responsibility for giving directives in addition to actually giving instructions. Giving instructions is easy; accepting responsibility for those orders is another matter. Equity requires managers to treat staff with kindness and fairness. Discipline is simply enforcing policies of the organization uniformly, justly, fairly, and with consequences appropriate to infractions. Authority, equity, and discipline are closely connected and require the use of interpersonal skills which, according to Johnson and his colleagues (1992), are skills needed for effective Early Intervention administrators. Order involves systemic social and material organization, meaning every employee and object has a place which needs to be maintained throughout the institution for the institution to operate efficiently and smoothly.

Unity of command is Fayol's (1916/1949) concept that each staff member should be responsible for reporting directly to only one supervisor. Having a mentor or a clinical supervisor from whom to seek guidance would be an example of this in Early Intervention. Mentorship and supervision improve the delivery of family-centered care

(Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Dunst, Trivette, & Deal, 2011; King et al., 1999, 2011).

Fayol's (1916/1949) principle of the unity of direction is having activities of the institution occurring with the same objective. This principle is similar to Fayol's (1916/1949) notion of subordination of individual interests to general interests, where the manager maintains the focus of efforts on the best interests and overall welfare of the organization. Having an agency with a unified focus of family-centered care that is infused throughout the agency from the administrator to the security personnel and buildings operations staff (Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002) demonstrates this concept. A consistent, single minded mission of providing family-centered care that governs all facets of the organization and its activities, thanks to the clear vision of a leader (Epley et al., 2010), would provide focus for an agency's activities. Fayol's (1916/1949) unity of direction is expressed when all systems of an agency are designed to support the provider and families in the delivery of family-centered services.

The principle of remuneration is monetary compensation for work performed, although Fayol (1916/1949) notes that no system of determining wages is ideal. Dunst (2012) and Bruder (2000) state that there are significant issues with the reimbursement system for Early Intervention, and those issues appeared before Public Law 99-457 was passed (Florian, 1995). Additionally, the limits of funding and the Early Intervention reimbursement system are often cited as barriers to the delivery of family-centered services (Bruder, 2000; Crais & Wilson, 1996; Dunst, 2012; O'Neil & Palisano, 2000; Perrin et al., 2007).

Centralization or decentralization of power in decision making depends on the nature of the organization, according to Fayol (1916/1949). Dinnebeil, Hale, and Rule (1999) as well as Walter and Petr (2000) contend that the practice of treating staff as competent, capable professionals will enhance family-centered service delivery in programs. Epley and her team (2010) note that an organizational climate that promotes family-centered care is one that encourages professional autonomy balanced with accountability. In addition, practitioners should be involved in the planning and decision making regarding staff development opportunities (Bailey, Mc William, & Winton, 1992; Campbell & Halbert; 2002; Garland & Linder, 1992). Garland and Linder (1994) as well as Sandall, McLean, and Smith (2000) assert that shared leadership is important for effective Early Intervention service delivery. All of these practices favor decentralization of power in Early Intervention programs, according to Fayol's (1916/1949) model.

Although hierarchical or scalar, communication is important, Fayol (1916/1949) recognized the significance of lateral communication also. Lateral communication and collaboration, both formal and informal, among staff impacts the delivery of family-centered care in organizations (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Garland & Linder, 1994). Epley and her team (2010) note the simple arrangement of office furniture enabled opportunities for informal staff collaboration and influenced the organizational climate of the agency by promoting a sense of teamwork among providers, thus impacting the delivery of family-centered services. Affording Early Intervention teams the opportunity to collaborate creates a synergistic effect, according to Garshelis and McConnell (1993). These examples of teamwork and staff collaboration demonstrate the importance of lateral communication under Fayol's (1916/1949) construct.

Stability of tenure involves carefully selecting staff with the intention of staff having long-term careers with the organization, according to Fayol's principle (1916/1949). Fayol (1916/1949) notes that because of the time, effort, and financial resources involved in training staff, there is an economic incentive for agencies to offer stability of tenure, which applies to Early Intervention programs also. Dinnebeil, Hale, and Rule (1999), as well as Epley and her colleagues (2010), stress the importance of vetting candidates based on personality traits and a belief system compatible with the delivery of family-centered services. Because many pre-service graduate and undergraduate programs are not adequately preparing graduates to provide family-centered care (Murray & Curran, 2008, Rupiper & Marvin, 2004; Sewell, 2012), the responsibility falls on agencies to provide staff training on how to the provide family-centered services. Interpersonal skills can be taught and family-centered practices can be learned (Dinnebeil & Rule, 1994; Dinnebeil, Hale, & Rule, 1996; McWilliam, Tocci, & Harbin, 1998), but imparting these skills and knowledge requires a long-term commitment and financial investment on the part of the administrator and agency. This coincides with Fayol's (1916/1949) idea of stability of tenure.

Regarding initiative, Fayol (1916/1949) explains although it may be uncomfortable and distressing, it is essential that managers support and welcome the inventiveness and creativity of staff. Applying Fayol's (1916/1949) principle of initiatives of staff to Early Intervention, the competencies, input, and preferences of staff should be accounted for in professional development opportunities (Dinnebeil, Hale, & Rule, 1999; Bailey, McWilliam, & Winton, 1992; Walter & Petr, 2000). Fayol

(1916/1949) contends that nurturing the initiatives of staff will lead to increased morale in the workplace.

Fayol's (1916/1949) principle of morale asserts that fostering a positive work environment will lead to increased productivity. In the case of an Early Intervention program, productivity involves services to families. Organizational climate has been shown to impact the quality of services provided (Denis & O'Connor, 2013; Epley et al., 2010; Law et al., 2003); thus, the organizational climate of the program impacts the family-centered care provided. Fayol (1916/1949) contends the manager is responsible for morale and climate of the organization.

Fayol's (1916/1949) model and theory demonstrate the essential nature and role that administrators have in the organizations they oversee. Administrators decide how an agency will be organized, the type of management style that will be employed, the vision for the agency, how to navigate the obstacles that impede the agency's operation, and other factors that influence the functioning of the agency. These decisions occur explicitly or implicitly. In the case of an Early Intervention program, these decisions impact the implementation of family-centered programming. Consequently, the trickle-down effect, reflective of top-down management illustrated by Fayol (1916/1949), is crucial to the delivery of family-centered services, as Dinnebeil, Hale, and Rule (1999) attest to in the following statement:

> If program personnel truly believe in collaboration and working with families, their behaviors as administrators, individuals and team members, and the manner in which their programs are organized and operated, will send a message that reflects these basic principles. This belief will be translated into . . . the support

and the respect the administrators give their staff, all of which affect the

individual relationship established with each family (p. 228).

The philosophy, polices, and practices of the program are determined by the program's

administrator, which influences the delivery of family-centered care. Effective leadership

impacts the quality of the services provided by an organization, according to Fayol

(1916/1949), which can be applied to the delivery of family-centered services provided

by an Early Intervention program (Epley et al., 2010; Garland & Linder, 1994;

Henneman & Cardin, 2002; Johnson et al., 1992; Mandell & Murray, 2009).

Synthesis of Literature Review

Several key factors were illuminated in this review of the literature. Specifically,

family-centered care in Early Intervention grew out of special education, even though the

precedent for the relationships between families and members of the education

community has not always been positive. In practice, family-centered care lacks basic

elements, such as a concise definition, standard set of guidelines for implementation, and

measure of outcomes, which negatively impacts the field. The basis of family-centered

care lies in the relationship between the provider and family. Additionally, and perhaps

most significantly, family-centered care has relevance to the field of education outside of

Early Intervention.

The role families had in their child's education changed dramatically in an

approximately 20 years period due to legislative initiatives and parental advocacy.

Families went from being bystanders and having no formal role in their child's education

prior to the passage of Head Start in 1965, to being the consumers of services with the

enactment of EAHCA Part H in 1986. During that time span, parents sat on policy

councils with Head Start, learned intervention strategies to use with their children with special needs from practitioners in model preschool programs under HCEEP, and partnered with school personnel concerning their children ages 3 to 21 with special needs when EAHCA was passed. Each change altered the nature of the relationship between professionals and families.

Although special education was born out of parent advocacy, the relationships between parents and members of the educational community have not always been harmonious. Acrimonious relationships frequently occur between school personnel and families instead of partnerships the EAHCA intended to create. With the EAHCA Part H amendment, Congress mandated that the staff of the educational system and families work more closely by shifting the focus of service delivery from a child under three with special needs to the family of the child under three with special needs. The new initiatives of Part H required families to be equal partners with educational professionals or for professionals to be agents of families (Allen & Petr, 1996; Crais, Roy, & Free, 2006; Dunst, 2000; Dunst et al., 1991), in regard to service delivery planning and decisions. This required a significant transformation in paradigm and practice from members of the education community and providers of services to young children with special needs. The model of service delivery outlined in IDEA, Part C, commonly referred to as Early Intervention, became known as "family-centered care."

Despite the extensive research illustrating its effectiveness, providing family-centered care is an elusive goal and is not delivered in all programs universally (Bailey et al., 1992; Bailey, Raspa, & Fox, 2012; Campbell & Sawyer, 2007; Dempsey & Dunst, 2004; Dunst, 2012; Law et al., 2003; Raghavendra et al., 2007). The use of family-

centered practices differs from setting to setting (Bailey, McWilliam, & Winton, 1992; Crais & Wilson, 1996; Dunst, Humphries, & Trivette, 2002; Kuo et al., 2012; McWilliam et al., 2000; Murphy et al., 1995; Thompson et al., 1997; Trivette et al., 1995). This may be attributable to the fact that at the most fundamental level, a universal definition of family-centered care does not exist (Allen & Petr, 1996, Bamm & Rosenbaum, 2008; Chong et al., 2012; Epley, Summers, & Turnbull, 2010, Murphy et al., 1992). Consequently, the definitions of family-centered care and use of the term have changed over time (Epley, Summers, & Turnbull, 2010). Additionally, there is no standard set of practices that constitute family-centered service delivery, consensus as to outcomes that should serve as a benchmark (Bailey, 2001; Mannon et al., 2006; Wang et al., 2006; Warfield et al., 2000) or instrument to measure quality of service or efficacy (Bailey, 2001; Bailey et al., 2006; Wang et al., 2006). This has created confusion and ambiguity for the field to the detriment of families.

The primary agenda for the field of family-centered Early Intervention, therefore, should be establishing a concise, transdisciplinary definition of family-centered care. Identifying an objective, standard set of characteristics that represent family-centered care and practices from a programmatic, administrative, as well as provider perspective, needs to take precedence also. After that has occurred, an objective instrument to assess program and provider quality in the provision of family-centered services must be developed; then outcomes appropriate to individualized family progress can be created and utilized. Until then, research will continue to focus on an assortment of family outcomes, which address the effectiveness of family-centered care from various perspectives as opposed to a unified point of measure.

How services are delivered in Early Intervention is more influential on outcomes than what services are provided (Dunst, Hamby, & Brookfield, 2007; Dunst, Hamby, & Trivette, 1996, 2007; Thompson et al., 1997). This reinforces the concept that the crux of family-centered care resides in the relationship between providers and families (Brinker, 1992; Dunst, Trivette, & Hamby, 1996; Minke & Scott, 1995; Peterander, 2000; Trute & Hiebert-Murphy, 2007; Zhang, Bennet, & Dahl, 1999). Therefore, the role of Early Intervention programs should be to build and sustain the relationships between providers and families in the delivery of family-centered services. This occurs through policies and practices that support providers in delivering, and enable families to receive, family-centered services. Consequently, all policies and practices of Early Intervention agencies should be designed with the focus and intent of supporting the delivery of family-centered care (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Henneman & Cardin, 2002). The explicit or implicit policies and practices of an organization originate with the administrator of the organization.

The results of the limited research on the role administrators have in the delivery of family-centered services underscores the direct impact that administrators have in the implementation of family-centered programming (Epley et al., 2010; Mandell & Murray, 2009). Administrators of agencies have a wide, pervasive, and far-reaching influence on the delivery of family-centered services. Program administrators need to provide a clear vision and leadership; an organizational climate that fosters collaboration, autonomy, and accountability; and an efficient use of their resources to provide quality family-centered programming (Epley et al., 2010). Practices and policies that support the delivery of family-centered care should be infused throughout every aspect of an agency and with all

personnel (Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002; King et al., 1998; Mandell & Murray, 2009).

The philosophy and culture of a program, in addition to the policies and practices of the organization, are channeled through the agency's administrator. The breadth and scope of this influence of an administrator attests to the level of administrative and programmatic commitment required to deliver family-centered services. It is the role of the administrator to ensure that the mission, policies, practices, philosophy, and orientation of the program revolve around the provision of family-centered care and support providers in that task. Consequently, the responsibility for prioritizing and setting the tone for delivering family-centered programming rests with the administrator of the program, as the administrator, explicitly or implicitly, sets the tone and priorities for the agency. Every facet of a program's administration and operation influences the delivery of family-centered services.

Fayol's (1916/1949) classical administrative theory provides a lens to understand the influence that administrators have in delivering family-centered programming. Fayol (1916/1949) contends that managers control, coordinate, organize, plan, and command organizations, and the effectiveness of the manager leads to the success of the institution. This applies to Early Intervention programs delivering family-centered services as well. Skilled, competent, effective, and adequately trained administrators can lead Early Intervention programs that successfully provide family-centered programming.

Delivering family-centered services involves confronting a multitude of barriers. The implication of barriers to providing family-centered care is that families are not receiving the standard of family-centered programming they should and deserve to be,

which impacts the efficacy of the program as well as outcomes of families. These barriers are likely the reason why most policies and practices are not family-centered (Dunst et al., 1991); many programs do not provide the level of family-centered care they claim to (Dempsey & Carruthers, 1997; Dunst, 2002; Dunst et al., 1991; Mahoney & Filer, 1996; Mandell & Murray, 2009; Minke & Scott, 1995; Roush, Harrison, & Palsha, 1991), and most Early Intervention programs deliver family-allied and family-focused services, rather than family-centered programming (Dunst, 2002; Mahoney & Filer, 1996; Mahoney & O'Sullivan, 1990; McBride et al., 1993). Whether the reasons involve factors internal to an agency or external to an organization, barriers to implementing family-centered services will always exist. The issue becomes how those obstacles are dealt with by program administrators. Will the hindrances be ignored, accepted as fact and used as an excuse, or accounted for by adapting or adopting program practices and policies to reflect ways to adjust to the obstacles? Again, that power of how to face the challenges lies with the administrator of the program.

Last, family-centered care is not only relevant to the discipline of Early Intervention but to the field of education as well. Although family-centered care is, at present, only mandated as a service delivery approach in Early Intervention, it has the potential to be a model for developing collaborative partnerships with families throughout elementary and secondary schools. Parental involvement improves academic achievement (Al-Shammari & Yawkey, 2008; Edwards & da Fonte, 2012; Jeynes, 2005, 2012; Spann, Kohler, & Soenksen, 2003; Tucker & Schwartz, 2013), and schools are continually seeking programs and methods to increase parental involvement (Blue-Banning et al., 2004; Coots, 2007; deFur, 2012; Edwards & da Fonte, 2012; Howland et

al., 2006; Osher & Osher, 2002; Staples & Diliberto, 2010; Valle, 2011). A family-centered model may hold that key to bolstering parental involvement and thus academic achievement for students. If families develop the ability to engage in collaborative partnerships, based in a family-centered approach with the professionals from the onset of a child's educational career and while the family is enrolled in Early Intervention, then the foundation for ongoing collaboration with members of the educational community has been set (Blue-Banning et al., 2004; Dinnebeil, Hale, & Rule, 1999; McBride et al., 1993; Summers et al., 1993; Thompson et al., 1997). This only heightens the importance of implementing and delivering quality family-centered programming in Early Intervention, thus enabling families to carry over the skills they developed to form collaborative partnerships with providers while enrolled in Early Intervention to other professionals in their child's educational career.

Yet, the arena of administrative influence on the delivery of family-centered programming remains largely untapped. The intent of this study was to contribute to this discourse by further investigating the role administrators have in delivering family-centered Early Intervention services. The purpose of this study was to explore how administrators of New York City Early Intervention programs conceptualized and implemented family-centered care by examining the administrators' definition and purpose of family-centered care, identified challenges to delivering family-centered services, ways the obstacles were negotiated, and how those factors impacted the implementation of family-centered programming.

CHAPTER 3

METHODOLOGY

This qualitative case study examined how New York City Early Intervention program administrators defined and viewed the purpose of family-centered care, what challenges they identified to delivering family-centered services, and the way the obstacles were negotiated, as well as the how those factors impacted the implementation of family-centered programming. A web-based questionnaire was used to accrue narrative and demographic data. The questionnaire was emailed to 100 site administrators of the 93 Early Intervention programs serving the families of New York City, and 21 questionnaires were completed. Questionnaire completion was anonymous. The data were analyzed utilizing descriptive statistics and the general steps of qualitative data analysis, which included organizing the collected data, coding the data, analyzing the codes for themes, formulating generalizations, preparing the data for dissemination, and drawing conclusions (Creswell, 2003, 2008).

Research Design

This project was a qualitative case study. Qualitative research employs both inductive and deductive reasoning strategies. It is constructionist, with the intent of the research being to develop an understanding of the experiences of others, based on the responses of participants (Creswell, 2003).   Yin (2009) explains, "A case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within real-life contexts, especially when the boundaries between the phenomenon and context are not clearly evident" (p. 18). Cases can be an individual(s), program(s), institution(s), group(s), situation(s), event(s), or process(es) that is separated by time, space, or other

physical boundaries (Creswell, 2008; Krathwohl, 1998). The boundaries provide the

context and perspective from which to identify, frame, and observe a case (Creswell,

2008; Krathwohl, 1998).

This project was an exploratory, holistic, single-case study. Case studies are

employed to illuminate a problem (Creswell, 2003; Krathwohl, 1998), with exploratory

case studies serving to explain "operational links" in "contemporary events" (Yin 2009,

p. 9). Consequently, exploring how administrators conceptualize and implement family-

centered care falls within the parameters of a case study design. A case study is holistic

when there are no subunits of analysis (Yin, 2009). Single-case studies examine one

case, whereas multiple-case studies observe more than one case (Yin, 2009). Case

studies are intended to compare results with and build upon existing theories,

propositions, and existing literature (Yin, 2009).

Participants

The site directors of 133 different sites providing Early Intervention services to

the families of the five boroughs of New York City were invited and encouraged to

participate in this project. When the site administrators were initially contacted via

telephone to confirm their email addresses, several site administrators indicated that it

would be more appropriate for one site director to be the contact person for their agency,

which had multiple sites, and such requests were respected. These requests reduced the

potential number of participants from 133 to 100 site administrators. Additionally, if at

any time during the process of contacting agencies or reminding administrators of the

study, a program or administrator indicated by phone or by email that he or she was not

interested in being contacted about this study, such requests were respected.

New York City Early Intervention site administrators were chosen as the cases for this project due to the unique features of New York City and its Early Intervention system. Because New York City is the most populated city in the United States, it was assumed to have the largest number of children aged birth to three years with special needs eligible for Early Intervention services as well as the largest Early Intervention system of any city in the United States. In turn, it was presumed there were a large number of agencies that provided services to these families, thus offering a large potential number of study participants for this project.

Early Intervention services are provided to families in New York City through community based organizations that are awarded contracts by the New York City Department of Health and Mental Hygiene Bureau of Early Intervention.   The structure and organization of each agency is determined by the agency itself, which creates tremendous diversity and heterogeneity in the institutions that deliver Early Intervention services in New York City. Table 2 describes the potential organizational variables for agencies providing Early Intervention services to families who reside in New York City.

Table 2

New York City Early Intervention Agency Variables

Potential Early Intervention Agency Variables

- ❖ Agency Type:
  - o Part of a larger organization that provided other services (eg. hospital or Easter Seals)
  - o Stand alone agency that provided only Early Intervention services

- ❖ Profit Status:
  - o For-profit
  - o Not-for-profit

- ❖ Services Provided (one, all, or a combination of):
  - o Evaluations for eligibility
  - o Service Coordination, similar to case management
  - o Home-based services
  - o Center-based services, where children attend the program without a caregiver

- ❖ Geographic Area Served (one, all, or a combination of):
  - o Bronx
  - o Brooklyn
  - o Manhattan
  - o Queens
  - o Staten Island

- ❖ Population Served:
  - o Children with specific diagnoses only (eg. diagnoses along the continuum of Autism Spectrum Disorders, hearing loss)
  - o Children regardless of diagnosis

As of July 11, 2012, there were 97 agencies awarded contracts by the New York City Department of Health and Mental Hygiene Bureau of Early Intervention to provide Early Intervention services to families of the City on New York at 139 different sites, as identified by the publically available *NYC Early Intervention Program Contracted Providers & Services Directory*. Four programs ceased operating between July 2012 and July 2013, when this research project was initiated. The four programs that stopped providing Early Intervention services operated six sites, reducing the potential cases to 133 site administrators, and 93 agencies.

96

Questions and Selection Criteria

The questionnaire created for this project was divided into two sections. The first section was eight open-ended and multiple-choice questions that were separated into three categories, which corresponded to the research questions for this project. Table 3 lists the research questions and corresponding questions from the first section of the questionnaire used to answer the research questions. The question about the practices and policies that represented ideal family-centered care was the last question of the first section of the questionnaire so that the participants' responses to the questions concerning the policies and practices implemented in their programs did not influence or bias their responses to what represented ideal family-centered care. Questions 4 and 8 were "value based questions [which] were included to increase the likelihood of capturing accurate accounts of the participants' understanding of the construct" of family-centered care (Mandell & Murray, 2009, p. 22). The second section of the questionnaire consisted of demographic questions about the administrator, site, and agency.

Table 3

Research Questions and Corresponding Questions from Questionnaire

RESEARCH QUESTIONS	QUESTIONS FROM QUESTIONNAIRE	RESPONSE FORMAT
How did administrators of New York City Early Intervention programs define family-centered care and its purpose in the delivery of services to families who have children under three with special needs?	1) What is your definition of family-centered care? 2) What is the purpose of family-centered care in Early Intervention?	Open response Open response
What barriers did administrators of New York City Early Intervention programs identify to delivering family-centered services, and how did they respond to those challenges?	6) What barriers do you face to implementing family-centered care? 7) How do you respond to the challenges?	Multiple choice (option to add responses) Open response
How did an administrator's definition of family-centered care and its purpose impact the implementation of family-centered programming?	3) What practices are implemented in your program?	Multiple choice (option to add responses)

	4) What policies are in place at your program?	Multiple choice (option to add responses)
	5) What is the most valuable family-centered practice your program provides to families?	Open response
	8) What 6 policies and practices represent ideal family-centered care?	Multiple choice

It should be noted that many of the questions in this questionnaire are related to the questions from the Mandell and Murray (2009) study, the only study focusing specifically on an administrator's role in the implementation of family-centered care. The aim of Mandell and Murray's (2009) study was to assess an administrator's understanding of family-centered care, the interplay between an administrator's understanding and the support offered to families and staff in delivering family-centered services, as well as the role of early professional experiences in an administrator's understanding of family-centered care. Mandell and Murray (2009) developed their interview questions from a broad base of literature. Their intent was to assess their research goals by asking questions of their participants from multiple perspectives. The focus of the questions asked by Mandell and Murray (2009) was to assess what family-centered care represented to the administrators, how their programs support families and providers, to identify policies and procedures that facilitated the delivery of family-centered services, and to identify barriers to implementing family-centered programming. Although the intent of this research project was not to ascertain administrators' understandings of family-centered care, there are many parallels in the premise of this work to that of Mandell and Murray (2009). For example, both endeavors addressed an administrator's role in delivering of family-centered services, examined policies and practices of programs, as well as barriers in providing family-centered programming.

98

Consequently, many of the interview questions asked by Mandell and Murray (2009) were used as a basis for the questions asked in the questionnaire developed for this study. The questionnaire used for this project, found in Appendix A, lists the literature citations for all of the questions posed, as well as for the multiple-choice options provided.

Question Validity

The questionnaire was pilot tested by a panel of five former administrators of programs that offered Early Intervention services in New York City. In addition to responding to the questionnaire, the panel members were asked to provide insight and feedback regarding the overall clarity of the questions, length of time it took to respond to the questions, and suggestions for improving the questionnaire. Their feedback was incorporated into the construction and design of the questionnaire.

Data Collection Procedures

Upon receipt of approval from the Institutional Review Board of Seton Hall University (Appendix E), an email of solicitation to participate in this research project (Appendix B) was sent to the email addresses of the 100 site administrators who expressed interest in participating in the study, the morning the website hosting the questionnaire was active. The email informed the site directors of the project, explained the goal of the research, directed the administrators to the web address of the study, and provided the password needed to enter the questionnaire directly.

The questionnaire was hosted by ASSET (Academic Survey and Evaluation Tool), the secure online survey program created by Dr. Bert Wachsmuth, Chair of the Department of Mathematics at Seton Hall University. ASSET was developed for the purpose of creating and hosting academic web-based surveys and questionnaires.

Questionnaire completion was anonymous. In order to participate in the study, respondents had to access the ASSET web page dedicated for the questionnaire by linking to the specific website, then type a specified password to enter the questionnaire itself. Consequently, consent and agreement to participate in the study was implied when the participants connected to the ASSET webpage designated for this project, typed the designated password, and completed the questionnaire.

On the seventh business day after the website for the study was operational, and after the initial email had been sent to the site administrators, a telephone call was placed to each site reminding the site administrators of the study (see Appendix C). It should be noted that a research assistant was procured solely for the purpose of placing all telephone calls for this study. On the same day, subsequent to the phone calls to each organization, an email was sent to the site administrators, thanking participants for their participation. This email was also intended to serve as an additional reminder of the study for potential respondents who had not yet completed the questionnaire (Appendix D). The following week, week three of the study, the same email was sent again (Appendix D). Week 4 of the study, an additional reminder phone call was placed, followed by the email that had been sent previously during week two and week three of the study (Appendix D). In total, the initial email of invitation was sent, followed by two telephone calls and three emails that served as a thank you to respondents for participating or as a reminder to administrators that the study was still in progress.

To maintain the integrity of the data, only the researcher had access to the password used to maintain the data for ASSET. Once the questionnaire website was closed, the results were downloaded onto a USB data memory stick. A sole copy of the

data was maintained by the researcher on a USB data memory stick in the researcher's home. Data were stored in a safe in the researcher's home for a period of three years. Questionnaire completion was anonymous, and no identifying information was revealed in the responses.

Within the framework of qualitative data analysis (Krathwol, 1998; Leedy, 1998; Creswell, 2003, 2008), data organization began once the questionnaires were completed; the researcher did wait until the end of the data collection period to initiate data organization.

<p style="text-align:center">Data Analysis Procedures</p>

The data were examined following the six stages of qualitative data analysis protocol as outlined by Creswell (2003, 2008). Qualitative analysis methodology is a process in which collected data are organized, read through, and coded; codes are then collapsed into themes, the data are prepared for written as well as visual presentation, and interpretations are formulated (Creswell, 2003, 2008). Qualitative data analysis is a systematic approach and process. The process of analyzing the data is interactive, involving interplay between the data and researcher (Corbin & Strauss, 1998). Qualitative data analysis is a "non mathematical process of interpretation carried out for the purpose of discovering concepts and relationships in raw data and then organizing these into a theoretical explanatory scheme" (Corbin & Strauss, 1998, p. 11). The interpretive strategy of inquiry involves the researcher delving deeply into the data for meaning and understanding (Creswell, 2003, 2008).

The initial step of qualitative data analysis is organizing and preparing the data for analysis, which occurs once the data are collected (Creswell, 2003, 2008). In a

qualitative study, a researcher typically amasses a large quantity of raw data that needs to be systematically stored and managed. How the data are organized and prepared is based on the preference of the researcher. Computer programs, cutting and pasting, and color coding are examples of ways that researchers can sort through and prepare data for analysis. In this study computer software was not utilized to analyze collected data; however, data were organized using a multi-tier system. Respondents were assigned a number, based on the questionnaire return order. Large segments of data were cut into smaller segments and pasted onto index cards. During the coding process, data codes were pasted onto separate index cards and then organized, using a color coding system. Colors were used to indicate various codes as well as categories.

After the data are prepared, the data are read through in their entirety to ascertain overall meanings and general impressions of the material (Creswell, 2003, 2008). All the while, the researcher reflects on the data, making notations, referred to as memos, of insights or observations that arise from reviewing the material (Corbin & Strauss 1998; Creswell, 2003, 2008; Glaser & Strauss 1967). Memoing is a process that occurs throughout every stage of data collection and analysis. Specifically, memos are written notes that record the analysis, descriptions, thoughts, directions, reactions, progress, reflections, or conceptualizations of the researcher. Diagrams can be used in much the same way (Corbin & Strauss 1998; Glaser & Strauss 1967). Memos and diagrams take on various formats and tend to increase in conceptual depth and complexity as the researcher is immersed in data analysis (Corbin & Strauss, 1998).

The next step in qualitative data analysis is to code the data. "Coding is the process of segmenting and labeling text to form descriptions and broad themes in the

data," according to Creswell (2008, p. 251). When coding, the researcher searches for repetitious elements in the data to uncover links that will provide a structure for connections in the data and concepts (Krathwohl, 1998). The basis of coding is a continuous process of comparing data segments and codes (Leedy, 1998). During coding, researchers read through the data, microanalyze the data line by line or word for word, dissect large sections of data into smaller pieces, and examine the data for patterns, repetitions, similarities, and differences. The codes are assigned labels to describe the concept or given an *in vivo* label, taken as a quote from the participant's responses (Corbin & Strauss, 1998; Creswell, 2008). Codes can be predetermined from the literature, as opposed to being created solely from the raw data (Creswell, 2003).

For the purpose of this study, a combination of codes predetermined from the literature, in addition to codes identified from repetitious elements and patterns identified from the data, were utilized. The 10 key concepts of family-centered care, as outlined by Allen and Petr (1996), provided the foundation for the initial codes for responses to Question 1 of the questionnaire. Those 10 concepts, abbreviated into codes, are as follows: (1) family-focused, (2) partnerships, (3) family needs-driven, (4) individualized services, (5) family as decision makers, (6) strength-based, (7) respect culture, (8) empower families, (9) reduce institutionalization, and (10) normalization. For Question 2 of the questionnaire, the initial codes were taken from proposed family outcomes as specified by Bailey and his team (2006): (a) know child; (b) advocate (Bailey et al., 2005); (c) help child; (d) use support (Bailey et al, 2005; Dempsey & Keen, 2008; Dunst et al., 2006; Thompson et al., 1997; Warfield et al., 2000); (e) access services (Bailey et al., 2005; Dempsey & Keen, 2008; Raspa et al., 2010; Thompson et al., 1997; Warfield et

103

al., 2000); (f) child development; (g) parent satisfaction (Broggi & Sabatelli, 2010; Dempsey & Keen, 2008; Dunst et al., 2006); (h) parent empowerment (Dempsey & Dunst, 2004; Dempsey et al., 2009; Dunst & Dempsey, 2007; Thompson et al., 1997); (i) parent well-being (Dunst et al., 2006; Dunst, Hamby, & Brookfield, 2007; Dunst & Trivette, 2009b; McBride et al., 1993; Trivette, Dunst, & Hamby, 2010). For responses to Question 5 of the questionnaire, the initial codes utilized were based on the multiple-choice response options to Questions 4 and 6.

A code book was created as a reference for the codes used in this study. The code book included the label, definition, general description, possible subcodes, as well as inclusion and exclusion criteria for each code. Table 4 is an example code book entry for the family-centered care definition code of "family focus," as identified by Allen and Petr (1996).

Table 4

Sample Code Book Entry

LABEL	Family-focused
DEFINITION	Family as unit of attention in treatment or planning
GENERAL DESCRIPTION	Intervention, planning, and services are provided to the family as a whole, not just to the child
INCLUSION CRITERIA	Parents, siblings, caregivers, extended family/whole family included in treatment, session, planning, or intervention
EXCLUSION CRITERIA	• Only child is mentioned • Family, parents, siblings, caregivers, extended, or the whole family were not mentioned
POSSIBLE SUBCODES	• Specific roles of family members • Family constellation defined by family • Cultural implications of family in service delivery • Participation of the entire family • Negotiating needs of individual family members (difficulty)

The goal of coding is to "make sense out of text data, divide it into text or image segments, label the segments with codes, examine codes for overlap and redundancy, and

collapse the codes into broad themes" (Creswell, 2008, p. 251). Hence, the next phase of qualitative data analysis is to reduce the number of codes into themes or categories (Creswell 2003, 2008). Creswell (2008) notes "themes are similar to codes aggregated together to form a major idea in the database, they form a core element in qualitative data analysis" (p. 256). Codes that are closely related or have similar properties or characteristics are merged to form themes. After all of the themes are identified and relevant data categorized, in other words, the themes are saturated (Corbin & Strauss, 1998; Creswell, 2008; Glaser & Strauss, 1967) the research is prepared for dissemination.

Preparing the data for presentation, the subsequent step of qualitative data analysis, involves formulating a cohesive written, as well as visual, representation of the material (Creswell, 2008). The researcher creates visual displays, such as charts, graphs, diagrams, and matrices of the concepts discovered during the research process, in addition to the written narrative. The process of formatting the detailed written summary of the findings begins with organizing the materials into an unified, understandable narrative that is valid and reliable under the guidelines of qualitative research.

The final step in the process of qualitative data analysis is to draw conclusions from the data (Creswell, 2008). The researcher reflects upon the meaning of the data and findings in relation to existing literature, theories, or practices of the field (Creswell, 2008). Specifically, interpretations are made regarding how the results correspond with, connect to, add to, or challenge existing literature in the field. It is the cumulative process of the project.

In addition to qualitative data analysis, descriptive statistical analysis was conducted on the data collected as well. This data included the multiple choice responses

to the first section of the questionnaire as well as the second section of the questionnaire, which asked demographic questions of the respondents and their agencies.

Demographic Information of Respondents

Out of the 100 site administrators who expressed an interest in participating in this study, 21 completed the questionnaire.

Participants

The participants came from a variety of human service backgrounds, but the majority of respondents had a background in education. Most of respondents with a background in education reported training in special education and educational administration and supervision. Table 5 lists the professional backgrounds for the respondents of this study. The percentage totals exceed 100% because respondents reported backgrounds in multiple fields; for example, special education and clinical psychology. Seventy percent of the respondents with a background in education, or 33.32% in total, possessed a New York State Education School Leadership and Administration (NYSESLA) certificate. All of the participants had earned a master's degree, and 19.04% had earned doctoral degrees. Regarding training in family-centered care, 95.2% of the participants reported having received their training from work experience, 85.86% from professional development opportunities, 52.36% from life or personal experiences, 33.32% from college coursework, and 14.28% from intensive certificate-based training programs.

Table 5

Respondents' Professional Background

Professional Background	% of Total
Education	47.6
• Special Education	33.32
• Early Childhood Education	9.52
• Infant/Parent Development & Early Intervention	9.52
• Educational Administration & Leadership	33.32
Social Work	23.8
Clinical Psychology	19.04
Occupational Therapy	4.76
Physical Therapy	4.76
Speech/Language Pathology	4.76
Public Health	4.76

Table 6 shows the range and mean years of experience the respondents worked as administrators in Early Intervention as well as in Early Intervention prior to becoming administrators of a program. Although 23.8% of the respondents had three years experience or less as administrators of an Early Intervention program, 57.12% of participants reported having 10 or more years of experience. Similarly, 9.52% of respondents reported two years experience working in Early Intervention, whereas 85.68% of the participants had 10 or more years of experience working in Early Intervention. Data revealed that 42.84% of the administrators had no prior experience working in Early Intervention before becoming program administrators. For the respondents who had previous experience working in Early Intervention before becoming program administrators, the mean number of years they worked in Early Intervention prior to becoming administrators was 8.17 years, and the range was two to 17 years.

Table 6

Range and Mean Years of Experience

	Worked as Administrators	Worked in Early Intervention	Worked in Early Intervention Before Becoming Administrator
Range	1 to 20 years	2 to 33 years	0 to 17 years
Mean	10.33 years	15 years	4.67 years

Organizations

Respondents were asked a series of demographic multiple-choice questions regarding the numbers of families served in their site and agency, the number of staff employed at their site and agency, their supervisory practices, and professional development practices. The participants reported that the number of sites at which the agency that employs them provides Early Intervention services ranges from one to six. The majority of the agencies, 61.88%, had more than one site, with the mean being 2.333 sites per agency. Table 7 supplies the number of families of the City of New York to whom Early Intervention services were provided annually, based on the respondent's site and the multiple locations of the agency by which the respondent was employed.

Table 7

Families Served Annually

# of Families	% At the Site	% By the Agency*
>50	19.04	
51 to 100	23.8	7.69
101 to 250	33.32	30.76
251 to 500	14.28	23.07
501 to 750	9.52	
751 to 1000		38.45

Note: *of the 61.88% of respondents who worked for organizations that provided services at more than one location

Participants were asked about staffing patterns, including staff retention rates, the number of full-time and part-time direct service providers that work both at the site for

which the administrator was responsible, as well as the agency by which they were employed. A staff retention rate of 90% or above was reported by 57.12% of participants, with a range of 75% to 100%, and a mean of 86.62%. Table 8 displays the data of full-time and part-time or per-diem direct service providers, such as special instructors or physical therapists employed at a site and by an agency with multiple service locations.

Table 8

Percentage of Full-Time and Part-Time Staff Employed

# of Staff	% FT at Site	% PT at Site	% FT with Agency*	% PT with Agency*
>10	76.16	42.84	23.07	7.69
11 to 25	19.04		23.07	7.69
26 to 40	4.76	4.76	15.38	
41-60		9.52		7.69
61-75		4.76	7.69	
76-90		4.76		
91+		33.32	30.76	76.9

*of the 61.88% of respondents who worked for organizations that provided services at more than one location

Administrators were asked if their organization offered services other than Early Intervention and what Early Intervention services their agency provided. Other services, in addition to Early Intervention, were offered by 80.92% of programs. Evaluations, service coordination, home-based services, and center-based services were offered by 42.84% of the programs, whereas 9.52% of the participants oversaw programs that offered only one service, evaluations. In total, 85.68% of the sites provided evaluations, 71.4% service coordination, 80.92% home-based services, and 61.88% center-based services.

Participants were asked how frequently they held case conferences, staff meetings, professional development sessions, and staff observations, as well as whether

supervision or mentoring was offered to staff and if monies were available for staff to attend training off-site. Funding for staff to attend training off-site was available in 57.12% of programs. Supervision or mentorship was offered to staff in 76.16% of programs. Table 9 lists the data regarding the frequency of case conferences, staff meetings, and professional development opportunities, as well as the frequency that center-based and home-based providers were observed.

Table 9

Professional Practices and Frequency

Frequency	Case Conference	Staff Meetings	Professional Development	Observe Staff Center-Based	Observe Staff Home-based
Weekly	9.52%	4.76%	4.76%		
Monthly	19.04%	57.12%	14.28%	46.69%	5.88%
Quarterly		9.52%	33.32%	13.34%	17.64%
Twice a Year		4.76%	19.04%	6.67%	23.52%
Annually			4.76%		
As Needed	33.32%	9.52%	23.8%	13.34%	41.16%
Not At All	38.08%	14.28%		20.01%	11.76%

Profit Status

In regard to profit status, 61.88% of the programs were not-for-profit, and 38.08% were for-profit. Several differences were noted regarding the profit status and characteristics of the agency regarding agency size, staffing retention rates, professional practices, and administrator characteristics. Of the programs that served 751 to 1,000 families each year, 80% were for-profit organizations. Of the agencies that provided solely Early Intervention services, all were for-profit programs. Of the 23.8% of programs that did not offer supervision or mentorship to staff, 60% were for-profit agencies. Of the 23.8% of organizations that did not hold staff meetings, or only did so on an as-needed basis, 60% of those agencies were for-profit. Of the 23.8% of agencies that held professional development opportunities on an as-needed basis, 80% were for-

profit programs. Of the agencies which provided home-based services that observed their

providers on an as-needed basis, 56.16% were for-profit programs. Table 10 shows other

differences in programs based on profit status.

Table 10

Differences Based on Program Profit Status

Characteristics of Program & Administrators	For-Profit	Not-for-Profit
Mean Service Sites	3.375 sites	1.83 sites
Range Staff Retention Rates	75% to 90%	80% to 100%
Mean Rate Staff Retention	82.5%,	89.153%
Administrators with Education Background	37.5%	53.83%
Administrators with NYSESLA certificate	25%	38.45%
Received family-centered training in college/intensive training programs	37.5%	46.14%
Mean Years Experience as Administrators	9.5 years	10.85 yrs
Range Years Experience as Administrators	1 to 20 yrs	2 to 20 yrs
Mean Years Experience in Early Intervention	15.62 yrs	14 yrs
Range Years Experience in Early Intervention	6 to 20 yrs	2 to 33 yrs
Mean Years Experience Before Becoming Administrator	4.5 yrs	4.76 yrs
Range Years Experience Before Becoming Administrator	0 to 13 yrs	0 to 17 yrs

The majority of the participants had a background in education. The respondents

had, on average, more than 10 years experience as administrators and 15 years of

experience working in Early Intervention. In most programs, staff meetings took place

monthly, professional development quarterly, and case conferences were not held. More

than 75% of programs offered supervision and mentoring to staff, however, one-third of

center-based and more than half of home-based programs did not regularly observe staff.

The data suggest slight variances between the organizational infrastructures and

characteristics of administrators employed in for-profit versus not-for-profit programs.

Summary

This qualitative, exploratory, holistic case study was designed to explore New

York City Early Intervention program administrators' definitions and viewed purpose of

family-centered care, and identified barriers to providing family-centered services and

how the challenges were managed in order to determine how those perceptions and obstacles impacted the delivery of family-centered programming. A web-based questionnaire was created and used to elicit narrative and demographic data for this project. Out of 100 New York City Early Intervention site administrators invited to participate, via four emails and two follow-up telephone calls, 21 completed the questionnaire. All of the respondents in this study had a background in Human Services, and most were experienced in the field of Early Intervention and as program administrators. Descriptive statistics and qualitative data analysis, as outlined by Creswell (2003, 2008), were utilized to analyze the data collected. This is a process of comparative data analysis that entails organizing the collected data, coding, merging codes into categories, identifying themes from categories, preparing the data for presentation, and forming generalizations from the categories and data (Creswell 2003, 2008).

CHAPTER 4

PRESENTATION OF DATA

Administrators of New York City Early Intervention programs were invited to participate in this project to further examine the role administrators have in the delivery of family-centered services. The purpose of this project was to explore how administrators of New York City Early Intervention programs conceptualized and implemented family-centered care by examining the administrators' definition and purpose of family-centered care, identified challenges to delivering family-centered services, ways the obstacles were negotiated, and how those factors impacted the implementation of family-centered programming. This qualitative case study utilized a web-based questionnaire composed of a series of multiple-choice and open-ended questions to elicit narrative and demographic data from participants. The following research questions were addressed in this project:

1. How did administrators of New York City Early Intervention programs define family-centered care and its purpose in the delivery of services to families who have children under three with special needs?

2. What barriers did administrators of New York City Early Intervention programs identify to delivering family-centered services, and how did they respond to those challenges?

3. How did an administrator's definition of family-centered care and its purpose impact the implementation of family-centered programming?

Answer to Research Question 1

Administrators participating in this study were asked to define family-centered care as well as what purpose family-centered care served in Early Intervention. Many of the categories that emerged from coding the definitions of family-centered care in this study were similar to those identified by Allen and Petr (1996) and Epley, Summers, and Turnbull (2010). Table 11 lists the categories, codes that comprised the categories, and frequency with which the elements of the definition of family-centered care were represented in this study, as well as in the works of Allen and Petr (1996) and Epley, Summers, and Turnbull (2010).

Table 11

Definition of Family-Centered Care Categories, Codes, and Frequency of Elements

Category	Codes	Frequency of Element	Frequency in Allen & Petr (1996)	Frequency in Epley, Summers, & Turnbull (2010)
Family focus of intervention	• Entire family unit focus of service delivery • Include siblings & extended family in programming	33.32%	100%	Approximately 66%
Focus on child	• Intervention directed to child • Goal of services to enhance developmental potential or progress of child	66.64%	---	---
Family carryover of intervention strategies	• Providers instruct, coach, & train families how to implement intervention strategies • Families carry over intervention strategies outside of therapeutic sessions	23.8%	---	---
Natural environment	Child's everyday: • routines • activities • settings	14.28%	---	---
Family needs, priorities, & concerns	Goals based on family's expressed: • concerns • needs • priorities	23.8%	32%	---
Individualized family services	Services based on a family's unique: • background • culture	47.6%	32%	Almost 50%

	• circumstances • norms • dynamic • resources • support systems			
Family choice	Regarding decisions for planning & implementing services • families having sole decision making power • families involved in making decisions with Early Intervention providers	9.52%	29%	About 75%
Professionals & families working together	• Partnering with families • Including families • Involving families • Encouraging family participation	57.12%	36%	90%
Family support & empowerment	• Assisting families • Supporting families • Empowering families	23.8%	25%	Approximately 50%

Purpose of Family-Centered Care

      The categories that emerged from the administrators' viewed purpose of family-centered care were similar to the categories that were evolved from the respondents' definitions of family-centered care. The categories that developed from the participants' stated purpose of family-centered care were (a) professionals and families working together, (b) providers coaching families, (c) focus on the child, (d) natural environment of the family, (e) family carrying over intervention techniques, (f) supporting the family, and (g) strengthening the family's functioning. Table 12 displays the categories, codes, and frequency with which each aspect was mentioned in the respondents' stated purpose of family-centered care.

Table 12

Purpose of Family-Centered Care Categories, Codes, and Frequency of Elements

Category	Codes	Frequency of Elements
Professionals & families working together	• Partnering with families • Including families • Involving families • Encouraging family participation	38.08%

Strengthening family's functioning	• Empowering family • Enhancing ability of family to care for child	42.84%
Supporting family	• Assisting families • Supporting families	42.84%
Natural environment of family	Family's daily: • routines • activities • settings	33.32%
Coaching the family	Providers instructing, teaching, & training families how to implement intervention strategies	33.32%
Family carrying over intervention techniques	Families carry over intervention strategies outside of therapeutic sessions	47.6%
Focus on the child	• Intervention directed to child • Goal of services to enhance developmental potential or progress of child	71.4%

Definition and Stated Purpose of Family-Centered Care

In the combined responses to the questions regarding the definition and purpose of family centered care, 23.8% of respondents used the terminology or described the process of partnering with families. The themes that emerged from the combined definitions and viewed purpose of family-centered care were (a) focus on the child (95.2%), (b) parents and professionals working together (71.4%), (c) coaching families to carry over techniques into child's natural environment (66.64%), (d) providing individualized services to families (61.88%), and (e) supporting and strengthening families (57.12%).

Trends in Definition and Stated Purpose of Family-Centered Care

Several patterns became evident during the analysis of the respondents' definitions and stated purpose of family-centered care. Various factors appeared to influence an administrator's definition or stated purpose of family-centered care. Those factors were how the administrator received his or her training in family-centered care, the administrator's professional background, and the administrator's years of experience in the field. The patterns identified in the definitions and stated purpose of family-centered care are depicted in Table 13

Table 13

Patterns Identified in Responses to Definitions and Purpose of Family-Centered Care

Patterns Identified

- ❖ Training in Family-Centered Care
    - o Definition:
        - ▪ College coursework: Professionals & families working together (58.31%)
        - ▪ Life or personal experience: Natural environment (66.66%)
    - o Purpose:
        - ▪ College coursework: Professionals & families working together (62.5%)
        - ▪ Life or personal experience: Coaching the family (71.4%)

- ❖ Professional Background
    - o Definition
        - ▪ Education: Family as the focus of intervention (72.4%)
        - ▪ Special education: Professionals & families working together (85.68%)
        - ▪ Clinical psychology: Professionals & families working together (75.0%)
        - ▪ Doctoral degree:
            - • Focus on the child (100%)
            - • Family as the focus of intervention (75%)
            - • Family carrying over intervention strategies (75%)
    - o Purpose
        - ▪ Social work:
            - • Focus on the child (80%)
            - • Supporting the family (80%)
            - • Strengthening the family's functioning (80%)
        - ▪ Doctoral degree: Focus on the child (75%)

- ❖ Least Experienced
    - o Definition
        - ▪ Working in Early Intervention: Family support & empowerment (mean 11.2 yrs)
        - ▪ Administrators: Family support & empowerment (mean 4.6 yrs)
        - ▪ No prior experience working in Early Intervention before becoming administrators: Professionals & families working together (50%)
    - o Purpose
        - ▪ Working in Early Intervention:
            - • Professionals & families working together (mean 11.13 yrs)
            - • Strengthening a family's functioning (mean 11.44 yrs)
        - ▪ Administrators :
            - • Professionals & families working together (mean 6.15 years)
            - • Supporting the family (mean 7.33 years)
        - ▪ No prior experience working in Early Intervention before becoming administrators: Strengthening a family's functioning (66.66%)

- ❖ Most Experienced
  - o Definition
    - ▪ Working in Early Intervention:
      - • Family choice (mean 26.0 yrs)
      - • Natural environment (mean 17.67 yrs)
    - ▪ Administrators: Family choice (mean 13.0 yrs)
  - o Purpose
    - ▪ Working in Early Intervention:
      - • Family carrying over intervention techniques (mean 18.1 yrs)
      - • Natural environment (mean 17.57 yrs)
    - ▪ Administrators:
      - • Family carrying over intervention techniques (mean 15.2 yrs)
      - • Natural environment (mean 12.57 yrs)

The definitions and stated purpose of family-centered care of administrators in New York City Early Intervention programs emphasized including, involving, and engaging families with the goal being to work with families, support families, and coach families to carry over intervention strategies for the benefit of the child. Several patterns were evident in the responses provided based on the participants training in family-centered care, professional background, and years of experience.

Answer to Research Question 2

Participants were asked questions regarding what barriers hindered their delivery of family-centered services and how they handled the obstacles they encountered. The results indicated a very clear dichotomy regarding how administrators faced the challenges to providing family-centered programming, as well as commonalities as to what administrators identified as barriers to delivering family-centered services.

Barriers Identified

Participants identified the barriers to providing family-centered programming. The barriers were separated into two categories: (1) barriers internal to an organizational and (2) barriers external to an organization. The barriers internal to an organization were divided to three subcategories: (1) barriers related to staff, (2) barriers related to families, and (3) programmatic barriers. Thus, four categories of barriers that inhibited the delivery of family-centered services were created, three categories of barriers which were endemic to an agency and one category of barriers external to an organization. To ascertain where administrators placed the greatest weight on barriers that interfered with providing family-centered services, the mean percentage of the categories was calculated. Table 14 displays the barriers, by category, from the multiple-choice options with which the respondents were presented, the frequency each barrier was indicated, and the mean frequency for each category.

Table 14

Barriers to Delivering Family-Centered Care and Frequency Barriers Citied

Category	Internal Barriers	Staff Barriers	Family Barriers	External Barriers
Barrier & Frequency Indicated	Difficulty supervising staff in home-based setting (38.08%) Financial limitations prohibit staff training (38.08%) Lack of time & opportunity for staff development (33.32%) Agency organizational characteristics (19.04%)	Staff attitudes & beliefs regarding family-centered care (28.56%) Lack of providers' understanding of family-centered care (23.8%) Lack of providers' knowledge & skills to partner with families (14.28%) Staff reluctance to change professional practices (14.28%) Staff prefer working with children as opposed to adults/ families (9.52%)	Parents' lack of skills, abilities, knowledge & resources (47.6%) Lack of parent participation & attitudes (42.84%) Cultural barriers with families (23.8%)	Bureaucracy & constraints of Early Intervention system (80.92%) Quality of staff available to hire due to pre-service/college training programs not providing adequate instruction on family-centered care (38.08%) Geographic location, size, setting, & features of service provision area (28.56%) Interagency collaborations & relationships (23.8%) Lack of clear standards or practices outline family-centered care (19.04%)

	Lack of administrative support from supervisor (4.76%)	Staff unwilling to accept views that differ from personal values (9.52%) Conflict in philosophical perspective between staff & administrator regarding family-centered care. (4.76%)		Services & delivery options available do not meet families' needs (19.04%) Treatment philosophies, such as Applied Behavior Analysis, or disciplines are not family-centered (19.04%) Lack of quality staff development materials available (9.52%) Lack of quality research applicable to practice (9.52%)
Category Mean	26.66%	14.96%	38.08%	22.93%

Response to Barriers

Two clear themes emerged from coding the responses of how administrators confronted the challenges they faced in providing family-centered services. There were administrators who accepted the obstacles as inevitable with an apparent sense of powerlessness and those who confronted the barriers, taking action to negotiate the hindrances. One administrator noted their program was in the process of closing. Figure 2 represents the divergent categories of the responses, the codes that composed the categories, and the frequency with which each category was cited in the responses. Several trends emerged in analyzing the responses, which are illustrated in Table 15.
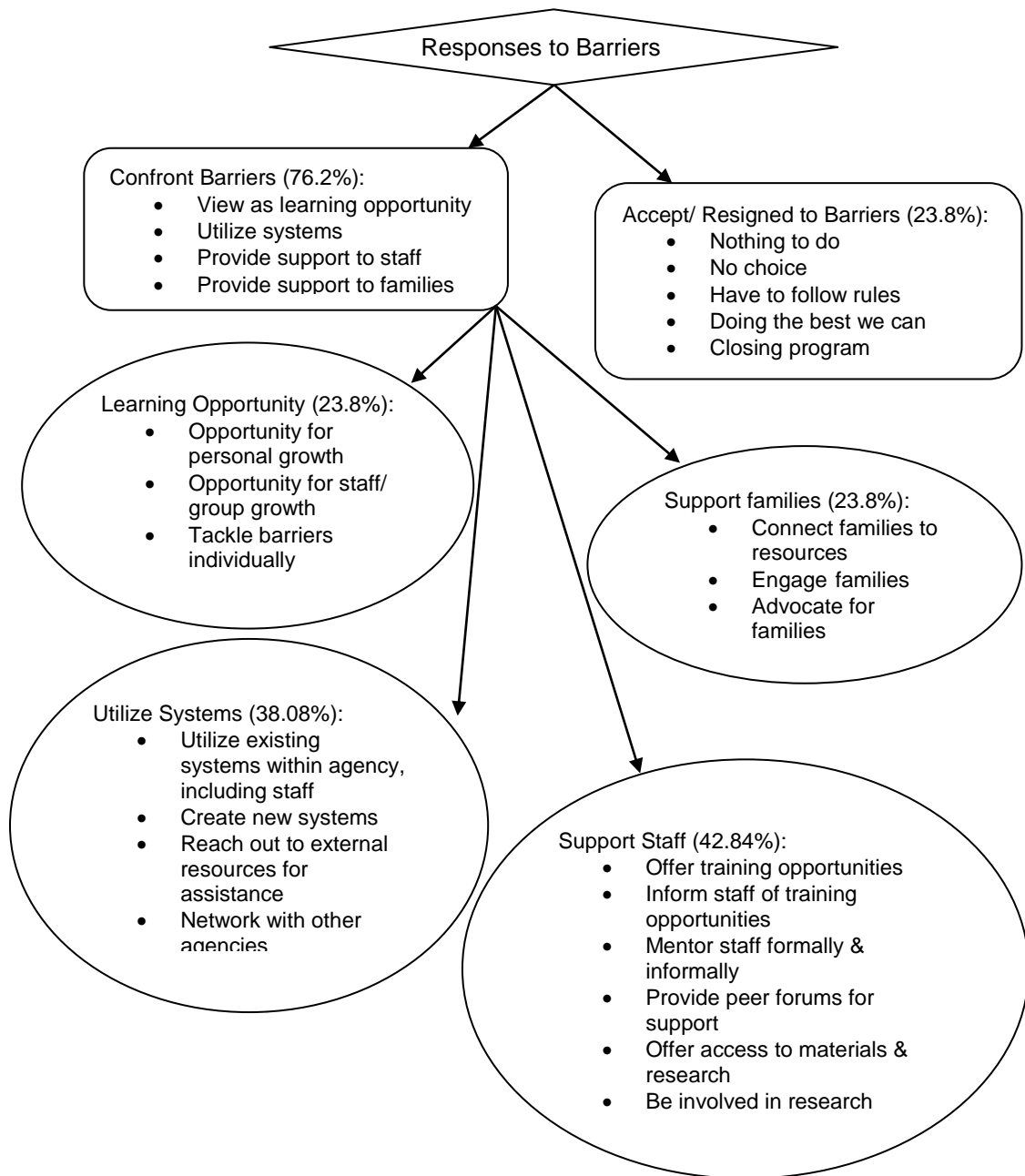
Figure 2. How administrators responded to barriers in delivery of family-centered care.

Table 15

Patterns in Responses to How Barriers to Delivering Family-Centered Care were Handled

Patterns Identified

- ❖ Training on Family-Centered Care
  - o College coursework: support families (60%)
  - o Life of personal experience:
    - ▪ Learning opportunity (60%)
    - ▪ Utilize systems (60%)
    - ▪ Resigned to barriers (60%)

- ❖ Professional Background
  - o Education:
    - ▪ Support families (60%)
    - ▪ Utilize staff (60%)
    - ▪ Resigned to barriers (60%)
  - o Social Work: Utilize systems (50%)

- ❖ Least Experienced
  - o No experience working in Early Intervention before becoming administrators: Resigned to barriers (100%)
  - o Working In Early Intervention: Support families (mean 11.6 yrs)
  - o Administrators: Support families (mean 5 yrs)

- ❖ Most Experienced
  - o Working in Early Intervention:
    - ▪ Learning opportunity (mean 20.0 yrs)
    - ▪ Utilize staff (mean 17.2 yrs)
  - o Administrators: resigned to barriers (mean 15.0 yrs)

The data suggest that participants believed the rules, regulations, and policies of Early Intervention inhibited their ability to provide family-centered services. Yet, categorically, factors connected to families were the most problematic barriers to delivering family-centered programming. Although many administrators found ways to negotiate the challenges they faced, some appeared resolute in their belief that nothing could be done except to accept the obstacles they encountered and that those hindrances would continually inhibit their program's delivery of family-centered services.

Answer to Research Question 3

Program Practices and Policies

Respondents were asked what practices were implemented in their programs,

what policies were in place in their programs, what was the most valuable family-

centered practice provided by their programs, and what six practices and policies

represented ideal family-centered care. The practices and policies listed as options in the

multiple-choice Questions 3, 4, and 8 were divided into the categories of (a) respecting

the backgrounds of families, (b) partnering with families, (c) focusing on the family, (d)

supporting families, (e) supporting the relationship between families and providers, (f)

supporting staff, and (g) organizational traits of programs. The practices and policies

were then ranked to determine what practices and policies were most frequently

implemented, based on the responses indicated, by determining the mean percentage for

each category. Table 16 indicates the categories, policies, and practices of each category,

the frequency of each policy and practice implemented, and the mean frequency with

which the category of policies and practices was implemented.

Table 16

Categories of Policies and Practices with Frequency Implemented

Categories of Policies & Practices	Respect backgrounds of families	Support relationships between families & providers	Support staff
Mean Frequency	85.68%	84.5%	76.76%

Policies & Practices with frequency implemented	Policy that respects cultural, ethnic, & linguistic backgrounds of the families (95.2%) Staff speak same languages as families, or use interpreters for all interactions, & translate all written material (80.92%) Staff reflect ethnic backgrounds of families (71.4%) Account for & respect cultural traditions & practices of families regarding gender, customs, scheduling, etc. (95.2%).	Policy to maintain consistency of relationships between family & providers (100%) Match providers with families based on commonalities, eg. cultural characteristics, needs of family (76.16%) Assign staff cases (66.64%) Policy to create or adapt practices based on needs of families & providers (95.2%)	Policy that recognizes staff as competent professionals (90.44%) Offer staff development on how to collaborate with families (71.4%) Create staff development based on staff competencies, input & preferences (66.64%) Provide supervision & mentoring (76.16%) Require all staff to attend professional development (85.68%) Policy that prioritizes on-going staff development regarding family-centered care (80.92%) Policy to create opportunities for formal & informal staff collaboration (85.68%) Establish environment that creates opportunities for formal & informal staff collaboration, as a practice (57.12%)

Categories of Policies & Practices	Organizational traits of programs	Focus on family	Support family	Partner with family
Mean Frequency	72.99%	68.69%	60.11%	40.65%
Policies & Practices with Frequency Implemented	Emphasize family-centered culture throughout agency, with all staff (71.4%) Have mission statement reflecting family-centered care (85.68%) Screen prospective staff based on family-centered beliefs & personality traits (61.88%)	Policy emphasizing family outcomes over child outcomes (57.12%) Stress family outcomes, as a practice (66.64%) Focus on child's development, as practice (100%) Use flexible practices to support family participation (42.84%) Service Coordinators & home-based providers work schedules based on family's needs (71.4%).	Policy that ensures varied service delivery options are available to support family participation in program (76.16%) Formally prepare families for meetings & assist families to develop advocacy skills (85.68%) Opportunities for parent-to-parent mentoring (42.84%) Host program sponsored social events for families (47.68%) Staff accompany families to meetings & appointments, outside of IFSP mandates (52.36%) Offer resources for families facing economic hardships within program, such as a food pantry (38.08%)	Respect decisions of families, even when decisions differ from those staff may consider most appropriate for family (90.44%) Refer to parents by given names, as opposed to "Mom" or "Dad" (66.64%) Provide trainings to families, or staff & families jointly, on how to form collaborative relationships (33.08%) Use daily 2-way communication logs with families (66.64%) Distribute a handbook of the program's policies & philosophy (61.88%) Publish regular newsletters about program for families (14.28%) Offer stipend to cover expenses associated with participating in program events (14.28%)

		Policy to consider needs of all family members in programming (85.68%)	Refer families facing economic challenges to outside agencies (85.68%)	Have open-door visitation policy (42.04%)
				Encourage families to volunteer in program (28.56%)
		Incorporate all family members, into programming, as a practice (57.12%)	Resource materials available to families, e.g., books, DVD's, equipment, & specialized toys (52.36%)	Families sit on governing committees (9.52%)
				Center-based staff make home visits (19.04%)

Ideal Family-Centered Care

The rank order of the categories representing ideal family-centered care, as identified by the participants of this study, differed from the practices and policies implemented in programs. Table 17 illustrates the mean of the categories of practices that represented family-centered care, as well as the policies and practices that were identified most frequently and least frequently to represent ideal family-centered care.

Table 17

Categories of Most and Least Frequently Identified Policies and Practices Representing Ideal Family-Centered Care

Categories of Policies & Practices	Most Frequently Identified Policies & Practices	Least Frequently Identified Policies & Practices
Focus on family (mean of 30.15%)	Prepare family for meetings & help them develop effective advocacy skills (71.4%)	Offer opportunities for parent-to-parent mentoring (0%)
Supporting family & provider relationships (mean of 26.97%)	Match family with providers based on needs & commonalities (52.36%)	Families sit on governing committees (0%)
Support family (mean of 20.4%)	View family as collaborative partner/ equal (42.84%)	Create environment for formal & informal staff collaboration (0%)
Partner with family (mean of 17.61%)	Respect & abide by the decisions of family even if differs from what staff may feel is best for family (38.08%)	Host program sponsored social events for families (4.76%)
Organizational traits (mean of 17.45%)	Offer trainings to families, or staff & families jointly, on how to form collaborative relationships (38.08%)	Distribute handbook of program's policies & philosophy (4.76%),
Respect background of family (mean of 11.99%)	Use flexible practices to find ways to support family participation in program (38.08%)	Center-based staff make home visits (4.76%),
Support staff (mean of 11.11%)	Emphasize family outcomes over child outcomes (33.32%)	Refer to parents by given name as opposed to "Mom" or "Dad" (4.76%)

Most Valuable Family-Centered Practice

Respondents were also asked to identify the most valuable family-centered practice their program offered families. The categories that developed from the coding process included (a) engaging families, (b) supporting families, (c) utilizing staff, (d) communication with families, and (e) flexible practices. Table 18 lists the codes that encompassed each category, as well as the frequency with which each category was represented in the responses. Listed in Table 19 are the trends that emerged from the data regarding the most valuable family-centered practice offered by a program.

Table 18

Most Valuable Family-Centered Practice Categories, Codes, and Frequency Represented

Category	Engaging families	Supporting families	Utilizing staff	Communication with families	Flexible practices
Codes	Include families in sessions Hold special program-wide events for families, such holiday events Maintain an open-door policy Hold monthly team meetings for families to attend	Address concerns of families Assist families in advocating for themselves Offer opportunities for parent-to-parent mentoring Enable families to develop relationships with providers	Employ skilled & competent staff Staff are available to families Staff understand cultural backgrounds of families Staff share common ethnic heritage with families Staff speak the same languages as families	Maintain ongoing communication with families Utilize communication notebooks Provide families with activity sheets	Accommodate family's scheduling needs Provide services in natural environments Offer community-based therapy rooms to families
Frequency Represented	47.6%	33.32%	23.8%	19.04%	14.28%

Table 19

Patterns Identified from Most Valuable Family-Centered Practice Offered by Programs

Patterns Identified

- ❖ Training on Family-Centered Care
  - o College coursework: Engaging families (50.0%)
  - o Personal or life experience:
    - ▪ Utilize staff (60%)
    - ▪ Engaging families (60%)

- ❖ Professional Background
  - o Education:
    - ▪ Flexible practices (66.66%)
    - ▪ Engaging families (50%)
  - o Doctorate degree: Flexible practices (50%)

- ❖ Least Experienced
  - o No experience working in Early Intervention before becoming administrators: Communication with families (75%)
  - o Working in Early Intervention: Utilizing staff (mean 11.6 yrs)
  - o Administrators:
    - ▪ Utilizing staff (mean 7 yrs)
    - ▪ Flexible practices (mean 7 yrs)

- ❖ Most Experienced
  - o Working in Early Intervention: Communication with families (mean 21.75 yrs)
  - o Administrators: Communication with families (mean 18.25 yrs)

From the categories of the most valuable family-centered practice programs provide to families, the themes of engaging families, utilizing staff, and supporting families arose. The theme of engaging families mirrored that of professionals and families working together as identified in the participants' definitions and viewed purpose of family-centered care. The theme of utilizing staff included codes that involved staff reflecting and respecting the cultural, linguistic, and ethnic background of the families, similar to the category of practices and policies that were most frequently implemented in programs.

Implementing Family-Centered Care

The theme of engaging families was prominent throughout the definitions and stated purpose of family-centered care, as well as identified as the most valuable family-centered practice provided by programs in this study. The responses emphasized including, involving, and encouraging families to participate in programming. Practices and policies that facilitated the relationships between providers and families, as well as those that respected the cultural, linguistic, and ethnic backgrounds of families, were the most frequently implemented in programs. Supporting the relationships between providers and families, as well as focusing on the family as the unit of service, were the most frequently selected categories of practices to represent ideal family-centered care, indicating they were the priorities of administrators in this study.

The definition and stated purpose of family-centered care by participants placed prominence on services to and progress of the child. All programs stressed child outcomes, and 95.2% of the definitions or stated purpose of family-centered care included the focus on the child. The definitions and viewed purpose of family-centered care emphasized engaging families in programming with the intent of teaching families intervention strategies to carry over into their daily routines in order to enhance the child's well-being and maximize the child's developmental potential.

The most frequently implemented category of policies and practices were those that involved respecting families and their backgrounds as well as those that supported the relationships between providers and families. Although 57.12% of administrators attested to the importance of supporting and strengthening families in their definitions and stated purpose of family-centered care, the practices and policies that support and

128

strengthen families were among those least frequently implemented in programs. The practices and policies that support and strengthen families were also not representative of ideal family-centered care.

The practices and policies of programs involved in this project demonstrated that partnering with families was the practice that was implemented the least frequently, categorically. Although the statement of "developing collaborative partnerships with families" was considered to represent ideal family-centered care by 42.84% of respondents, the category of practices and policies indicative of collaborative partnerships with families did not represent ideal family-centered care to participants, which demonstrated those policies and practices were not were not priorities for administrators. Only 23.8% of the definitions and stated purposes of family-centered care used the words or described the process of "partnering" with families.

Categorically, families were also seen as the largest barrier to the delivery of family-centered services. The participation, resources, and abilities of families were considered impediments to providing family-centered programming by 57.12% of respondents. However, workshops to assist families in developing the skills to form collaborative partnerships with providers were offered in only 38.08% of programs. The category of practices and policies that involved offering support to families were among the least frequently implemented in programs, yet these practices would potentially enable families to overcome challenges and facilitate their participation in programming. A family's culture was seen as a barrier to providing family-centered care by 19.04% of respondents; however, respecting a family's background was the category of policies and practices that was most frequently implemented in programs.

Although 47.6% of the participants cited at least one barrier related to staff concerning the delivery of family-centered services, 23.8% of respondents considered utilizing program staff as the most valuable family-centered practice provided by their agencies, and 23.8% of administrators used staff as a way to navigate the obstacles to providing family-centered programming. Offering ongoing professional development and support was listed as a means to confronting the challenges to delivering family-centered care by 42.84% of respondents, yet 80.92% of programs offered staff development four times a year or less frequently and only when needed in 23.8% of organizations. More than 38% of administrators reported supervising home-based providers as a barrier to providing family-centered services, yet in 59.92% of agencies there was no protocol in place to observe home-based providers on a routine basis. Center-based providers were not observed on a regular basis in 33.35% of programs. Although 76.16% of agencies offered supervision and mentoring, 56.25% of those organizations provided mentoring or supervision to staff without observing the provider.

From the data collected, the practices and policies of New York City Early Intervention programs emphasized respecting the cultural backgrounds of families as well as supporting the relationships between families and providers. Focusing on families and enhancing the relationships between families and providers appeared to be the goals of programs, epitomized by what administrators in this study identified as policies and practices that represent ideal family-centered care. Additionally, administrators considered utilizing their staff, supporting families, and engaging families to be the most valuable family-centered practices their program offered to families. Policies and practices that supported families and those intended to facilitate the development of

130

collaborative partnerships with families were implemented with the least frequency. This is in concert with the definitions, stated purpose, and most valuable family-centered practices programs provided, which stressed including, engaging, and involving families in programming, as opposed to partnering with families.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

Limited research exists regarding the roles administrators have in the delivery of family-centered Early Intervention services. The purpose of this qualitative case study was to explore how administrators of New York City Early Intervention programs conceptualized and implemented family-centered care by examining the administrators' definition and purpose of family-centered care, identified challenges to delivering family-centered services, ways the obstacles were negotiated, and how those factors impacted the implementation of family-centered programming. Twenty-one administrators anonymously completed the web-based questionnaire created to gather narrative and demographic data.

Implications of the Study

Although participants valued and recognized the importance of collaborative relationships with families, the results suggested programs operated under a traditional educational model rather than a family-centered paradigm. The data collected reinforced previous research demonstrating the influence administrators have in the delivery of family-centered programming (Epley et al., 2010; Mandell & Murray, 2009). The conceptualizations that administrators of New York City Early Intervention programs held regarding family-centered care mirrored how family-centered care was implemented, which is similar to the findings of Mandell and Murray (2009). The results also echo similar studies regarding the delivery of family-centered services in Early Intervention programs. Patterns identified in the data indicated that characteristics of administrators and organizations may influence the delivery of family-centered services.

The data suggested that administrators of New York City Early Intervention programs conceptualized and implemented family-allied and family-focused programming, using the family-oriented program model outlined by Dunst and his colleagues (1991). The basis of family-centered care lies in the collaborative partnerships between practitioners and families (Broggi & Sabatelli, 2010; Dinnebeil, Hale, & Rule, 1996; Keen, 2007; Law et al., 2003; Mannan et al., 2006; Murphy et al., 1995; Murray & Mandell, 2006; McWilliam, Tocci, & Harbin, 1998; Park & Turnbull, 2003; Piper, 2011; Roush, Harrison, & Palsha, 1991; Woods et al., 2011) and a partnership "creates the medium for effective work with families," according to Dunst, Trivette, and Deal (1994b, p. 10). However, partnering or collaborating with families was described or mentioned in only 23.8% of definitions and viewed purpose of family-centered care. Rather, participants emphasized including, involving, or engaging families in programming, as these concepts or words were used by 100% of the respondents in their definitions, stated purpose, or the most valuable family-centered practice provided by their programs. Additionally, the category of practices and policies that involved partnering or collaborating with families was the least frequently implemented in programs and was not selected by respondents as embodying ideal family-centered care. This work is aligned with previous authors and findings that indicate that programs providing services to families with young children who have special needs typically provide family-focused and family-allied programming (Dunst, 2002; Mahoney & Filer, 1996; Mahoney & O'Sullivan, 1990; McBride et al., 1993).

The emphasis on services to and outcomes of the child evident in the definitions and stated purpose of family-centered care as well as in the policies and practices

implemented in programs, further illustrate why family-focused and family-allied care was delivered. According to Epley, Summers, and Turnbull (2010), as well as McBride and her colleagues (1993), the mainstay of family-centered care is the family as the focus of service delivery; and that should be present in all definitions of family-centered care. In this study, "families as the focus of intervention" was present in only one-third of definitions, yet "focus on the child" was mentioned in two-thirds of definitions and in 95.2% of the combined definitions and stated purpose of family-centered care. This was in conjunction with a policy in place in only 57.12% of agencies that emphasized family outcomes over child outcomes, while 100% of programs practiced focusing on child outcomes, but only 66.64% of programs stressed family outcomes. This demonstrated an emphasis on the child, superseding a focus on the family by respondents, which is the antithesis of family-centered care.

The importance of involving and engaging families with the intent of teaching families intervention strategies to carry over into their daily routines was emphasized by administrators in this study. This model is often referred to as participation-based services (Campbell & Sawyer, 2007; Fleming, Sawyer, & Campbell, 2011; Sawyer & Campbell, 2009). Fleming, Sawyer, and Campbell (2011) explain the following:

> [The] purpose of participation-based services is to promote a child's participation in family and community activities and routines. Providers directly teach caregivers how to embed learning strategies within a family's naturally occurring activities and routines by maximizing already existing learning opportunities or creating individualized learning opportunities (p. 233).

Participation-based services can be delivered within the confines of a family-centered framework (Fleming, Sawyer, & Campbell, 2011) or a family-allied paradigm (Trivette et al., 1995; Dunst, 1991). The determining factor lies in the relationships providers have with families. If the relationships are collaborative partnerships, then participation-based services are provided in the context of a family-centered program model. If the relationships between families and practitioners are not collaborative partnerships, then participation-based services are provided under the auspices of a family-allied orientation (Trivette et al., 1995; Dunst et al., 1991). Because the data implied that collaborative partnerships with families were not being developed, it appeared participation-based services were being delivered under a family-allied program model.

When the focus of service delivery is on imparting knowledge and coaching families on how to implement intervention strategies, there is the potential for an unequal power dynamic between families and practitioners to develop, with the provider serving as a teacher, not a partner. If the goal of service becomes parent education or training, that also may perpetuate the paternalistic dynamic between practitioners and families which typically occurs in the traditional educational model. In such a situation, the emphasis shifts to teaching and coaching families how to implement intervention strategies, which prioritizes the needs of the child as opposed to supporting and partnering with families. The results suggested this is what may to have occurred in New York City Early Intervention programs. Hence, McWilliam and Scott (2001) contend that the goal of Early Intervention is to provide support to families as opposed to services.

The mechanism for effectiveness in Early Intervention lies in the support offered to families. Caring for a child with special needs impacts and creates stress for a family

(Bailey et al., 1999; Doll & Bolger, 2000; Jackson, Traub, & Turnbull, 2008; Mahoney et al., 1998; Tomasello, Manning, & Dulmus, 2010; Thompson et al., 1997). The support provided to families in Early Intervention mitigates the stress created by the child's special needs (Guralnick, 1998) by altering the experiences, interactions, and behaviors of the family and child (Ramey & Ramey, 1998). Families who are stressed, unsupported, overwhelmed, and dissatisfied are less able to meet the needs of their children as well as less able to actively participate in Early Intervention programming (Summers et al., 2007). Until a family's concerns and needs have been addressed, the family cannot focus on Early Intervention programming, such as carrying over intervention strategies (Dunst, Leet, & Trivette, 1988; Zhang, Bennett, & Dahl, 1999). Garshelis and McConnell (1993) found that families with more needs are less involved in Early Intervention programming. When programs are not addressing the needs of families, it can create a cycle where programs continue to focus on including, involving, and engaging families; however, families are preoccupied with their unmet needs and unable to devote their attention to Early Intervention programming. According to Doll and Bolger (2000), if services are not aligned with a family's needs and abilities, intervention can become an extra burden that can overwhelm a family. This is why Pang (2010) contends that "only when they understand family needs can service providers render appropriate services" (p. 185). Consequently, the priority of Early Intervention needs to be to provide individualized, supportive services to families to address their unique priorities, needs, and concerns.

Family-centered care is the vehicle to address the needs of a family with a child who has special needs (Tomasello, Manning, & Dulmus, 2010), so families can, in turn,

meet the needs of their child. According to Summers and her colleagues (2007), the purpose of family-centered care is to provide resources and support to the family of a child with special needs, which improves the well-being of the family and enables the family to better care for their child. The components of family-centered practice identified by Mahoney and his team (1998) include providing families with comprehensive supports and services that correspond with their identified needs and goals, which facilitate the family's ability to interact more effectively with their child and, in turn, promote their child's developmental growth.   This occurs, according to Dunst, Trivette, and Deal (1994b), when programs assist families "to locate the informal and formal resources and supports for meeting those needs and help families use existing capabilities as well as learn new skills in order to mobilize needed resources" (p. 3), which they contend is the goal of family-centered Early Intervention.

These new skills that families should acquire while enrolled in Early Intervention need to encompass both long-term strategies that will enable families to better cope with parenting a child with special needs as well as short-term child-focused intervention techniques. Examples of the long-term coping capacities that should be cultivated include developing advocacy skills (Bailey et al., 2005, 2006; Thompson et al., 1997), navigating the complexities of human service bureaucracies (Thompson et al., 1997), empowering families (Chao et al., 2006; Dempsey & Dunst, 2004; Dunst & Dempsey, 2007; Dunst & Trivette, 1996; Fordham, Gibson, & Bowes, 2011), creating partnerships with professionals (Bailey et al., 2005; Dinnebeil & Rule, 1994; Doll & Bolger, 2000; Blue-Banning et al., 2004; McBride et al., 1993; Peterander, 2000; Summers et al., 1990), and learning how to parent a child with special needs (Bailey et al., 2006; Dinnebeil,

1999; Guralnick, 2001, 2005; Mahoney et al., 1998; McWilliam & Scott, 2001; Odom & Wolery, 2003; Romski et al., 2011; Woods et al., 2011). These are techniques that will benefit a family beyond their enrollment in Early Intervention and skills a family can utilize for the rest of their lives. However, the respondents in this study primarily emphasized coaching families on how to use short-term child-focused intervention strategies to promote a child's developmental potential and progress.

The essential elements of family-centered Early Intervention include supporting and collaborating with families. Although the administrators of New York City Early Intervention programs appeared to value collaborative partnerships with families, that was incongruent with practices and policies implemented in programs. The discrepancies found in this work between practice and rhetoric are consistent with the results of other researchers (Ingber & Dromi, 2010; Jackson, Traub, & Turnbull, 2008; Mahoney, O'Sullivan, & Fors, 1989; Minke & Scott, 1995; Roush, Harrison, & Palsha, 1991). This research and other works found that participants stated they were invested in providing family-centered care, but further analysis of their responses indicated they were experiencing difficulty delivering the level of family-centered services they claimed to be providing. In this project, 42.84% of respondents indicated viewing families as collaborative partners represented ideal family-centered care. Despite this declaration, additional data analysis demonstrated little programmatic action towards forming collaborative partnerships with families based on the policies and practices implemented in programs.

Also, in this study, families were the most frequently cited category of barriers to providing family-centered programming. More than 57% of participants reported that

families were an obstacle to providing family-centered services. However, perceiving a family as a barrier to providing family-centered care negates the premise and intent of a family-centered paradigm. Family-centered care is based on an empowerment model that respects and accepts the unique characteristics, strengths, capacities, needs, priorities, and cultural background of families and utilizes those features to enhance the abilities of and empower families to achieve their goals. Additionally, the nature of family-centered care resides in the collaborative partnership that is formed between a practitioner and a family. Although forming that relationship may not always be an easy task, the professional has to be intent on establishing a collaborative partnership, as the onus of creating that relationship rests with the professional (Dinnebeil & Rule, 1994). Therefore, if the professional views the family as a barrier to delivering family-centered services, the partnership is sabotaged. How a professional perceives a family impacts the relationship between the professional and the family (Sewell, 2012). Research indicates that class, cultural, and socioeconomic differences influence the perceptions practitioners have of families (Brinker, 1992; Dinnebeil & Rule, 1994: Fleming, Sawyer, & Campbell, 2011; Nelson, Summers, & Turnbull, 2004), which, in turn, may affect the provider's view of a family as an obstacle to the delivery of family-centered services.

Most significantly, the results of this work confirmed the influential role administrators have in the delivery of family-centered services. Mandell and Murray (2009) determined that administrators create policies and practices that correspond to their understanding of family-centered care, and the results of this project mirrored those findings. New York City Early Intervention program administrators conceptualized family-allied and family-focused care based on their definitions and viewed purpose of

139

family-centered care, and the policies and practices implemented in their programs reflected family-allied and family-focused programming. This reinforces the need for Early Intervention program administrators to be skilled, trained professionals (Fayol, 1916/1949; Johnson et al., 1992; Sandall, McLean, & Smith, 2000) who are well versed in best practice guidelines (Johnson et al., 1992), specifically delivering family-centered services.

The results of this project indicated administrators of New York City Early Intervention programs are not using recommended practice guidelines when delivering Early Intervention services. Supporting and partnering with families, cornerstones of family-centered care, were the least frequently implemented practices and policies in programs and were not strongly represented in the definitions and stated purpose of family-centered care provided by respondents. Conversely, focusing on the child was emphasized in the definitions and stated purpose of family-centered care, and families were seen as the largest category of barriers to providing family-centered care, both of which represent the antithesis of a family-centered service delivery model.

Patterns in Findings

Several noteworthy trends connected to the definitions and stated purpose of family-centered care, traits of the participants, and features of the agencies emerged during data analysis. Characteristics of administrators, program practices, and organizational traits appeared to impact the delivery of family-centered services in New York City Early Intervention programs. The findings concerning administrators are connected to their experience, training in family-centered care, and professional

backgrounds. The results that emerged relating to organizational practices involved practices that support staff and characteristics of programs.

Definitions of Family-Centered Care

The conceptualizations of family-centered care provided by the participants were further scrutinized based on existing literature. Mandell and Murray's (2009) framework of understanding of family-centered care was applied to the definitions and viewed purpose of family-centered care to determine if the administrators of this project exhibited a comprehensive or limited understanding of family-centered care. The definitions from the participants of this project were also compared to the work of Fingerhut and her team (2013), as well as that of Allen and Petr (1996) and Epley, Summers, and Turnbull (2010)

According to Mandell and Murray (2009), a comprehensive understanding of family-centered care is based on responses that value and promote partnerships between professionals and families; value and promote the needs, goals, and desires of a family; value and respond to the diversity of a family; and value and empower a family. Using Mandell and Murray's (2009) guidelines, none of the responses met the criteria indicative of a comprehensive understanding of family-centered care. One participant in this study noted the importance of partnering with a family, while respecting the diversity, needs, and priorities of a family in their stated definition and purpose of family-centered care. Of the other administrators, 33.32% included two elements in their responses, and 33.32% contained one component of Mandell and Murray's (2009) criteria for a comprehensive understanding of family-centered care.

The definitions provided by the participants of this project were compared to those collected by Fingerhut and her colleagues (2013). The definitions from this study corresponded to those Fingerhut and her team (2013) compiled from providers who worked in center-based or clinic settings. All of the practitioners in the study conducted by Fingerhut and her colleagues (2013) identified the family as part of the intervention team as well as the need to listen to parents to ascertain goals, whereas in this project 57.12% of definitions included working with the family and only 23.8% noted a family's needs, priorities concerns were to be the basis for goals. Fingerhut and her team (2013) concluded that providers who worked in a clinic setting described family-centered care "in terms of having a relationship with the parents to provide support and resources and to improve family involvement and carryover" (p. 230), which incorporated several elements of what is considered family-centered practice. This definition paralleled those of the respondents of this project in the emphasis of working with families, supporting families, involving or including families, and promoting family carryover of intervention strategies. Practitioners from a clinic setting provided a moderate amount of family-centered services compared to home-based providers who offered care and definitions that were more aligned with a family-centered paradigm and school-based providers who delivered care and definitions that were least in line with a family-centered philosophy (Fingerhut et al., 2013).

In comparing the definitions found in this study to the work of Epley, Summers, and Turnbull (2010), as well as Allen and Petr (1996), several themes became apparent. The previously identified categories of "individualized family services" (Epley, Summers, & Turnbull, 2010), "family as the focus of intervention" (Allen & Petr, 1996;

142

Epley, Summers, & Turnbull, 2010), "family needs, priorities, and concerns" (Allen &

Petr, 1996; Epley, Summers, & Turnbull, 2010), and "family choice" (Allen & Petr,

1996; Epley, Summers, & Turnbull, 2010) were evident in the definitions provided by the

respondents of this study. The categories of "family support and empowerment,"

"professionals and families working together," "focusing on the child," "natural

environment," as well as "family carryover of intervention strategies," emerged from the

definitions provided by the administrators of New York City Early Intervention

programs.

The categories of "relationships between professionals and families" and

"emphasizing a family's strengths" were noted by Allen and Petr (1996) as well as Epley,

Summers, and Turnbull (2010). Although the categories identified in this work as

"family support and empowerment" and "professionals and families working together"

were similarly titled, different labels were applied because the data collected did not

match the spirit of the original categories outlined by Allen and Petr (1996) as well as by

Epley, Summers, and Turnbull (2010). The category of "professionals and families

working together" encompassed codes from "partnering with families" to "including

families" as well as "encouraging family involvement or participation in programming."

"Including families in sessions" is not indicative of a relationship, although it may be

laying the groundwork for building a relationship. Additionally, the category of "family

support and empowerment" included codes from "assisting the family," to "empowering

the family to better care for their child." The aggregate of these responses also did not

reflect the meaning of building on a family's strengths. The intent of the category

"family choice," as outlined by Allen and Petr (1996) as well as by Epley, Summers, and

Turnbull (2010), was for the family to maintain control regarding decision-making powers in the planning and implementation of services. The definition of the category was expanded in this study to include family input in the decision-making process.

Comparing the frequency of the elements of the definitions of family-centered care by the participants in this study to those found in the works of Epley, Summers, and Turnbull (2010) as well as Allen and Petr (1996) confirmed the use of family-allied and family-focused program paradigms by New York City Early Intervention program administrators. "Individualized family services" reflects the uniqueness of a family. Family-allied programs value the strengths of families which could be the reason that facet of the definition of family-centered care was noted at almost the same rate in this study as by Epley, Summers, and Turnbull (2010). The component of "family choice" was mentioned in 9.52% of the definitions in this project, contrasted to approximately 75% of the definitions analyzed by Epley, Summers, and Turnbull (2010), and in 29% of those examined by Allen and Petr (1996), likely because under a family-allied program model, families carry over intervention strategies dictated by providers. "Family as the focus of intervention" was represented in one-third of the definitions in this project, but in 100% of those found by Allen and Petr (1996) and about two-thirds of those identified by Epley, Summers, and Turnbull (2010). The decrease in frequency of focusing services and intervention on the family is likely due to the participants in this study emphasizing services to and outcomes of the child. Focusing on the child and practitioners dictating treatment plans under a family-allied program paradigm was likely why "family needs, priorities, and concerns" were represented in 23.8% of definitions in this study compared to almost one-third in Allen and Petr (1996) findings. Under family-allied and family-

144

focused program paradigms, professionals consider families to require their assistance, advice, and guidance to function and improve. Therefore, professionals may not view themselves as having to work in concert with families, which may be the reason the element of "professionals and families working together" was found in 57.12% of the definitions of this study compared to 90% of the definitions reviewed by Epley, Summers, and Turnbull (2010). This study provided further evidence that the term family-centered care does not have a stable definition (Allen & Petr, 1996; Bamm & Rosenbaum, 2008; Chong et al., 2012; Epley, Summers, & Turnbull, 2010; McWilliam et al., 2000; Murphy et al., 1995).

Using principles established by Mandell and Murray (2009) for assessing an administrator's understanding of family-centered care, the respondents in this study demonstrated a limited understanding of family-centered care. The definitions provided by participants coincided with what Fingerhut and her colleagues (2013) reported in professionals who worked in a center-based setting. Many elements of the definitions of family-centered care identified in this project are similar to what has been found in previous studies (Allen & Petr, 1996; Epley, Summers, & Turnbull, 2010).

Administrator Characteristics

Trends emerged from the data regarding characteristics of the administrators which may have impacted the delivery of family-centered services in New York City Early Intervention programs. Those patterns involved the experience of the administrator, where and how the administrator received his or her training in family-centered care, and the administrator's professional background.

145

The respondents who were newest to the field as administrators and working in Early Intervention were most likely to note "strengthening a family's functioning," "supporting families," "professionals and families working together," and "family support and empowerment" in their definition and stated purpose of family-centered care in addition to how they handled the challenges to delivering family-centered services. Consequently, it can be assumed that those newest to the field recognized the importance of and were most invested in working with, supporting, empowering, and strengthening families.

Included in the definitions and viewed purpose of family-centered care of the respondents with the most years of experience as administrators and working in Early Intervention were the themes of "natural environment" and "family carrying over intervention techniques." This suggested the most experienced participants considered family-centered care as a vehicle for families to carry over intervention strategies into their natural environment and daily routines. The category of "family choice" present in the definitions of the respondents with the most years experience working in Early Intervention coincides with the work of Dempsey and Carruthers (1997), who found professionals with more experience were more likely to indicate family choice as a component of family-centered practice. Unfortunately, the respondents with the most years of experience as administrators of Early Intervention programs indicated there was no way to confront the barriers involved in delivering family-centered programming but to accept them. This may indicate that because these administrators have been working in the field so long, they have grown jaded to the challenges and developed a pessimistic attitude, akin to experiencing a level of burnout. Therefore, the findings of this project do

not necessarily support previous research (King et al., 2003; Pereira & Serrano, 2014; Roush, Harrison, & Palsha, 1991; Tang et al., 2011), which determined that those with more experience had stronger beliefs in or provided higher levels of family-centered care.

The data revealed, surprisingly, that nearly 43% of respondents had no prior experience working in Early Intervention before becoming program administrators. Yet, more than 95% of the respondents reported receiving their training in family-centered care from work experience. Work experience is a key component in the formation of a professional's conceptualization of family-centered care (Mandell & Murray, 2009; Sawyer & Campbell, 2009). An administrator's understanding of family-centered care affects the family-centered services provided by the agency he or she oversees (Mandell & Murray, 2009). Consequently, there is a subset of administrators leading programs who had no experience delivering family-centered services in Early Intervention before they assumed positions as administrators. However, if an administrator's prior work experience influences his or her understanding of family-centered care and an administrator's understanding of family-centered care affects the family-centered services provided by that agency (Mandell & Murray, 2009), what impact does having an administrator with no experience working in Early Intervention before assuming a managerial position have on those agencies delivering family-centered programming?

Another factor that emerged when analyzing the data was that all of the respondents who were resigned to accept the barriers to delivering family-centered services as obstacles that could not be overcome and saw no way to confront the hindrances had no prior experience working in Early Intervention before becoming program administrators. This may be attributed to the fact that the administrators with no

prior experience working in Early Intervention were not familiar with the bureaucracy and constraints of Early Intervention which were cited as barriers to the delivery of family-centered care by 80.92% of the participants in this project. Typically, knowledge of Early Intervention's intricate system of rules and regulations would be obtained by working in the field and becoming familiar with all of its guidelines and restrictions prior to becoming a program administrator. The apathy expressed by this group reinforces the need for administrators of Early Intervention programs to have specialized training, as called for by Johnson and his team (1992), due to the complexities and requirements of the Early Intervention system.

With respect to training in family-centered care, the theme of "professionals working together with families" was evident in the definitions and stated purpose of family-centered care of all of the respondents who received their training in family-centered care from college coursework. Half of the participants who listed the practice of "engaging families" as the most valuable family-centered practice provided by their program received their training in family-centered care from college coursework as well. Therefore, it may be surmised that when pre-service institutions are providing coursework on family-centered care, the material emphasized professionals working together with families. Additionally, 71.4% of the participants who received their training in family-centered care from college coursework had backgrounds in special education. This implied that college coursework in special education included the mandates of IDEA related to professionals working with and engaging families, and the coursework provided guidelines for how future practitioners were to interact with families.

However, only one-third of participants reported receiving training in family-centered care from college coursework, which supports previous research stating there is a lack of training regarding family-centered care offered in many pre-service college training programs (Murray & Curran, 2008; Rupiper & Marvin, 2004; Sawyer & Campbell, 2009; Sewell, 2012). Almost all of the participants in this study said their training in family-centered care came from work experience. This solidifies research concerning the significance of work experience on the development of family-centered philosophies (Mandell & Murray, 2009; Sawyer & Campbell, 2009; Roush, Harrison, & Palsha, 1991).

Personal or life experience influenced the development of the concept of family-centered care for two-thirds of the participants who included the "natural environment" and 71.4% of respondents who noted "coaching the family" in their viewed purpose of family-centered care. This seemed to reveal that personal or life experience, as opposed to professional experience or college coursework, regarding family-centered care led these participants to recognize the importance of teaching families how to carry over and implement intervention strategies into their daily routines. It could be that these respondents were themselves parents of children with special needs or have other close family members who have special needs. That may be the personal or life experience which had provided their training in family-centered care or demonstrated for them the importance of having families integrate intervention strategies into daily routines as they themselves were in the role of "family."

In regard to responses based on professional backgrounds, it was unexpected that 90% of professionals with a background in education acknowledged the family in their

149

definitions, 70% in their purpose, and 90% in the most valuable family-centered practice provided by their program, as the field of education is typically child-centered. This study, however, did not support previous research (Bailey, Palsha, & Simeonsson, 1991; King et al., 2003; Woodside, Rosenbaum, King, & King, 2001), which found social workers, as a discipline, demonstrated a more family-centered mindset. The findings of this project also did not necessarily coincide with the work of Humphry and Geissinger (1993), who determined that professionals with higher levels of education and advanced degrees adopted more family-centered paradigms.

Organizational Characteristics and Practices

Several patterns regarding organizations were evident in the data that potentially influenced the delivery of family-centered programming. Those trends involved the profit status of agencies and the institutional practices that could provide support to staff in delivering family-centered services.

The data revealed there were slight differences between the organizational infrastructures of agencies and characteristics of administrators employed in for-profit versus not-for-profit programs. The for-profit programs were larger, operated more sites, and provide services to more families annually. The for-profit programs seemed to have fewer infrastructures in place for practices that would support staff in providing family-centered services. In for-profit organizations, 37.5% did not hold staff meetings on a regular basis, 37.5% did not offer providers supervision or mentoring, 50% conducted professional development sessions only when needed, 50% observed home-based providers only when the need arose, and 50% did not offer funding for staff to attend training off-site. This may be a factor in the lower rates of staff retention found in the

for-profit programs in this study. Because the for-profit agencies provided services to a greater number of families annually, the fiscal resources should have been available to develop the infrastructure to offer support to staff, as agencies were reimbursed on a fee-for-service billing model by the New York City Department of Health and Mental Hygiene Bureau of Early Intervention for contracted and approved services. However, if the organization was providing only Early Intervention services, which was more likely found in the for-profit institutions, and did not have the financial backing of a larger umbrella organization to support and share expenditures, such as general overhead costs, then perhaps fiscal resources available for staff support were more limited.

Also of note were the characteristics of the administrators employed by programs based on profit status. Fewer administrators supervising the for-profit programs had a background in education compared to the administrators supervising not-for-profit programs. Administrators in for-profit programs were less likely to have training in family-centered care from college coursework or intensive certificate-based training programs. This is significant because formal training in family-centered care impacts service delivery (Fleming, Sawyer, & Campbell, 2011; King et al., 2003; Pereira & Serrano, 2014; Sewell, 2012). Fewer administrators of for-profit organizations held NYSESLA certificates. Possessing a NYSESLA certificate is equated with specialized training in leading educational programs and in part addresses the call for specialized preparation that Fayol (1916/1949) contends managers need and which Johnson and his team (1992), as well as Sandall, McLean, and Smith (2000), assert is crucial for effective administrators of Early Intervention programs. It was also noted that administrators of

151

for-profit institutions had slightly less experience as administrators and working in Early Intervention compared to their peers in not-for-profit programs.

With regard to organizational practices that have the potential to support staff, several trends were identified. These patterns involved staff observation practices, opportunities for staff collaboration, and professional development in programs. There was a gap in program infrastructure regarding observation of staff in the programs that responded to this study. Alarmingly, one-third of programs offering center-based services and more than half of the programs providing home-based services to families do not observe their direct service providers at all unless there is a concern. Additionally, although more than three-fourths of programs offered supervision and mentoring to staff, not all of that support involved observation of direct practice. It is difficult to judge the quality of family-centered care that is provided if it is not observed.

Meetings may be an opportunity to create support for staff through staff collaboration, which was found to be underutilized in New York City Early Intervention programs. In most programs, staff meetings took place monthly, and case conferences were not conducted. These meetings serve a specific purpose but also provide opportunities for staff collaboration, which fosters a culture of family-centered care (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Garland & Linder, 1994) and creates synergy for Early Intervention teams (Garshelis & McConnell, 1993). Based on the data, many agencies relied predominantly on part-time direct service providers, most likely as a cost-saving measure, which limited chances for staff collaboration from the outset. The use of part-time employees, coupled with the practice implemented in 71.4% of programs

where home-based providers and service coordinators synchronized work schedules based on the needs of families, further limited prospects for staff collaboration.

The data suggested that professional development opportunities were another area of concern in New York City Early Intervention programs. Professional development impacts the delivery of family-centered services (Fleming, Sawyer, & Campbell, 2011; King et al., 2003; Pereira & Serrano, 2014; Sewell, 2012), yet staff development occurred quarterly or less frequently in 80.92% of programs, with 23.8% of programs conducting professional development sessions only when needed. This begets the question of whether the staff development opportunities offered by programs were meeting the needs of programs and providers. Single-format workshops are considered ineffective for producing changes in practitioner behavior and practice (Campbell & Sawyer, 2007; Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; McWilliam, Tocci, & Harbin, 1998; Odom, 2009). Forms of professional development that offer opportunities for learning, practice, and reflection are considered most effective (Dunst & Raab, 2010; Sawyer & Campbell, 2009; Trivette, Dunst, & Deal, 2011). These professional development formats include (a) teaming and team building (Odom, 2009); (b) communities of learning (Bailey, McWilliam, & Winton, 1992); (c) mentoring, coaching, and ongoing consultation (Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; Odom, 2009); and (d) online instruction that includes visual access with feedback and an interactive system (Odom, 2009). Professional development, therefore, should be consistent, ongoing, and based on the needs of practitioners.

Based on the results, there were several reasons why it would behoove programs to invest in professional development for staff regarding the delivery of family-centered

153

care. Staff was considered the most valuable family-centered practice offered by 23.8%
of participants. More than 61% of the administrators found staff to be a barrier to
providing family-centered programming. Utilizing staff was how 23.8% of
administrators confronted the barriers to delivering family-centered services, and 42.84%
of participants responded that supporting staff, which included providing staff
development, was how they navigated the challenges to providing family-centered
programming. The category of practices and policies that support the relationships
between families and providers were among those most frequently implemented,
illustrating the value respondents placed on supporting providers in their work with
families. Finally, the category of policies and practices that supported the relationships
between families and practitioners was identified to represent ideal family-centered care,
which also signified the importance of providers to program administrators.

This study identified several factors related to administrators and agencies that
appeared to impact the delivery of family-centered services in New York City Early
Intervention programs.

Implications for Practice

The results of this study outlined four implications for practice: (a) the
implications for administrators, (b) the implications for the infrastructure of programs, (c)
the implications for the practice of family-centered care in New York City Early
Intervention programs, and (d) the implications for policy.

Administrators

The results demonstrated implications for administrators of Early Intervention
programs and for administrators of New York City Early Intervention programs. This

project confirmed previous studies (Epley et al., 2010; Mandell & Murray, 2009) regarding the impact administrators have on the delivery of family-centered services. Consequently, it is imperative that administrators of programs be capable and competent in overseeing the delivery of family-centered programming as well as in supporting practitioners and families to ensure quality care is provided. Administrators need to have specialized training in management (Fayol, 1916/1949), overseeing Early Intervention programs (Johnson et al., 1992; Sandall, McLean, & Smith, 2000) as well as in delivering family-centered care. Program administrators must be able to lead Early Intervention programs that are infused with a family-centered philosophy, horizontally and vertically, with all staff, throughout all policies and practices of the agency.

The outcomes of this project determined that Early Intervention program administrators need support to provide family-centered programming. In answering the question regarding practices and policies that represent ideal family-centered care, many participants identified focusing on the family as well as facilitating the relationships between providers and families, indicating they were priorities for participants. Epley, Summers, and Turnbull (2010), as well as McBride and her team (1993), note that focusing on the family is the cornerstone of family-centered care; therefore, it was promising that respondents considered focusing on the family to represent ideal family-centered care, and thus an objective for their programs. Equally, the policies and practices of Early Intervention programs should foster the relationships between providers and families, according to Dinnebeil, Hale, and Rule (1999); therefore, it was encouraging that administrators recognized this as well. Assisting administrators to create policies and practices to realize these goals should take precedence.

Providing support to administrators to confront the challenges they face in implementing family-centered care should be a goal as well. This is of special concern for the administrators who perceived those challenges as obstacles that cannot be negotiated and must be accepted. Finding ways to support the creation of organizational infrastructure to ensure professional development and staff support needs are met should be an objective as well. Avenues to support administrators of Early Intervention programs may include informal support networks, formalized cohorts, mentoring and supervision, municipality-sponsored programs, or college training courses and programs.

Infrastructure of Programs

The data demonstrated there are opportunities for growth in the infrastructure of many New York City Early Intervention programs. Staff development, case conferences, and staff meetings should occur more frequently to provide opportunities for staff collaboration, which fosters a culture of family-centered care (Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010) and team synergy (Garshelis & McConnell, 1993). Additionally, a gap in program infrastructure was identified regarding the observation of staff. Although more than three-fourths of programs offered supervision and mentoring to staff, not all of that support involved observation of direct practice. This is problematic, as assisting staff to improve their delivery of family-centered care may be difficult if providers are not observed working with families. There were slight variations between the infrastructures of programs and characteristics of administrators employed in for-profit versus not-for-profit agencies.

Family-Centered Care in New York City Early Intervention Programs

The results of the project indicated that New York City Early Intervention

programs operated under family-allied and family-focused program models, as outlined

by Dunst and his team (1991). Consequently, there was opportunity for programs to shift

towards a more family-centered paradigm and delivery approach. This begets the

question of leadership as to spearheading an initiative towards family-centered

programming among agencies. Wade and Gargiulo (1989) found that site administrators

tend to have their attention concentrated on the day-to-day operations of their program

and the implementation of mandated policies as opposed to systemic issues outside the

walls of their organization. Consequently, a steering committee focused on

implementing family-centered services (Henneman & Cardin, 2002; Piper, 2011; Walter

& Petr, 2000) could be established or convened by the New York City Department of

Health and Mental Hygiene Bureau of Early Intervention or the local coordinating

council, a mandated component of Early Intervention under federal guidelines, to address

family-centered initiatives in the New York City Early Intervention system. There was

also the hope that administrators who were contacted to participate in this study were

sparked by this topic and will singularly, or in a joint effort, lead a movement to develop

family-centered initiatives within their organizations. This project outlined the need for

college training programs to prepare future Early Intervention administrators to operate

agencies using a family-centered service delivery model.

Policy Implications

Finally, this work opened the door for policy implications for family-centered

care as well as administrators of Early Intervention programs. Dunst (2012) contends

that municipalities and state agencies governing Early Intervention are inhibiting the delivery of family-centered programming because their service delivery practices, policies, language, and conceptualization of Early Intervention are not based on best practice guidelines or current research. Sandall, Smith, and McLean (2000) concur that most state and local municipality level agencies are not using recommended family-centered practices. Dunst's (2012) as well as Sandall, McLean, and Smith's (2000) statements were confirmed by this research, as the rules and regulations imposed by the New York City Department of Health and Mental Hygiene Bureau of Early Intervention were the most frequently cited barrier to providing family-centered care by participants, indicating they were considered the largest impediment to delivering family-centered services.

Additionally, the New York City Department of Health and Mental Hygiene Bureau of Early Intervention adopted the policy that Early Intervention treatment sessions were to be provided under the framework of a participation-based service model. This study indicated that administrators have incorporated that policy into their programs, based on their provided definitions and stated purpose of family-centered care, which emphasized participation-based services. This coincides with the work of Humphry and Geissinger (1993), who found that when local municipalities establish policies, administrators endorsed those policies and provided training for staff on those initiatives. Consequently, it can be assumed that if the New York City Department of Health and Mental Hygiene Bureau of Early Intervention adopted policies aimed at providing family-centered services through practices focused on supporting and partnering with families, New York City Early Intervention programs would respond by delivering

services that were more family-centered. The importance of regional leadership in providing family-centered services is espoused by James and Chard (2010) in the following statement:

> The value of family-centered practice and international best practice guidelines in early intervention for children with disabilities and their families are acknowledged . . . but perhaps the complexity of their practices are not fully realized. Their translation into effective service delivery is dependent on structures and processes being in place at national, regional, and organizational levels to ensure consistent and effective services across all regions and all areas of early intervention practice (p. 282).

Just as family-centered care within an organization originates with the administrator and is infused throughout an agency from the top down, a paradigm of family-centered care needs to originate with the local governing body and be infused through all agencies providing Early Intervention services.

Policy changes concerning administrators of Early Intervention programs were in order, as this project substantiates previous research (Epley et al., 2010; Mandell & Murray, 2009) which established the influential role administrators have on the delivery of family-centered programming. Policies should be instituted that specify qualifications for administrators of Early Intervention programs that equate with the requirements of the position. These qualifications should focus on developing administrators who are able to lead programs that emphasize a family-centered service delivery approach. This can be achieved by providing training to Early Intervention administrators in interpersonal skills, the rules and regulations of Early Intervention, and recommended practice guidelines,

(Johnson et al., 1992; Sandall, McLean, & Smith, 2000) as well as management (Fayol, 1916/1949; Sandall, McLean, & Smith, 2000). This preparation can be offered through college or university courses, intensive certificate-based training programs, or other institutions that can develop similar programs, such as the local coordinating council or New York City Department of Health and Mental Hygiene Bureau of Early Intervention. Because administrators impact the delivery of family-centered services (Epley et al., 2010; Mandell & Murray, 2009) and family-centered care affects outcomes for children and families, adequately preparing administrators to lead organizations that deliver Early Intervention services is paramount to ensuring positive outcomes for families.

This study highlighted implications for practice for administrators of programs, the infrastructure of programs, the delivery of family-centered care, as well as for policies regarding family-centered care in New York City Early Intervention programs.

Implications for Future Research

There were several implications for future research that emerged from this study. Clearly, more research on the role administrators have in the delivery of family-centered services is indicated. Changing the methodology and strategy of inquiry used in this project would yield valuable information for the field of family-centered care and the role administrators have in the delivery of family-centered programming. Polling a larger sample of administrators of Early Intervention programs in New York City or a different geographic region regarding their conceptualizations and practices concerning family-centered care would be one avenue for further research, utilizing similar or different research methodologies. Expanding the administrators studied to include those other than Early Intervention or early childhood program administrators would offer information

about collaborating and partnering with families that would benefit the field of education. Incorporating the feedback of practitioners and families, in conjunction with the responses of administrators, would provide further insight into family-centered program practices and the role administrators have in implementing family-centered programming. Additionally, this study is based purely on the feedback of administrators; therefore, an objective measure of a program's family-centered practices would balance the subjectivity involved.

The results of this study shed light on several factors that deserve closer examination. Further exploring factors related to administrators and programs may yield data as to how to increase the level and quality of family-centered services provided by programs as well as further delve into the role administrators have in the delivery of family-centered care. Specifically, it was determined that participants who were newest to the field were most likely to reference supporting and strengthening families in their definition, viewed purpose of, and response to the challenges of providing family-centered care. Overall, where and how an administrator received his or her training in family-centered care influenced their conceptualization of family-centered care. For example, participants who had a background in special education and received their training in family-centered care from college coursework tended to respond with professionals and families working together in their definition and viewed purpose of family-centered care. It was noted that the respondents who felt there was no way to respond to the barriers of providing family-centered services other than to accept the challenges had the most years of experience working in Early Intervention and had no prior experience working in the field before becoming program administrators. A

significant number of respondents indicated they had no prior experience working in Early Intervention before becoming administrators of programs. It was found that although many programs were providing supervision and mentoring to staff, not all of these programs observe staff on a routine basis. Slight variations were identified between programs based on profit status. Various research studies have identified some agency variables as being more family-centered then others, such as home-based programs (Fingerhut et al., 2013; Judge, 1997; Mahoney & Filer, 1996; Mahoney & O'Sullivan, 1990; Mahoney, O'Sullivan, & Dennebaum, 1990; Mahoney, O'Sullivan, & Fors, 1989; McWilliam et al., 2000; McBride & Peterson, 1997; McWilliam, Tocci, & Harbin, 1998). Most participants with a background in special education reported receiving training in family-centered care from college coursework, which may be the realization of the mandates of IDEA. Further research could be conducted to explore the aforelisted factors and how these elements impact the level of family-centered care provided by a program or an administrator's role in the delivery of family-centered services.

Limitations

There were several limitations to this study. Primarily, the results of this work need to be viewed in light of the response rate and respondents. Participation in this study was voluntary; therefore, the beliefs, practices, policies, and data of the respondents may not be representative of those who did not participate. Creswell (2003) asserts that the function of qualitative research is not necessarily to produce data that are generalizable, but rather to draw a set of conclusions and framework of principles that can be related to other circumstances. The goal of this and all qualitative research was

for the insights, interpretations, and conclusions inferred to have applicability to other situations (Krathwohl, 1998).

This project was designed as a qualitative case study to explore in greater depth the narrative responses of participants, using a questionnaire as the instrument of data collection. However, only 21 administrators participated in this study out of 100 administrators contacted. Mortality of returns, or loss of potential participants, was noted in this study, as 30 questionnaires were incomplete and therefore could not be used in the data analysis. The questionnaire was sent during the summer months, a time when many administrators and staff take vacation. Perhaps only administrators who were invested in the use of family-centered practices were interested in participating. Demographic data revealed that all of the participants had a background in human services, and the majority were experienced program administrators in addition to working in Early Intervention.

Completion of a questionnaire such as used in this project may also have unexpected positive outcomes for the participants. Engaging in a process of self-assessment by examining practices, policies, and conceptualizations may lead to a heightened sense of awareness for program administrators. Participating in a research study may increase sensitivity toward family-centered programming, encourage reflection among administrators, spawn the adoption of new policies and practices, spur dialogue with staff, spark professional development, or rekindle initiatives in programs connected to developing collaborative relationships with families.

Although the administrators who participated may not be representative of all Early Intervention program administrators, the data collected began to offer insights into how administrators conceptualized and implemented family-centered care.

163

Validity and Reliability

To bolster the validity and reliability of this study, an audit trail (Krathwohl, 1998) was created and a rival explanation was explored.

Audit Trail

An audit trail was created to enhance the validity of this study. The audit trail consisted of (a) the data collected, (b) memos generated during the process of analyzing the data, (c) the code book created during the coding process, (d) the interpretative summaries developed as the data analysis process progressed, (e) researcher notes, (f) written documentation of the evolution of codes, categories, and themes that emerged.

Rival Theory

Because all of the respondents in this study demonstrated a limited understanding of family-centered care, according to guidelines established by Mandell and Murray (2009) for assessing an administrator's understanding of family-centered care, it could be suggested that the participants could not clearly articulate the elements of best practice, similar to the findings of Fleming, Sawyer, and Campbell (2011). However, the aggregate of responses provided by the administrators, which included the policies and practices implemented in their programs, the policies and practices identified to represent ideal family-centered care, the most valuable family-centered practice their program offered to families, the barriers to delivering family-centered services, and the definitions and stated purpose of family-centered care all illustrated the same conclusions. The results of the study indicated that New York City Early Intervention programs are implementing the category of practices and policies that support and partner with families least frequently. The semantics and language used by respondents further demonstrated

that programs did not emphasize partnering with families but focused on involving, including, and engaging families to participate in programming. The results were consistent with a family-allied or family-focused program orientation as opposed to a family-centered service delivery paradigm. Unfortunately, the data suggested that until practices and policies that emphasized developing collaborative partnerships with and supporting families were in place, most programs will continue to focus on engaging families in a manner similar to the traditional educational model.

Conclusions

The results of this study indicated that New York City Early Intervention programs were implementing family-focused and family-allied programming according to the family oriented program models outlined by Dunst and his colleagues (1991). The findings in this study were consistent with other works (Dunst, 2002; Mahoney & Filer, 1996; Mahoney & O'Sullivan, 1990; McBride et al., 1993) regarding the delivery of family-centered care in programs providing services to families who have young children with special needs. This project also corroborated the work of Mandell and Murray (2009), by demonstrating that an administrator's conceptualization of family-centered care is reflected in the policies and practices implemented by their program.

The results revealed that administrators emphasized participation-based services while programs were invested in supporting the relationships between practitioners and families as well as respecting the backgrounds of families, which are important components to providing Early Intervention services. Unfortunately, the data suggested that programs were not committed to supporting and collaborating with families, which are the basis of family-centered programming. Additionally, the results indicated

children were prioritized over families and families were identified as of barriers to providing family-centered services, both of which are antithetical to a family-centered paradigm.

This posed the question as to the future of family-centered Early Intervention services in New York City. The opportunity existed for a more family-centered paradigm to be implemented in programs, with the support of stakeholders. This study illuminated the opportunity for growth in the infrastructure of programs, specifically involving practices that support staff, which may lead to the adoption of more family-centered practices. Supporting staff is crucial, as they were simultaneously considered barriers, the most valuable family-centered practice a program offered, and a way to confront the challenges of providing family-centered services. Identifying the issues for growth is the first step in the process of change, change that would benefit the families and children of New York City.

This study highlighted the need to explore characteristics of administrators and programs in future research endeavors, in an effort to improve the quality of family-centered services provided to families enrolled in Early Intervention. Several patterns were noted in the findings related to the administrators newest to the field, how and where administrators receive their training in family-centered care, the profit status of agencies, the organizational practices that involved supporting staff, and administrators who had no prior experience working in Early Intervention before becoming program administrators. These trends deserve to be explored further in future research studies.

This work built on the limited research regarding the role administrators have in the delivery of family-centered services (Mandell & Murray, 2009; Epley et al., 2010).

How administrators conceptualized family-centered care impacted how family-centered care was implemented. This signified the top-down influence of management, based on Fayol's (1916/1949) classical administrative theory, which demonstrated the tremendous leadership potential that administrators have in organizations that provide family-centered services. Additional research is needed to further explore the role administrators have in delivering family-centered care. Such research will not only improve the quality of services for families enrolled in Early Intervention, where family-centered care is mandated, but will also benefit administrators in pre-schools, elementary, middle, junior high, and high schools seeking to adopt a family-centered paradigm as a means to develop collaborative partnerships with families to enhance academic outcomes for students.

REFERENCES

Abidin, R. R., & Seltzer, J. (1981). Special education outcomes: Implications for implementation of Public Law 94-142. *Journal of Learning Disabilities*, *14*(1), 28-31.

Allen, R. I., & Petr, C. G. (1996). Towards developing standards and measurements for family-centered practice in family support programs. In G. H. W. Singer, L. E. Powers, & A. L. Olsen (Eds.), *Redefining family support: Innovations in public-private partnerships* (pp. 57-85). Baltimore, MD: Paul H. Brookes.

Al-Shammari, Z., & Yawkey, T. D. (2008). Extent of parental involvement in improving the students' levels in special education programs in Kuwait. *Journal of Instructional Psychology*, *35*(2), 140-150.

Applequist, K. L., & Bailey, D. B., Jr. (2000). Navajo caregivers' perceptions of Early Intervention services. *Journal of Early Intervention, 23*(1), 47-61.

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine. *Archives of Physical Medicine and Rehabilitation*, *89*(8), 1618-1624.

Bailey, D. B., Jr. (2001). Evaluating parent involvement and family support in Early Intervention and preschool programs. *Journal of Early Intervention*, *24*(1), 1-14.

Bailey, D. B., Jr., Aytch, L. S., Odom, S. L., Symons, F., & Wolery, M. (1999). Early Intervention as we know it. *Mental Retardation and Developmental Disabilities Research Review*, *5*(1), 11-20.

Bailey, D. B., Jr., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., Kahn, L., Mallik, S., Markowitz, J., Spiker, D., Walker, D., & Barton, L.

(2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28*(4), 227-251.

Bailey, D. B., Jr., Buysse, V., Edmundson, R., & Smith, T. M. (1992). Creating family-centered services in Early Intervention: Perceptions of professionals in four states. *Exceptional Children*, *58*(4), 298-309.

Bailey, D. B., Jr., Hebbeler, K., Spiker, D. Scarborough, A., Mallik, S., & Nelson, L. (2005). Thirty-six month outcomes for families of children who have disabilities and participated in Early Intervention. *Pediatrics*, *116*(6), 1346-1352.

Bailey, D. B., Jr., McWilliam, P. J., & Winton, P. J. (1992). Building family-centered practices in Early Intervention: A team-based model for change. *Infants and Young Children*, *5*(1), 73- 82.

Bailey, D. B., Jr., Nelson. L., Hebbeler, K., & Spiker, D. (2007). Modeling the impact of formal and informal supports for young children with disabilities and their families. *Pediatrics*, *120*(4), 992-1002.

Bailey, D. B., Jr., Palsha, S. A., & Simeonsson, R. J. (1991). Professional skills, concerns, and perceived importance of work with families in Early Intervention. *Exceptional Children*, *58*(2), 156-165.

Bailey, D. B., Jr., Raspa, M., & Fox, L. C. (2012). What is the future of family outcomes and family-centered services? *Topics in Early Childhood Special Education*, *31*(4), 216-223.

Bailey, D. B., Jr., Raspa, M., Olmsted, M. G., Novak, S. P., Sam, A. M., Humphreys, B. P., Nelson, R., Robinson, N., & Guillen, C. (2011). Development and psychometric validation of the Family Outcomes Survey - Revised. *Journal of*

Early Intervention, 33(1), 6-23.

Bamm, E. L., & Rosenbaum, P. (2008). Family-centered theory: Origins, development,

barriers, and supports to implementation in rehabilitation medicine. *Archives of*

Physical Medicine and Rehabilitation, *89*(8), 1618-1624.

Belcher, H. M. E., Hairston-Fuller, T. C., & McFadden, J. (2011). How do we

assess family supports and fairness in Early Intervention? *Developmental*

Disabilities Research Reviews, *17*(1), 36-43.

Bellin, M. H., Osteen, P., Heffernan, C., Levy, J. M., & Snyder-Vogel, M. F. (2011).

Parent and health care professional perspectives on family-centered care for

children with special health care needs: Are we on the same page? *Health and*

Social Work, *36*(4), 281-290.

Bensky, J. M., Shaw, S. F., Gouse, A. S., Bates, H., Dixon, B., & Beane, W. E. (1980).

Public Law 94-142 and stress: A problem for educators. *Exceptional Children*,

47(1), 24- 29.

Blue-Banning, M., Summers, J. A., Frankland, H., Nelson, L. L., & Beegle, G. (2004).

Dimensions of family and professional partnerships: Constructive guidelines for

collaboration. *Exceptional Children*, *70*(2), 167-184.

Branson, D. M., & Bingham, A. (2009). Using interagency collaboration to support

family-centered transition practices. *Young Exceptional Children, 12*(3), 15-31.

Brewer, E. J., McPherson, M., Magrab, P. R., & Hutchins, V. L. (1989). Family-centered,

community-based, coordinated care for children with special health care needs.

Pediatrics, *83*(6), 1055-1060.

Brinker, R. P. (1992). Family involvement in Early Intervention: Accepting the

unchangeable, changing the changeable, and knowing the difference. *Topics in Early Childhood Special Education*, *12*(3), 307-322.

Broggi, M. B., & Sabatelli, R. (2010). Parental perceptions of the parent-therapist relationship: Effects on outcomes of Early Intervention. *Physical and Occupational Therapy in Pediatrics*, *30*(3), 234-247.

Bronfenbrenner, U. (1975). Is early intervention effective? In M. Guttentag & E. L. Struening (Eds.), *Handbook of evaluation research, Volume 2* (pp. 519-603). Beverly Hills, CA: Sage.

Brotherson, M. J., Summers, J. A., Naig, L. A., Kyzar, K., Friend, A., Epley, P., Gotto, IV, G. S., & Turnbull, A. P. (2010). Partnership patterns: Addressing emotional needs in Early Intervention. *Topics in Early Childhood Special Education*, *30*(1), 32-45.

Brown, P. M., & Remine, M. D. (2008). Flexibility of programme delivery in providing effective family-centered intervention for remote families. *Deafness and Education International, 10*(4), 213-225.

Bruder, M. B. (2000). Family-centered Early Intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education*, *20*(2), 105-115.

Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for their future. *Exceptional Children*, *76*(3), 339-355.

Bruder, M. B., Dunst, C. J., & Mogro-Wilson, C. (2011). Confidence and competence appraisals of Early Intervention and preschool special education practitioners. *International Journal of Early Childhood Special Education*, *3*(1), 13-37.

Burton, C. B. (1992). Defining family-centered early education: Beliefs of public school,

child care, and Head Start teachers. *Early Education and Development*, *3*(1), 45-59.

Campbell P. H., & Halbert, J. (2002). Between research and practice: Provider perspectives on Early Intervention. *Topics in Early Childhood Special Education*, *22*(4), 213-226.

Campbell, P. H., & Sawyer, L. B. (2007). Supporting learning opportunities in natural settings through participation-based services. *Journal of Early Intervention*, *29*(4), 287-305.

Campbell, P. H., Strickland, B., & La Forme, C. (1992). Enhancing parent participation in the Individualized Family Service Plan. *Topics in Early Childhood Special Education*, *11*(4), 112-124.

Caulfield, J. M. (1989). *The role of leadership in the administration of public schools*. Union, NJ: Nevfield Press.

Carpenter, B. (2007). The impetus for family-centered early childhood intervention. *Child: Care, Health and Development*, *33*(6), 664-669.

Chao, P., Bryan, T., Burstein, K., & Ergul, C. (2006). Family-centered intervention for young children at risk for language and behavior problems. *Early Childhood Education Journal, 34*(2), 147-153.

Childress, D. C. (2004). Special instruction and natural environments: Best practices in Early Intervention. *Infants and Young Children*, *17*(2), 162-170.

Chong, W. H., Goh, W., Tang, H. N., Chan, W. P., Choo, S. (2012). Service practice evaluation of the Early Intervention programs for infants and young children in Singapore. *Children's Health Care, 41*(4), 281-301.

Conroy, T., Yell, M. L., Katsiyannis, A., & Collins, T. S. (2010). The U.S. Supreme

  Court and parental rights under the Individuals with Disabilities Education Act.

  Focus on Exceptional Children, *43*(2), 1-16.

Coots. J. J. (2007). Building bridges with families: Honoring the mandates of IDEIA.

  Issues in Teacher Education, *16*(2), 33-40.

Corbin, J. M., & Strauss A. L. (1998). *Basics of qualitative research: Techniques and*

  procedures for developing grounded theory (2nd ed.). Thousand Oaks, CA: Sage.

Crais, E. R., & Belardi, C. (1999). Family participation in child assessment: Perceptions

  of families and professionals. *Infant-Toddler Intervention: The Transdisciplinary*

  Journal, 9(3), 209-238.

Crais, E. R., Roy, V. P., & Free, K. (2006). Parents' and professionals' perceptions of the

  implementation of family-centered practices in child assessments. *American*

  Journal of Speech-Language Pathology, *15*(4), 365-377.

Crais, E. R., & Wilson, L. B. (1996). The role of parents in child assessment: Self-

  evaluation by practicing professionals. *Infant-Toddler Intervention: The*

  Transdisciplinary Journal, *6*(2), 125-143.

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods*

  approaches (2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating*

  quantitative and qualitative research (3rd ed.). Upper Saddle River, NJ: Pearson.

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional

  support characteristics on the quality of life in families of young children with

  disabilities. *Journal of Intellectual and Developmental Disabilities, 34*(2),

153-162.

deFur, S. (2012). Parents as collaborators: Building partnerships with school and

community-based providers. *Teaching Exceptional Children*, *44*(3), 58-67.

Dempsey, I., & Carruthers, A. (1997). How family-centered are Early Intervention

services: Staff and parent perceptions? *Journal of Australian Research in Early*

Childhood Education, *1*(1), 105-114.

Dempsey, I., & Dunst, C. J. (2004). Helpgiving styles and parent empowerment in

families with a young child with a disability. *Journal of Intellectual and*

Developmental Disability, *29*(1), 40-51.

Dempsey, I., & Keen, D. (2008). A review of processes and outcomes in family-centered

services for children with a disability. *Topics in Early Childhood Special*

Education, 28(1), *42-52.*

Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress,

parenting competence, and family-centered support to young children with an

intellectual or developmental disability. *Research in Developmental Disabilities*,

30(3), 558-566.

Dennis, S. E., & O'Connor, E. (2013). Reexamining quality in early childhood

education: Exploring the relationship between the organizational climate and

the classroom. *Journal of Research in Childhood Education*, *27*(1), 74-92.

Dinnebeil, L. A. (1999). Defining parent education in Early Intervention. *Topics in Early*

Childhood Special Education, *19*(3), 161-164.

Dinnebeil, L. A., Hale, L. M., & Rule, S. (1996). A qualitative analysis of parents' and

service coordinators' descriptions of variables that influence collaborative

relationships. *Topics in Early Childhood Special Education, 16*(3), 322-347.

Dinnebeil, L. A., Hale, L., & Rule, S. (1999). Early Intervention program practices that

    support collaboration. *Topics in Early Childhood Special Education*, *19*(4), 225-

    235.

Dinnebeil, L. A., & Rule, S. (1994). Variables that influence collaboration between

    parents and service coordinators. *Journal of Early Intervention*, *18*(4), 349-361.

Dirks, T., Blauw-Hospers, C. H., Hulshof, L. J., & Hadders-Algra, M. (2011).

    Differences between the family-centered "COPCA" program and traditional

    infant physical therapy based on neurodevelopmental treatment principles.

    Physical Therapy, 91(9), 1303-1322.

Doll, B., & Bolger, M. (2000). The family with a young child with disabilities. In M. J.

    Fine & R. L. Simpson (Eds.), *Collaboration with parents and families of children*

    and youth with exceptionalities (2nd ed., pp.237-256). Austin, TX: Pro-Ed.

Duby, J. C. (2007). Role of the medical home in family-centered Early Intervention

    services. *Pediatrics, 120*(5), 1153-1158.

Dunst, C. J. (1979). Program evaluation and the Education for All Handicapped Children

    Act. *Exceptional Children, 46*(1), 24-31.

Dunst, C. J. (1985). Rethinking Early Intervention. *Analysis and Intervention in*

    Developmental Disabilities, *5*(1), 165-201.

Dunst, C. J. (1999). Placing parent education in conceptual and empirical context.

    Topics in Early Childhood Special Education, *19*(3), 141-147.

Dunst, C. J. (2000). Revisiting "Rethinking Early Intervention." *Topics in Early*

    Childhood Special Education, *20*(2), 95-104.

Dunst. C. J. (2002). Family-centered practices: Birth through high school. *Journal of Special Education*, *36*(3), 139-147.

Dunst, C. J. (2012). Parapatric speciation in the evolution of Early Intervention for infants and toddlers with disabilities and their families. *Topics in Early Childhood Special Education*, *31*(4), 208-215.

Dunst, C. J., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-oriented program models and professional helpgiving practices. *Family Relations*, *51*(3), 221-229.

Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education*, *54*(3), 305-318.

Dunst, C. J., Hamby, D. W., & Brookfield, J. (2007). Modeling the effects of early childhood intervention variables on parent and family well-being. *Journal of Quantitative Methods*, *2*(3), 268-288.

Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2000). Everyday family and community life and children's naturally occurring learning opportunities. *Journal of Early Intervention*, *23*(3), 151-164.

Dunst, C. J., Humphries, T., & Trivette, C. M. (2002). Characterizations of the competence of parents of young children with disabilities. *International Review of Research in Mental Retardation*, *25*, 1-34.

Dunst, C. J., Johanson, C., Trivette, C. M., & Hamby, D. (1991). Family-oriented Early Intervention policies and pratices: Family-centered or not? *Exceptional Children*, *58*(2), 115-126.

Dunst, C. J., Leet, H. E., & Trivette, C. M. (1988). Family resources, personal well-being, and Early Intervention. *Journal of Special Education*, *22*(1), 108-116.

Dunst, C. J., & Raab, M. (2010). Practitioners' self-evaluations of contrasting types of professional development. *Journal of Early Intervention*, *32*(4), 239-254.

Dunst, C. J., & Trivette, C. M. (1994a). Aims and principles of family support programs. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices family support* (pp. 30-48). Cambridge, MA: Brookline.

Dunst, C. J., & Trivette, C. M. (1994b). What is effective helping? In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices family support* (pp. 162-170). Cambridge, MA: Brookline.

Dunst, C. J., & Trivette, C. M. (1996). Empowerment, effective helpgiving practices and family-centered care. *Pediatric Nursing*, *22*(4), 334-337.

Dunst, C. J., & Trivette, C. M. (2009a). Capacity building family-systems intervention practices. *Journal of Family Social Work*, *12*(2), 119-143.

Dunst, C. J., & Trivette, C. M. (2009b). Meta-analytic structural equation modeling of the influences of family-centered care on parent and child psychological health. *International Journal of Pediatrics*. doi:10.115/2009/576840

Dunst, C. J., & Trivette, C. M. (2009c). Using research evidence to inform and evaluate early childhood intervention practices. *Topics in Early Childhood Special Education*, *29(*1), 40-52.

Dunst, C. J., Trivette, C. M., Boyd. K., & Brookfield, J. (1994). Help-giving practices and the self-efficacy appraisals of parents. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices in family support* (pp. 212-220). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., Davis, M., & Cornwell, J. C. (1994). Characteristics of effective helpgiving practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices in family support* (pp. 171-186). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1994a). Final thoughts concerning adoption of family-centered intervention practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices in family support* (pp. 222-225). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1994b). Meaning and key characteristics of empowerment. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices family support* (pp. 2-11). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1994c). Resource-based family-centered intervention practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting & strengthening families: Methods, strategies and practices family support* (pp. 140-151). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (2011). Effects of in-service training on Early Intervention practitioners' use of family-systems intervention practices in the USA. *Professional Development in Education*, *37*(2), 181-196.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (1996). Measuring the helpgiving

practices of human services program practitioners. *Human Relations*, *49*(6), 815-

835.

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered

helpgiving practices research. *Mental Retardation and Developmental Disabilities*

Research Reviews, *13*(4), 370-378.

Dunst, C. J., Trivette, C. M., Hamby, D. W., & Bruder, M. B. (2006). Influences of

contrasting natural learning environment experiences on child, parent and family

well-being. *Journal of Developmental and Physical Disabilities*, *18*(3), 235-250.

Dunst, C. J., Trivette, C. M., & Johanson, C. (1994). Parent-professional collaboration

and partnerships. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting*

& strengthening families: Methods, strategies and practices family support (pp.

197-211). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Mott, D. W. (1994). Strengths-based family-centered

intervention practices. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.),

Supporting & strengthening families: Methods, strategies and practices family

support (pp. 115-131). Cambridge, MA: Brookline.

Dunst, C. J., Trivette, C. M., & Snyder, D. M. (2000). Family-professional partnerships:

A behavioral science perspective. In M. J. Fine & R. L. Simpson (Eds.),

Collaboration with parents and families of children and youth with

exceptionalities (2nd ed., pp.27-48). Austin, TX: Pro-Ed.

Duwa, S. M., Wells, C., & Lalinde, P. (1993). Creating family-centered programs and

policies. In D. M. Bryant & M. A. Graham (Eds.), *Implementing Early Intervention: From research to effective practice* (pp. 92-123). New York, NY: Guilford Press.

Edwards, C. C., & Da Fonte, A. (2012). The 5-point plan: Fostering successful partnerships with families of students with disabilities. *Teaching Exceptional Children*, *42*(3), 6-13.

Edwards, M. A., Millard, P., Praskac, L. A., & Wisniewski, P. A. (2003). Occupational therapy and Early Intervention: A family-centered approach. *Occupational Therapy International, 10*(4), 239-252.

English, F. W. (1994). *Theory in educational administration*. New York, NY: Harper Collins College.

Epley, P., Gotto IV, G. S., Summers, J. A., Brotherson, M. A., Turnbull, A. P., & Friend, A. (2010). Supporting families of young children with disabilities: Examining the role of administrative structures. *Topics in Early Childhood Special Education*, *30*(1), 20-31.

Epley, P. H., Summers, J. A., & Turnbull, A. (2011). Family outcomes of Early Intervention: Families' perceptions of need, services, and outcomes. *Journal of Early Intervention*, *33*(3), 201-219.

Epley, P., Summers, J. A., & Turnbull, A. (2010). Characteristics and trends in family-centered conceptualizations. *Journal of Family Social Work*, *13*(3), 269-285.

Espe-Sherwindt, M. (2008). Family-centered practice: Collaboration, competency and evidence. *Support for Learning*, *23*(3), 136-143.

Faramarzi, S., & Afrooz, G. (2009). The effect of psychological and educational family-centered Early Intervention on fathers' mental health of children with Down Syndrome. *Journal of Psychology*, *13*, 272-288.

Farrell, A. F. (2009). Validating family-centeredness in Early Intervention evaluation reports. *Infants and Young Children*, *22*(4), 238-252.

Fay, T., & Carr, F. (2010). Tailoring Early Intervention programs to the needs of families: Illustrative case studies from an integrated parent-child centre. *Developing Practices, 25*, 43-54.

Fayol, H. (1949). *General and industrial management* (C. Storrs, Trans.). London: Sir Isaac Pitman and Sons. (Original work published 1916).

Fingerhut, P. E., Piro, J., Sutton, A., Campbell, R., Lewis, C., Lawji, D., & Martinez, N. (2013). Family-centered principles implemented in home-based, clinic-based, and school-based pediatric settings. *American Journal of Occupational Therapy*, *67*(2), 228-235.

Fiorentini, C. (2012, April). *Bearing the cost of Early Intervention services: Recent changes not likely to shift much spending from city & state to private insurers* (Fiscal Brief). New York, NY: New York City Independent Budget Office. (online) Available at www.ibo.nyc.ny.us/iboreports/ei4192012.pdf

Fleming, J. L., Sawyer, L. B., & Campbell, P. H. (2011). Early Intervention providers' perspectives about implementing participation-based practices. *Topics in Early Childhood Special Education*, *30*(4), 233-244.

Florian, L. (1995). Part H Early Intervention program: Legislative history and intent of the law. *Topics in Early Childhood Special Education, 15*(3), 247-263.

Fordham, L., Gibson, F., & Bowes, J. (2011). Information and professional support: Key factors in the provision of family-centered early childhood intervention services. *Child: Care, Health and Development, 38*(5), 647-653.

Gallagher, J. J. (2000). The beginnings of federal help for young children with disabilities. *Topics in Early Childhood Special Education*, *20(*1), 3-6.

Garland, C. W., & Linder, T. W. (1994). Administrative challenges in Early Intervention. In L. Johnson, R. J. Gallagher, M. J. La Montange, & J. B. Jordan (Eds.), *Meeting Early Intervention challenges: Issues from birth to three* (2nd ed., pp. 133-166). Baltimore, MD: Paul H. Brookes.

Garrett, J. N., Thorp, E. K., Behrmann, M. M., & Denham, S. A. (1998). The impact of Early Intervention legislation: Local perceptions. *Topics in Early Childhood Special Education*, *18*(3), 183-190.

Garshelis, J. A., & McConnell, S. R. (1993). Comparison of family needs assessed by mothers, individual professionals, and interdisciplinary teams. *Journal of Early Intervention, 17*(1), 36-49.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago, IL: Aldine.

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L., & Berns, S. D. (2011). Family support and family-centered care in the neonatal intensive care unit: Origins, advances, impact. *Seminars in Perinatology*, *35*(1), 20-28.

Gorey, K. M. (2001). Early childhood education: A meta-analytic affirmation of the short- and long-term benefits of educational opportunity. *School Psychology Quarterly*, *16*(1), 9-30.

Guralnick, M. J. (1998). Effectiveness of Early Intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, *102*(4) 319-345.

Guralnick, M. J. (2001). A developmental systems model for Early Intervention. *Infants and Young Children*, *14(*2), 1-18.

Guralnick, M. J. (2005). Early Intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of Applied Research in Intellectual Disabilities*, *18*(4), 313-324.

Guralnick, M. J. (2011). Why Early Intervention works: A systems perspective. *Infants and Young Children*, *24*(1), 6-28.

Haring, K. A., & Lovett, D. L. (2001). Early Intervention and early childhood services for families in rural settings. *Rural Special Education Quarterly*, *29*(4), 16-23.

Hebbeler, K. (1997). A system in a system: Sociopolitical factors and Early Intervention. In S. K. Thurman, J. R. Cornwell, & S. R. Gottwald (Eds.), *Contents of early intervention: Systems and settings* (pp. 19-38). Baltimore, MD: Paul H. Brookes.

Hebbeler, K., Barton, L. R., & Mallik, S. (2008). Assessment and accountability for programs serving young children with disabilities. *Exceptionality*, *16*(1), 48-63.

Henneman, E. A., & Cardin, S. (2002). Family-centered critical care: A practical approach to making it happen. *Critical Care Nurse*, *22*(6), 12-19.

Herda, E. A. (1980). Aspects of general education governance and PL 94-142 implementation. *Focus on Exceptional Children*, *12*(5), 1-12.

Howland, A., Anderson, J. A., Smiley, A. D., & Abbott, D. J. (2006). School liaisons:

Bridging the gap between home and school. *The School Community Journal*, *16*(2), 47-68.

Humphry, R., & Geissinger, S, (1993). Issues in Early Intervention: Measuring attitudes about family-centered services. *The Occupational Therapy Journal of Research*, *13*(3), 147-162.

Ingber, S., & Dromi, E. (2010). Actual versus desired family-centered practice in Early Intervention for children with hearing loss. *Journal of Deaf Studies and Deaf Education*, *15*(1), 59-71.

Itkonen, T. (2007). PL 94-142: Policy, evolution, and landscape shift. *Issues in Teacher Education*, *16*(2), 7-17.

Iverson, M. D., Shimmel, J. P., Ciacera, S. L., & Prabhakar, M. (2003). Creating a family-centered approach to Early Intervention services: Perceptions of parents and professionals. *Pediatric Physical Therapy*, *15*(1), 23-31.

Jackson, C. W., Traub, R. J., & Turnbull, A. P. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication Disorders Quarterly, 29*(2), 82-98.

James, C., & Chard, G. (2010). A qualitative study of parental experiences of participation and partnership in an early intervention service. *Infants and Young Children, 23*(4), 275-285.

Jeynes, W. H. (2005). A meta-analysis of the relation of parental involvement to urban elementary school student academic achievement. *Urban Education*, *40*(3), 237-269.

Jeynes, W. (2012). A meta-analysis of the efficacy of different types of parental

involvement programs for urban students. *Urban Education*, *47*(4), 706-742.

Johnson, L. J., Kilgo, J., Cook, M. J., Hammitte, D. J., Beauchamp, K., & Finn. D. (1992). The skills needed by Early Intervention administrators/supervisors: A study across six states. *Journal of Early Intervention*, *16*(2), 136-145.

Jolley, J., & Shields, L. (2009). The evolution of family-centered care. *Journal of Pediatric Nursing*, *24*(2), 164-170.

Judge, S. L. (1997). Parental perceptions of help-giving practices and control appraisals in Early Intervention programs. *Topics in Early Childhood Special Education*, *17*(4), 457-476.

Judge, S. (2002). Family-centered assistive technology assessment and intervention practices for Early Intervention. *Infants and Young Children, 15*(1), 60-68.

Katsiyannis, A., & Herbst, M. (2004). 20 ways to minimize litigation in special education. *Intervention in School and Clinic*, *40*(2), 106-110.

Keen, D. (2007). Parents, families, and partnerships: Issues and considerations. *International Journal of Disability, Development and Education*, *54*(3), 339-349.

Kelly, A., Ghalaieny, T., & Devitt, C. (2012). A pilot study of Early Intervention for families with children with or at risk of an intellectual disability in northern Malawi. *Journal of Policy and Practice in Intellectual Disabilities, 9*(3), 195-205.

Keogh, B. K. (2007). Celebrating PL 94-142: The Education of All Handicapped Children Act of 1975. *Issues in Teacher Education*, *16(*2), 65-69.

King, G., Kertoy, M., King, S., Law, M., Rosenbaum, P., & Hurley, P. (2003). A measure of parents' and service providers' beliefs about participation in family-centered services. *Children's Health Care*, *32*(3), 191-214.

King, G., Law, M., Kertoy, M., King, S., Rosenbaum, P., & Pollack, N. (1998).

    Measures of Beliefs about Participation in Family-Centered Service: Provider's

    Scale. Hamilton, ON, Canada: CanChild Centre for Childhood Disability

    Research.

King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers'

    perceptions of family-centeredness of children's rehabilitation services. *Physical*

    and Occupational Therapy in Pediatrics, *18*(1), 21-40.

King, G., Tam, C., Fay, L., Pilkingtonton, M., Servais, M., & Petrosian, H. (2011).

    Evaluation of an occupational therapy mentorship program: Effects on therapists'

    skills and family-centered behavior. *Physical and Occupational Therapy in*

    Pediatrics, *31*(3), 245-262.

King, S., Rosenbaum, P., & King, G. (1995). *The Measures of Processes of Care*

    (MPOC): A means to access family-centered behaviors of health care providers.

    Hamilton, ON, Canada: CanChild Centre for Childhood Disability Research.

Kingsley, K., & Mailloux, Z. (2013). Evidence for the effectiveness of different service

    delivery models in Early Intervention services. *The American Journal of*

    Occupational Therapy, 67(4)*,* 431-436.

Krathwohl, D. R. (1998). *Methods of educational and social science research: An*

    integrated approach (2nd ed.). New York, NY: Longman.

Kummerer, S. E. (2012). Promising strategies for collaborating with Hispanic parents

    during family-centered speech-language intervention. *Communication Disorders*

    Quarterly, 33(2), 84-95.

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M.

(2012). Family-centered care: Current applications and future directions in

pediatric health care. *Maternal and Child Health*, *16*(2), 297-305.

Kyzar, K. B., Turnbull, A. P., & Summers, J. A. (2012). The relationship of family

support to family outcomes: A synthesis of key findings from research on severe

disability. *Research and Practice for Persons with Severe Disabilities*, *37*(1),

31-44.

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P.

(2003). Factors affecting family-centered service delivery for children with

disabilities. *Child: Care Health and Development*, *29*(5), 357-366.

Law, M., Teplicky, R., King, S., King, G., Kertoy, M., Moning, T., Rosenbaum, P., &

Burke-Gaffney, J. (2005). Family-centered service: Moving ideas into practice.

Child: Care, Health and Development, 31(6), 633-642.

Leafstedt, J. M., Iktonen, T., Arner-Costello, F., Hardy, A., Korenstein, B., Medina, M.,

Medina, E., Murray, A., & Regester, A. (2007). "Was it is worth it? You bet":

The impact of PL 94-142 on lives and careers. *Issues in Teacher Education*,

16(2), 19-31.

Leedy, P. D. (1997). *Practical research: Planning and design* (6th ed.). Upper

Saddle River, NJ: Merrill.

Mahoney, G. (2007). Social work and Early Intervention. *Children and Schools*, *29*(1),

3-5.

Mahoney, G., & Bella, J. M. (1998). An examination of the effects of family-centered

Early Intervention. *Topics in Early Childhood Special Education*, *18(*2), 83-94.

Mahoney, G., Boyce, G., Fewell, R. R., Spiker, D., & Wheeden, C. A. (1998). The

relationship of parent-child interaction to the effectiveness of Early Intervention services for at-risk children and children with disabilities. *Topics in Early Childhood Special Education*, *18*(1), 5-17.

Mahoney, G., & Filer, J. (1996). How responsive is Early Intervention to the priorities and needs of families? *Topics in Early Childhood Special Education*, *16*(4), 437-457.

Mahoney, G., Kaiser, A., Girolametto, L., MacDonald, J., Robinson, C., Safford, P., & Spiker, D. (1999). Parent education in Early Intervention: A call for renewed focus. *Topics in Early Childhood Special Education*, *19*(3), 131-140.

Mahoney, G., & O'Sullivan, P. (1990). Early Intervention practices with families of children with handicaps. *Mental Retardation*, *28*(3), 169-176.

Mahoney, G., O'Sullivan, P., & Dennebaum, J. (1990). A national study of mothers' perceptions of family-focused Early Intervention. *Journal of Early Intervention*, *14*(2), 133-146.

Mahoney, G., O'Sullivan, P., & Fors, S. (1989). The family practices of service providers for young handicapped children. *Infant Mental Health Journal*, *10*(2), 75-83.

Mahoney, G., & Wiggers, B. (2007). The role of parents in Early Intervention: Implications for social work. *Children and Schools*, *29*(1), 7-15.

Mandell, C. J., & Murray, M. M. (2009). Administrators' understanding and use of family-centered practices. *Journal of Early Intervention*, *32(1)*, 17-37.

Mannan, H., Summers, J. A., Turnbull, A. P., & Poston, D. P. (2006). A review of outcome measures in early childhood programs. *Journal of Policy and Practice in Intellectual Disabilities*, *3*(4), 219-238.

McBride, S. L., Brotherson, M. J., Joanning, H., Whiddon, D., & Demmit, A. (1993). Implementation of family-centered services: Perceptions of families and professionals. *Journal of Early Intervention*, *17*(4), 414-430.

McBride, S. L., & Peterson, C. (1997). Home-based Early Intervention with families of children with disabilities: Who is doing what? *Topics in Early Childhood Special Education*, *17*(2), 209-233.

McCoy, S., & Glazzard, P. (1978). Winning the case but losing the child: Interdisciplinary experiences with P.L. 94-142. *Journal of Clinical Child Psychology*, *7*(3),205-208.

McNaughton, D. (1994). Measuring parent satisfaction with early childhood intervention programs: Current practice, problems, and future perspectives. *Topics in Early Childhood Special Education*, *14*(1), 26-48.

McWilliam, R. A. (1999). Controversial practices: The need for a reacculturation of Early Intervention fields. *Topics in Early Childhood Special Education*, *19*(3), 177-188.

McWilliam, R. A., Ferguson, A., Harbin, G., Porter, P., Munn, D., & Vandiviere, P. (1998). The family-centeredness of Individualized Family Service Plans. *Topics in Early Childhood Special Education*, *18*(2), 69-82.

McWilliam, R. A., Lang, L., Vandiviere, P., Angell, R., Collins, L., & Underdown, G. (1995). Satisfaction and struggles: Family perceptions of Early Intervention services. *Journal of Early Intervention*, *19(*1), 43-60.

McWilliam, R. A., Maxwell, K. L., & Sloper, K. M. (1999). Beyond "involvement": Are

elementary schools ready to be family-centered? *School Psychology Review*, *28*(3), 378-394.

McWilliam, R. A., & Scott, S. (2001). A support approach to Early Intervention: A three-part framework. *Infants and Young Children*, *13*(4), 55-66.

McWillian, R. A., Snyder, P., Harbin, G. L., Porter, P., & Munn, D. (2000). Professionals' and families' perceptions of family-centered practices in infant-toddler services. *Early Education and Development*, *11*(4), 519-538.

McWilliam, R. A., Tocci, L., & Harbin, G. L. (1998). Family-centered services: Service providers' discourse and behavior. *Topics in Early Childhood Special Education*, *18*(4), 206-221.

Mead, J. F., & Paige, M. A. (2008). Parents as advocates: Examining the history and evolution of parents' rights to advocate for children with disabilities under IDEA. *Journal of Legislation*, *34*, 123-167.

Milligan, J., Neal, G., & Singleton, J. (2012) Administrators of special and gifted education: Preparing them for the challenge. *Education*, *133*(1), 171-180.

Minke, K. M., & Scott, M. M. (1995). Parent-professional relationships in Early Intervention: A qualitative investigation. *Topics in Early Childhood Special Education*, *15*(3), 335-352.

Moeller, M. P., Carr, G., Seaver, L., Stedler-Brown, A., & Holzinger, D. (2013). Best practices in family-centered Early Intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, *18*(4), 429-445.

Murphy, D. L., Lee. I. M., Turbiville, V., Turnbull, A. P., & Summers, J. A. (1992). *Family-Centered Program Rating Scale: Providers' Scale*. Lawrence, KS: University of Kansas, Beach Center on Policies and Disabilities.

Murphy, D. L., Lee, I. M., Turnbull, A. P., & Turbiville, V. (1995). The Family-Centered Program Rating Scale: An instrument for program evaluation and change. *Journal of Early Intervention*, *19*(1), 24-42.

Murray, M. M., & Curran, E. M. (2008). Learning together with parents of children with disabilities: Bring parent-professional partnership education to a new level. *Teacher Education and Special Education*, *31*(1), 59-63.

Murray, M. M., & Mandell, C. J. (2005). Innovative family-centered practices in personnel practices. *Teacher Education and Special Education*, *28*(1), 74-77.

Murray, M. M., & Mandell, C. J. (2006). On-the-job practices of early childhood special education providers trained in family-centered practices. *Journal of Early Intervention*, *28*(2), 125-138.

Nelson, L. G. L., Summers, J. A., & Turnbull, A. P. (2004). Boundaries in family-professional relationships: Implications for special education. *Remedial and Special Education*, *25*(3), 153-165.

Nevada State Health Division. (2011). *BA 3208 Early Intervention services for children under the age of 3 with disabilities.* Available at Health.nv.gov/BudgetDocuments/2012-2013/NEISImpactPaper.pdf (posted 4/6/2011).

Odom, S. L. (2009). The tie that binds: Evidence-based practice, implementation

science, and outcomes for children. *Topics in Early Childhood Special Education*, *29*(1), 53-61.

Odom, S. L., & Wolery, M. (2003). A unified theory of practice in Early Intervention/early childhood special education: Evidence-based practices. *Journal of Special Education*, *37*(3), 164-173.

O'Neil, M. E., & Palisano, R. J. (2000). Attitudes toward family-centered care and clinical decision making in Early Intervention among physical therapists. *Pediatric Physical Therapy*, *12*, 173-182.

Osher, T. W., & Osher, D. M. (2002). The paradigm shift to true collaboration with families. *Journal of Child and Family Studies*, *11*(1), 47-60.

Ozdemir, S. (2008). A paradigm shift in Early Intervention services: From child-centeredness to family centeredness. *e-Journal of New World Sciences Academy, 3*(2), 321-331.

Pang, Y. (2010). Facilitating family involvement in Early Intervention to preschool transition. *The School Community Journal, 20*(2), 183-198.

Park, J., & Turnbull, A. P. (2003). Service integration in Early Intervention: Determining interpersonal and structural factors for its success. *Infants and Young Children*, *16*(1), 48-58.

Parker, L. D., & Ritson, P. A. (2005). Revisiting Fayol: Anticipating contemporary management. *British Journal of Management*, *16*(3), 175-194.

Paul, D., & Roth, F. P. (2011). Guiding principles and clinical applications for speech-language pathology practice in Early Intervention. *Language, Speech, and Hearing Services in Schools*, *42*(3), 320-330.

Pereira, A. P. D. S., & Serrano, A. M. (2014). Early Intervention in Portugal: Study of
      professionals' perceptions. *Journal of Family Social Work*, *17*, 263-282.

Perrin, J. M., Romm, D., Bloom, S. R., Homer, C. J., Kuhlthau, K. A., Cooley, C.,
      Duncan, P., Roberts, R., Sloyer, P., Wells, N., & Newacheck, P. (2007). A family-
      centered, community-based system of services for children and youth with special
      health care needs. *Archives of Pediatric & Adolescent Medicine*, *161*(10), 933-
      936.

Peterander, F. (2000). The best quality cooperation between parents and experts in
      Early Intervention. *Infants and Young Children*, *12*(3), 32-45.

Peterson, C. A., Luze, G. J., Eshbaugh, E. M., Jeon, H. J., & Kantz, K. R. (2007).
      Enhancing parent-child interaction through home visiting: Promising practice or
      unfilled promise? *Journal of Early Intervention*, *29*(2), 119-140.

Pickering, D., & Busse, M. (2010). An audit of disabled children's services–what value
      is the MPOC-SP? *Clinical Audit*, *2*, 13-22.

Piper, L. E. (2011). The ethical leadership challenge: Creating a culture of patient-and
      family-centered care in the hospital setting. *The Health Care Manager*, *30*(2),
      125-132.

Podvey, M. C., Hinojosa, J., & Koenig, K. P. (2013). Reconsidering insider status for
      families during the transition from Early Intervention to preschool special
      education. *The Journal of Special Education. 46*(4), 211-222.

Pryor, M. G., & Taneja, S. (2010). Henri Fayol, practitioner and theoretician–revered
      and reviled. *Journal of Management History*, *16*(4), 489-503.

Pugh, D. S., & Hickson, D. J. (1997). *Writers on organizations* (5th ed.). Thousand Oaks,

CA: Sage.

Raghavendra, P., Murchland, S., Bentley, M., Wake-Dyster, W., & Lyons, T. (2007).
Parents' and service providers' perceptions of family-centered practice in a
community-based, paediatric disability service in Australia. *Child: Care, Health
and Development*, *33*(5), 586-592.

Ramey, C. T., & Ramey, S. L. (1998). Early Intervention and early experience. *American
Psychologist*, *53*(2), 109-120.

Rapport, M. J. K., McWilliam, R. A., & Smith, B. J. (2004). Practices across disciplines
in Early Intervention: The research base. *Infants and Young Children*, *17*(1),
32-44.

Raspa, M., Bailey, D. B., Murrey, G. O., Nelson, R., Robinson, N., Simpson, M. E.,
Guillen, C., & Houts, R. (2010). Measuring family outcomes in Early
Intervention: Findings from a large-scale assessment. *Exceptional Children,
76*(4), 496-510.

Richmond, J., & Ayoub, C. C. (1993). Evolution of Early Intervention philosophy. In D.
M. Bryant & M. A. Graham (Eds.), *Implementing Early Intervention: From
research to effective practice* (pp. 1-17). New York, NY: Guilford Press.

Roggman, L. A., Boyce, L. K., Cook, G. A., & Jump, V. K. (2001). Inside home visits: A
collaborative look at process and quality. *Early Childhood Research Quarterly*,
16(1), 53-71.

Romski, M., Sevcik, R. A., Adamson, L. B., Smith, A., Cheslock, M., & Bakeman, R.

(2011). Parent perceptions of the language development of toddlers with developmental delays before and after participation in parent-coached language interventions. *American Journal of Speech-Language Pathology*, *20*(2), 111-118.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centered service: A conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics*, *18*(1), 1-20.

Roush, J., Harrison, M., & Palsha, S. (1991). Family-centered Early Intervention: The perceptions of professionals. *American Annals of the Deaf*, *136*(4), 360-366.

Rupiper, M., & Marvin, C. (2004). Preparing teachers for family-centered services: A survey of preservice curriculum content. *Teacher Education and Special Education, 27*(4), 384-395.

Sandall, S., McLean, M. E., & Smith, B. J. (2000). *DEC recommended practices in Early Intervention/early childhood special education*. Longmont, CO: Sopris West.

Sawyer, L. B. E., & Campbell, P. H. (2009). Beliefs about participation-based practices in Early Intervention. *Journal of Early Intervention*. *31*(4), 326-343.

Sawyer, L. B. E., & Campbell, P. H. (2012). Early Interventionists' perspectives on teaching caregivers. *Journal of Early Intervention*, *34*(2), 104-124.

Sewell, T. (2012). Are we adequately preparing teachers to partner with families? *Early Childhood Education Journal*, *40*(5), 259-263.

Shannon, P. (2004). Barriers to family-centered services for infants and toddlers with developmental delays. *Social Work*, *49*(2), 301-308.

Shelton, T. J., Jeppson, E. S., & Johnson, B. H. (1987). *Family-centered care for*

children with special health care needs. Washington, DC: Association for the Care of Children's Health.

Smith, I., & Boyns, T. (2005). British management theory and practice: The impact of Fayol. *Management Decision*, *43*(10), 1317-1334.

Spann, S. J., Kohler, E. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, *18*(4), 228-237.

Staples, K. E., & Diliberto, J. A. (2010). Guidelines for successful parent involvement: Working with parents of students with disabilities. *Teaching Exceptional Children*, *42*(6), 58-63.

Stoneman, Z. (1993). The effects of attitude on preschool integration. In C. A. Peck, S. L. Odom, & D. D. Bricker (Eds.), *Integrating young children with disabilities into community programs: Ecological perspectives on research and implementation* (pp. 223-248). Baltimore, MD: Paul H. Brookes.

Summers, J. A., Dell'Oliver, C., Turnbull, A. P., Benson, H. A., Santelli, E., Campbell, M., & Siegel-Causey, E. (1990). Examining the individualized family service plan process: What are family and practitioner preferences? *Topics in Early Childhood Special Education*, *10*(1), 78-99.

Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the quality of family-professional partnerships in special education services. *Exceptional Children*, *72*(1), 65-81.

Summers, J. A., Marquis, J., Mannan, H., Turnbull, A. P., Fleming, K., Poston, D. J.,

Wang, M., & Kupzyk, K. (2007). Relationships of perceived adequacy of services, family-professional partnerships, and family quality of life in early childhood service programmes. *International Journal of Disability, Development and Education*, *54*(3), 319-338.

Summers, J. A., Steeples, T., Peterson, C., Naig, L., McBride, S., Wall, S., Liebow, H., Swanson, M., & Slowitschek, J. (2001). Policy and management supports for effective service integration in Early Head Start and Part C programs. *Topics in Early Childhood Special Education*, *21(*1), 16-30.

Sylva, J. A. (2005). Issues in Early Intervention: The impact of cultural diversity on service delivery in natural environments. *Multicultural Education, 13*(2), 26-29.

Tang, H. N., Chong, W. H., Goh, W., Chan, W. P., & Choo, S. (2011). Evaluation of family-centered practices in the Early Intervention programmes for infants and young children in Singapore with Measure of Processes of Care for Service Providers and Measure of Beliefs about Participation in Family-Centered Service. *Child: Care, Health and Development*, *38*(1), 54-60.

Thomas, S. B. (1998). Family-centered Early Intervention: Review of *Partnerships in Family-Centered Intervention: A Guide to Collaborative Early Intervention* by Peggy Rosin, Amy D. Whitehead, Linda J. Tuchman, George S. Jesien, Audrey L. Begun, and Liz Irwin. *Journal for a Just and Caring Education, 4*(3), 355-358.

Thompson, L., Lobb, C., Elling, R., Herman, S., Jurkiewicz, T., & Hulleza, C. (1997). Pathways to family empowerment: Effects of family-centered delivery of Early Intervention services. *Exceptional Children*, *64*(1), 99-113.

Tomasello, N. M., Manning, A. R., & Dulmus, C. N. (2010). Family-centered Early

Intervention for infants and toddlers with disabilities. *Journal of Family Social Work*, *13*(2), 163-172.

Trivette, C. M., Dunst, C. J., Boyd, K., & Hamby, D. W. (1995). Family-oriented program models, help-giving practices, and parental control appraisals. *Exceptional Children*, *62*(3), 237-248.

Trivette, C. M., Dunst, C. J., & Hamby, D. (1996a). Characteristics and consequences of help-giving practices in contrasting human service programs. *American Journal of Community Psychology*, *24*(2) 273-293.

Trivette, C. M., Dunst, C. J., & Hamby, D. W. (1996b). Factors associated with perceived control appraisals in a family-centered Early Intervention program. *Journal of Early Intervention, 20*(2), 165-178.

Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influences of family-systems intervention practices on parent-child interactions and child development. *Topics in Early Childhood Special Education*, *30*(1), 3-19.

Trute, B., & Hiebert-Murphy, D. (2007). The implications of "working alliance" for the measurement and evaluation of family-centered practice in childhood-disability services. *Infants and Young Children*, *20*(2), 109-119.

Tucker, V., & Schwartz, I. (2013). Parents' perspectives of collaboration with school professionals: Barriers and facilitators to successful partnerships in planning for students with ASD. *School Mental Health*, *5*(1), 3-14.

Turnbull, A. P., Summers, J. A., Turnbull, R., Brotherson, M. J., Winton, P., Roberts, R., Snyder, P., McWilliam, R., Chandler, L., Schrandt, S., Stowe, M., Bruder, M. B., Diveriere, N., Epley, P., Hornback, M., Huff, B., Miksch, P., Mitchell, L.,

Sharp, L., & Stroup-Rentier, V. (2007). Family supports and services in Early

Intervention: A bold vision. *Journal of Early Intervention*, *29*(3), 187-206.

Urwick, L. (1949). Foreword. Fayol, H. (1949). *General and industrial management* (C.

Storrs, Trans.) (pp. v-xx) London: Sir Isaac Pitman and Sons. (Original work

published 1916).

Valle, J. W. (2011). Down the rabbit hole: A commentary about research on parents and

special education. *Learning Disability Quarterly*, *34*(3), 183-190.

Valle, J. W., & Aponte, E. (2002). IDEA and collaboration: A Bakhtinian perspective on

parent and professional discourse. *Journal of Learning Disabilities, 35*(5), 469-

479.

Wade, P., & Gargiulo, R. M. (1989). Public school administrators' concerns with

implementing the least restrictive environment provision of Public Law 94-142.

National Forum of Special Education Journal, *1*(1), 59-66.

Walter, U. M., & Petr, C. G. (2000). A template for family-centered interagency

collaboration. *Families in Society*, *81*(5), 494-503.

Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D., & Mannan, H. (2006).

Perspectives of fathers and mothers of children in Early Intervention programmes

in assessing family quality of life. *Journal of Intellectual Disability Research*,

50(12), 977-988.

Warfield, M. E., Hauser-Cram, P., Krauss, M. W., Shonkoff, J. P., & Upshur, C. C.

(2000). The effect of Early Intervention services on maternal well-being. *Early

Education and Development*, *11*(4), 499-517.

Weatherley, R., & Lipsky, M. (1977). Street-level bureaucrats and institutional

    innovation: Implementing special education reform. *Harvard Educational*

    Review, *47(*2), 171-197.

Wehman, T. (1998). Family-centered Early Intervention services: Factors contributing to

    increased parent involvement and participation. *Focus on Autism and Other*

    Developmental Disabilities, 13(2), 80-86.

Wilkens, A., Leonard, H., Jacoby, P., MacKinnon, E., Clohessy, P., Forouhgi, S., &

    Slack-Smith, L. (2010). Evaluation of processes of family-centered care for young

    children with intellectual disability in Western Australia. *Child: Care, Health and*

    Development, *36*(5), 709-718.

Woods, J. J., Wilcox, M. J., Friedman, M., & Murch, T. (2011). Collaborative

    consultation in natural environments: Strategies to enhance family-centered

    supports and services. *Language, Speech, and Hearing Services in Schools*, *42*(3),

    379-392.

Woodside, J. M., Rosenbaum, P. L., King, S. M., & King, G. A. (2001). Family-centered

    service: Developing and validating a self-assessment tool for pediatric service

    providers. *Children's Health Care*, *30*(3), 237-252.

Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Washington, D C:

    Sage.

Yukl, G. (1998). *Leadership in organizations* (4th ed.). Upper Saddle River, NJ: Prentice

    Hall.

Zhang, C., Bennett, T., & Dahl, M. (1999). Family-centered practice in Early

    Intervention service delivery: A case study. *Infant-Toddler Intervention*: *The*

    Transdisciplinary Journal, *9*(4), 331-351.

Ziviani, J., Feeney, R., & Khan, A. (2011). Early Intervention services for children with

    physical disability: Parents' perceptions of family-centeredness and service

    satisfaction. *Infants and Young Children, 24*(4), 364-382.

APPENDIX A

QUESTIONNAIRE

1. What is your definition of family-centered care? *(Fingerhut et al., 2013; Mandell & Murray, 2009)*

2. What is the purpose of family-centered care in Early Intervention? *(Murray & Mandell, 2006)*

3. What practices are implemented in your program? (indicate all that apply) *(Mandell & Murray, 2009; Murray & Mandell, 2006)*
   - Incorporate fathers, siblings, grandparents, and extended family into programming by holding specialized groups, program sponsored activities, and including them into sessions *(Haring & Lovett, 2001; King et al., 1998; Murphy et al., 1992; Peterander, 2000; Shelton, Jeppson, & Johnson, 1987; Summers et al., 2007)*
   - Provide professional development on how to work collaboratively with families that all staff are required to attend *(Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Guralnick, 2005; Iverson et al., 2003; Mandell & Murray, 2009; Moeller et al., 2013; Pickering & Busse, 2010; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
   - Formally prepare families to participate in meetings, such as what to expect and how to advocate effectively for their family *(Jackson, Traub, & Turnbull, 2008; King et al., 1998; Mandell & Murray, 2009; Murphy et al., 1992; Staples & Dilberto, 2010)*
   - Focus on the child's development *(Bailey et al., 2006; Mandell & Murray, 2009)*
   - Offer opportunities for parent-to-parent mentoring *(Bronfenbrenner, 1975; Brown & Remine, 2008; Chong et al., 2012; Doll & Bolger, 2000; Fordham, Gibson, & Bowes, 2011; Gooding et al., 2011; Guralnick, 1998, 2001, 2011; Jackson, Traub, & Turnbull, 2008; James & Chard, 2010; King et al., 1998; Mandell & Murray, 2009; McWilliam & Scott, 2001; McBride et al., 1993; Moeller et al., 2013; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010; Summers et al., 2007)*
   - Provide program-sponsored social events for families *(Bronfenbrenner, 1975; Brown & Remine, 2008; Doll & Bolger, 2000; Jackson, Traub, & Turnbull, 2008; Mandell & Murray, 2009; Moeller et al., 2013; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010; Tomasello, Manning, & Dulmus, 2010)*
   - Accompany families to meetings and appointments, other than IFSP and IEP meetings, such as medical appointments *(Haring & Lovett, 2001; Mandell & Murray, 2009; Murphy et al., 1992; Staples & Dilberto, 2010)*

- Refer families with SES needs to other programs *(Guralnick, 1998; Haring & Lovett, 2001; Mandell & Murray, 2009; Moeller et al., 2013)*
- Offer support within the program for families with SES needs, such as diapers, vouchers for food, an emergency assistance fund *(Epley et al., 2010; Guralnick, 1998, 2001, 2005, 2011; Mandell & Murray, 2009; McWilliam & Scott, 2001; Shelton, Jeppson, & Johnson, 1987; Shannon, 2004)*
- Staff speak the same language of all families in the program, or use translators for all interactions; all written material is translated into the languages of all families in the program, not just reports *(Mandell & Murray, 2009; Moeller et al., 2013; Paul & Roth, 2011)*
- Account for and respect the cultural traditions of families, such as gender customs, time factors for religious observances *(Kuo et al., 2012; Mandell & Murray, 2009; Moeller et al., 2013; Odom & Wolery, 2004; Paul & Roth, 2011; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
- Staff reflect the ethnic background of families *(Mandell & Murray, 2009)*
- Publish regular newsletters regarding the program for families *(Chong et al., 2012; Mandell & Murray, 2009; Staples & Dilberto, 2010)*
- Emphasize a family-centered philosophy throughout the agency, including with office staff and security personnel *(Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002; Sandall, McLean, & Smith, 2000)*
- Assign cases to staff *(Dinnebeil, Hale, & Rule, 1999)*
- Match families with providers based on needs and commonalities, such as cultural backgrounds, languages spoken, scheduling, and areas of expertise *(Dinnebeil, Hale, & Rule, 1999; Moeller et al., 2013; Sandall, McLean, & Smith, 2000)*
- Offer resource materials to families, such as equipment, specialized toys, DVDs, or books *(Chong et al., 2012; Garshelis & McConnell, 1993; Gooding et al., 2011; Guralnick, 2001, 2005, 2011; Iverson et al., 2003; Jackson, Traub, & Turnbull, 2008; King et al., 1998; Law et al., 2003; McWilliam & Scott, 2001; Moeller et al., 2013; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
- Screen staff during the hiring process based on personality traits and beliefs that correspond to providing family-centered care *(Dinnebeil, Hale, & Rule, 1999; Dinnebeil & Rule, 1994; Henneman & Cardin, 2002)*
- Employ flexible practices to find ways to support family participation in the program; as an example, ways for working families to be involved in center-based activities *(Brown & Remine, 2008; Chong et al., 2012; Dinnebeil, Hale, & Rule, 1999; Guralnick, 2001, 2005; Iverson et al., 2003; Judge, 1997; Mandell & Murray, 2009; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987)*
- Use daily 2-way communication notebooks with families *(Chong et al., 2012; Mandell & Murray, 2009; Staples & Dilberto, 2010)*
- Offer training to families, as well as families and staff jointly, on how to work collaboratively with EI service providers *(Law et al., 2003; Mandell & Murray, 2009; Park & Turnbull, 2003; Shannon, 2004; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987)*

- Encourage families to volunteer in their child's class or within the program *(Bronfenbrenner, 1975; Mandell & Murray, 2009; Staples & Dilberto, 2010)*
- Distribute a printed handbook to each family that includes information about the program's philosophy, policies, and practices *(Edwards & DaFonte, 2012; Law et al., 2005; Staples & Dilberto, 2010; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987)*
- Plan staff development based on staff competencies, preferences, and input *(Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
- Give a stipend to families to cover costs, such as transportation, for participation in various events and activities *(Chong et al., 2012; Gooding et al., 2011; Mandell & Murray, 2009; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
- Emphasize family outcomes *(Bailey, Raspa, & Fox, 2012; Garland & Linder, 1994; Jackson, Traub, & Turnbull, 2008; Mandell & Murray, 2009)*
- All Service Coordinators' and home-based providers' work schedules based on the needs of families *(Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Mandell & Murray, 2009; Moeller et al., 2013; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
- Center-based staff, other than Service Coordinators, make home visits *(Mandell & Murray, 2009; Staples & Dilberto, 2010)*
- Have a program mission statement which reflects the importance of family care *(Epley et al., 2010; Law et al., 2003)*
- Provide ongoing mentoring and supervision to all staff *(Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Moeller et al., 2013; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
- Require all staff to attend professional development sessions, including home-based and center-based providers, on how to provide family-centered care *(Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Guralnick, 2005; Iverson et al., 2003; Mandell & Murray, 2009; Moeller et al., 2013; Pickering & Busse, 2010; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
- Have an open door/visitation for families in the center-based programs where children attend separately from their families, and families do not have to make an appointment or call ahead to announce their visit *(Gooding et al., 2011; Henneman & Cardin, 2002; Kuo et al., 2012; Mandell & Murray, 2009; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010)*
- Have families as members of program governance committees such as hiring, program evaluation, and policy development committees *(Bailey, McWilliam, & Winton, 1992; Duwa, Wells, & Lalinde, 1993; Garland & Linder, 1994; James & Chard, 2010; Kuo et al., 2012; Mandell & Murray, 2009; Moeller et al., 2013; Ozdemir, 2008; Piper, 2012; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
- Respect the decisions of families, even when they differ from what the staff may think is best for the child and family *(Iverson et al., 2003; Judge, 1997;*

King, Rosenbaum, & King, 1995; King et al., 1998; Kuo et al., 2012; Moeller et al., 2013; Murphy et al., 1992)

- Refer to the parents by their given name, as opposed to "Mom" or "Dad" *(King, Rosenbaum, & King, 1995)*
- Create opportunities for formal and informal collaboration between staff outside of IFSP Family Team Meetings *(Epley et al., 2010; Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Moeller et al., 2013; Sandall, McLean, & Smith, 2000)*
- Other (please specify):

4. What is the most valuable family-centered practice your program provides to families? *(Mandell & Murray, 2009)*

5. What policies are in place at your program? (indicate all that apply) *(Mandell & Murray, 2009; Murray & Mandell, 2006)*
   - Work to maintain the consistency of the relationship between practitioners and families *(Dinnebeil, Hale, & Rule, 1999; Peterander, 2000; Summers et al., 2001)*
   - Create or adapt program practices based upon the needs of the families and providers *(Brown & Remine, 2008; Dinnebeil, Hale, & Rule, 1999; Mandell & Murray, 2009; Moeller et al., 2013; Sandall, McLean, & Smith, 2000)*
   - Recognize the attributes, skills, and abilities of staff as competent professionals *(Dinnebeil, Hale, & Rule, 1999)*
   - Establish a work environment that facilitates and promotes formal and informal collaboration between staff *(Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Garland & Linder, 1994; Moeller et al., 2013; Sandall, McLean, & Smith, 2000)*
   - Prioritize ongoing professional development regarding the delivery of family centered care, including offering mentoring and supervision for all staff and administrators *(Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Moeller et al., 2013; Sandall, McLean, & Smith, 2000)*
   - Stress family outcomes and progress as opposed to child progress and achievement *(Bailey, Raspa, & Fox, 2012; Garland & Linder, 1994; Jackson, Traub, & Turnbull, 2008; Mandell & Murray, 2009)*
   - Respect families from diverse cultural, ethnic, and linguistic backgrounds *(Kuo et al., 2012; Mandell & Murray, 2009; Moeller et al., 2013; Odom & Wolery, 2003; Paul & Roth, 2011; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
   - Ensure varied service delivery options are available and flexible practices are utilized to meet the individual needs of families and support their participation in the program *(Brown & Remine, 2008; Chong et al., 2012; Dinnebeil, Hale, & Rule, 1999; Fay & Carr, 2010; Garland & Linder, 1994; Guralnick, 2001, 2005; Iverson et al., 2003; Judge, 1997; Mandell & Murray, 2009; McBride et al., 1993; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*

- Consider the needs of all family members in programming, including fathers, siblings, grandparents, extended family *(Jackson, Traub, & Turnbull, 2008; King et al., 1998; Murphy et al., 1992; Peterander, 2000; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Summers et al., 2007)*
- Other (please specify):

6. What barriers do you face to implementing family-centered care? (indicate all that apply) *(Bailey et al., 1992; Campbell & Halbert, 2002; Dinnebeil, Hale, & Rule, 1999; Fingerhut et al., 2013; Mandell & Murray, 2009; Shannon, 2004)*
   - Fear of lawsuits and litigation *(Tucker & Schwartz, 2013)*
   - Organizational characteristics of the larger agency, such as the infrastructure, history, established organizational climate, and bureaucracy *(Bailey et al., 1992; Bailey, McWilliam, & Winton, 1992; Bamm & Rosenbaum, 2008; Bruder, 2000; Campbell & Halbert, 2002; Dinnebeil, Hale, & Rule, 1996; Epley et al., 2010; Fingerhut et al., 2013; Jolley & Shields, 2009; Kuo et al., 2012; Pereira & Serrano, 2014; Perrin et al., 2008; Roush, Harrison, & Palsha, 1991; Shannon, 2004)*
   - Geographic location, size, setting, and features of the area in which the agency provides services *(Bailey, McWilliam, & Winton, 1992; Crais & Wilson, 1996; Dinnebeil, Hale, & Rule, 1996, 1999; Epley et al., 2010; Odom & Wolery, 2003)*
   - Quality of staff available to hire, due to pre-service undergraduate/graduate educational training programs that do not adequately prepare graduates to work with families *(Bailey et al., 1992; Bruder, 2000; Dinnebeil, Hale, & Rule, 1999; Guralnick, 2001; Crais, Roy, & Free, 2006; Fleming, Sawyer, & Campbell, 2011; Mahoney & Wiggers, 2007; Mandell & Murray, 2009; McBride & Peterson, 2007; Murray & Curran, 2008; Pereira & Serrano, 2014)*
   - Providers' attitudes and beliefs regarding family-centered care *(Bailey et al., 1992; Bailey, McWilliam, & Winton, 1992; Bamm & Rosenbaum, 2008; Bellin et al., 2009; Brotherson et al., 2010; Bruder, 2000; Campbell & Halbert, 2002; Crais, Roy, & Free, 2006; Dinnebeil, Hale, & Rule, 1996, 1999; Dinnebeil & Rule, 1994; Epley et al., 2010; Henneman & Cardin, 2002; Howland et al., 2006; Humphry & Geissinger, 1993; Mahoney, O'Sullivan, & Fors, 1989; Mandell & Murray, 2009; McBride & Peterson, 1997; McWilliam, Tocci, & Harbin, 1998; Pereira & Serrano, 2014; Shannon, 2004)*
   - Nature of the bureaucracy and constraints of the EI system, such as paperwork, the structure of EI billing and reimbursement requirements as well as the complex regulations *(Bruder, 2000; Campbell & Halbert, 2002; Crais & Belardi, 1999; Crais, Roy, & Free, 2006; Dinnebeil, Hale, & Rule, 1999; Dunst, 2012; Fingerhut et al., 2013; Humphry & Geissinger, 1993; McWilliam, Tocci, & Harbin, 1998; O'Neill & Palisano, 2000)*
   - Financial limitations that prohibit staff training on family-centered care *(Bailey et al., 1992; Campbell & Halbert, 2002; Crais, Roy, & Free, 2006;*

Dinnebeil, Hale, & Rule 1999; Epley et al., 2010; Jolley & Shields, 2009; Mahoney & O'Sullivan, 1990; Perrin et al., 2008)

- Lack of administrative support from your supervisors *(Bailey et al., 1992; Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1996, 1999; Epley et al., 2010; Guralnick, 2001; Jolley & Shields, 2009; Mahoney, O'Sullivan, & Fors, 1989; Mandell & Murray, 2009; Murray & Mandell, 2006)*
- Parents' lack of participation and attitudes *(Bailey et al., 1992; Campbell & Halbert, 2002; Childress, 2004; Crais, Roy, & Free, 2006; Dinnebeil & Rule, 1994; Edwards et al., 2003; Fingerhut et al., 2013; Fleming, Sawyer, & Campbell, 2011; Howland et al., 2006; Mahoney & O'Sullivan, 1990; McBride & Peterson, 1997; Roush, Harrison, & Palsha, 1991; Shannon, 2004; Tomasello, Manning, & Dulmus, 2010)*
- Parents' lack of skills, knowledge, resources, or abilities that prevent families from developing collaborative relationships with providers *(Bailey et al., 1992; Crais, Roy, & Free, 2006; Crais & Wilson, 1996; Dinnebeil & Rule, 1994; Fingerhut et al., 2013; Howland et al., 2006; McBride & Peterson, 1997)*
- Cultural barriers with families *(Dinnebeil, Hale, & Rule, 1996; Crais & Wilson, 1996; Fingerhut et al., 2013; Howland et al., 2006; Iverson et al., 2003; Mahoney, O'Sullivan, & Fors, 1989; McWilliam, Tocci, & Harbin, 1998; Roush, Harrison, & Palsha, 1991)*
- Conflict between the philosophical perspectives of staff and administrator *(Bailey et al., 1992)*
- Difficulty in supervising staff in home-based setting; for example, to know if providers are using family-centered practices *(Epley et al., 2010; Humphry & Geissinger, 1993)*
- Lack of providers' understanding of the importance of family-centered care *(Dinnebeil & Rule, 1994; Iverson et al., 2003; Mandell & Murray, 2009)*
- Philosophies of treatment disciplines and methods, such as ABA *(Bruder, 2000; McWilliam, 1999)*
- Lack of providers' knowledge and skills on how to develop partnerships and collaborative relationships with families *(Bailey et al.,1992; Bruder, 2000; Crais, Roy, & Free, 2006; Howland et al., 2006; Mahoney & Wiggers, 2007; Mandell & Murray, 2009; Pereira & Serrano, 2014; Shannon, 2004)*
- No clear standards and practices as to what constitutes family-centered care *(Bailey, McWilliam, & Winton, 1992; Bamm & Rosenbaum, 2008; Bruder, 2000; Epley, Summers, & Turnbull, 2010; Guralnick, 2005; Kuo et al., 2012; Perrin et al., 2007)*
- Service delivery options and programs offered do not meet the needs of families *(Dinnebeil, Hale, & Rule, 1996; Epley et al., 2010; Humphry & Geissinger, 1993; Iverson et al., 2003; Judge, 1997; Law et al., 2003; McBride et al., 1993; McWilliam, Tocci, & Harbin, 1998; Perrin et al., 2007; Shannon, 2004)*

- Relationships and collaborations with other agencies *(Dinnebeil, Hale, & Rule, 1999; Guralnick, 2001; Shannon, 2004; McWilliam, Tocci, & Harbin, 1998; Pereira & Serrano, 2014)*
- Staff express discomfort working with families and prefer working with children directly *(Bailey et al., 1992; Bruder, 2000; Crais, Roy, & Free, 2006; Dinnebeil, Hale, & Rule, 1999; Mandell & Murray, 2009)*
- Lack of access to quality staff development materials and resources *(Bruder, 2000; Campbell & Halbert, 2002; Pereira & Serrano, 2014)*
- Unwillingness by staff to accept the views of families that differ from their personal views *(Mandell & Murray, 2009)*
- Lack of quality research that is applicable to practice *(Bruder, 2000; Campbell & Halbert, 2002; Crais, Roy, & Free, 2006; McWilliam, 1999)*
- Staff are reluctant to change their professional practices *(Bailey et al., 1992; Bailey, McWilliam, & Winton, 1992; Bamm & Rosenbaum, 2008; Campbell & Halbert, 2002; Campbell & Sawyer, 2007; Epley et al., 2010; Humphry & Geissinger, 1993)*
- Lack of time and opportunity for staff development *(Bailey et al., 1992; Campbell & Halbert, 2002; Crais & Belardi, 1999; Crais, Roy, & Free, 2006; Crais & Wilson, 1996; Dinnebeil, Hale, & Rule, 1999; Mahoney, O'Sullivan, & Fors, 1989; McWilliam, Tocci, & Harbin, 1998; Roush, Harrison, & Palsha, 1991)*
- Other (please specify):

7. How do you respond to the challenges?

8. What 6 policies and practices represent ideal family-centered care? *(Bellin et al., 2011; Crais & Belardi, 1999; Crais & Wilson, 1996; Dempsey & Carruthers, 1997; Fleming, Sawyer, & Campbell, 2011; Ingber & Dromi, 2010; King et al., 1998; Mahoney, O'Sullivan, & Fors, 1989; McBride et al., 1993; McWilliam, Maxwell, & Sloper, 1999)*
- Emphasize family outcomes as opposed to child development *(Bailey, Raspa, & Fox, 2012; Garland & Linder, 1994; Jackson, Traub, & Turnbull, 2008; Mandell & Murray, 2009)*
- Formally prepare families to participate in meetings, such as what to expect, how to advocate effectively for their family *(Jackson, Traub, & Turnbull, 2008; King et al., 1998; Mandell & Murray, 2009; Murphy et al., 1992; Staples & Dilberto, 2010)*
- Offer opportunities for parent-to-parent mentoring *(Bronfenbrenner, 1975; Brown & Remine, 2008; Chong et al., 2012; Doll & Bolger, 2000; Fordham, Gibson, & Bowes, 2011; Gooding et al., 2011; Guralnick, 1998, 2001, 2011; Jackson, Traub, & Turnbull, 2008; James & Chard, 2010; King et al., 1998; Mandell & Murray, 2009; McWilliam & Scott, 2001; McBride et al., 1993; Moeller et al., 2013; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010; Summers et al., 2007)*
- Provide program sponsored social events for families *(Bronfenbrenner, 1975; Brown & Remine, 2008; Doll & Bolger, 2000; Jackson, Traub, & Turnbull,*

2008; Mandell & Murray, 2009; Moeller et al., 2013; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010; Tomasello, Manning, & Dulmus, 2010)

- Accompany families to meetings and appointments, other than IFSP and IEP meetings, such as medical appointments *(Haring & Lovett, 2001; Mandell & Murray, 2009; Murphy et al, 1992; Staples & Dilberto, 2010)*
- Offer support within the program for families with SES needs, such as diapers, vouchers for food, or an emergency assistance fund, rather than refer families with SES needs to other programs *(Epley et al, 2010; Guralnick, 1998, 2001, 2005, 2011; Mandell & Murray, 2009; McWilliam & Scott, 2001; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987)*
- Staff reflect the ethnic background of families *(Mandell & Murray, 2009)*
- Use daily 2-way communication notebooks, as well as publish regular newsletters about the program *(Chong et al., 2012; Mandell & Murray, 2009; Staples & Dilberto, 2010)*
- Match families with providers based on needs and commonalities, such as cultural background, languages spoken, scheduling requirements, and area of expertise, rather than assigning cases to staff *(Dinnebeil, Hale, & Rule, 1999; Moeller et al., 2013; Sandall, McLean & Smith, 2000)*
- Offer resource materials to families, such as equipment, specialized toys, DVDs, or books *(Chong et al., 2012; Garshelis & McConnell, 1993; Gooding, et al., 2011; Guralnick, 2001, 2005, 2011; Iverson et al., 2003; Jackson, Traub, & Turnbull, 2008; King et al., 1998; Law et al., 2003; McWilliam & Scott, 2001; Moeller et al., 2013; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*
- Screen staff during the hiring process based on personality traits and beliefs that correspond to providing family-centered care *(Dinnebeil, Hale, & Rule 1999; Dinnebeil & Rule, 1994; Henneman & Cardin, 2002)*
- Employ flexible practices to finds ways to support family participation in the program, such as ways for working families to be involved in center-based activities *(Brown & Remine, 2008; Chong et al. 2012; Dinnebeil, Hale, & Rule, 1999; Fay & Carr, 2010; Guralnick, 2001, 2005; Iverson et al., 2003; Judge, 1997; Mandell & Murray, 2009; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987)*
- Offer trainings to families, as well as to staff and families jointly, on how to form collaborative relationships *(Law et al., 2003; Mandell & Murray, 2009; Park & Turnbull, 2003; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987)*
- Encourage families to volunteer in their child's class or within the program *(Bronfenbrenner, 2000; Mandell & Murray, 2009; Sandall, McLean, & Smith, 2000; Staples & Dilberto, 2010)*
- Plan staff development based on staff competencies, preferences, and input *(Bailey, McWilliam, & Winton, 1992; Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*
- Give a stipend to families to cover costs, such as transportation, for participation in various events and activities *(Chong et al., 2012; Gooding et*

al., 2011; Mandell & Murray, 2009; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)

- All Service Coordinators and home-based providers work schedules based on the needs of families *(Dinnebeil, Hale, & Rule, 1999; Garland & Linder, 1994; Mandell & Murray, 2009; Moeller et al., 2013; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*

- Distribute a printed handbook to each family that includes information about the program's philosophy, policies, and practices *(Edwards & DaFonte, 2012; Law et al., 2005; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Staples & Dilberto, 2010)*

- Center-based staff, other than Service Coordinators, make home visits *(Mandell & Murray, 2009; Staples & Dilberto, 2010)*

- Have a program mission statement, which reflects the importance of family care *(Epley et al., 2010; Law et al., 2003)*

- Have families as members of program governance committees such as hiring, program evaluation, policy development committees *(Bailey, McWilliam & Winton, 1992; Duwa, Wells, & Lalinde, 1993; Garland & Linder, 1994; James & Chard, 2010; Kuo et al., 2012; Mandell & Murray, 2009; Moeller et al., 2013; Ozdemir, 2008; Piper, 2012; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*

- Respect and abide by the decisions of families, even when they differ from what the staff may think is best for the child and family *(Iverson et al., 2003; Judge, 1997; King, Rosenbaum, & King, 1995; King et al., 1998; Kuo et al., 2012; Moeller et al., 2013; Murphy et al., 1992)*

- Refer parents by their given name, as opposed to "Mom" or "Dad" *(King, Rosenbaum & King, 1995)*

- Work to maintain the consistency of the relationship between practitioners and families *(Dinnebeil, Hale, & Rule, 1999; Peterander, 2000; Summers et al., 2007)*

- Recognize the attributes, skills and abilities of staff as competent professionals *(Dinnebeil, Hale, & Rule, 1999)*

- Establish an environment that enables formal and informal collaboration between staff *(Dinnebeil, Hale, & Rule, 1999; Epley et al., 2010; Garland & Linder, 1994; Moeller et al., 2013 Sandall, McLean, & Smith, 2000)*

- Focus on as creating a family-centered culture throughout the organization with all staff, including security personnel and office staff *(Dinnebeil, Hale, & Rule, 1999; Henneman & Cardin, 2002; Sandall, McLean & Smith, 2000)*

- Ensure flexible and varied service delivery options are available for families *(Brown & Remine, 2008; Chong et al., 2012; Dinnebeil, Hale, & Rule, 1999; Fay & Carr, 2010; Garland & Linder, 1994; Guralnick, 2001, 2005; Iverson et al., 2003; Judge, 1997; Mandell & Murray, 2009; McBride et al., 1993; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000)*

- Develop and adopt program practices based upon the needs of the families and providers *(Brown & Remine, 2008; Dinnebeil, Hale, & Rule, 1999; Mandall*

> *& Murray, 2009; Sandall, McLean, & Smith, 2000; Shelton, Jeppson, & Johnson, 1987)*

- View families as collaborative partners, or equals *(Dinnebeil, Hale, & Rule, 1999; Garshelis & McConnell, 1993; Gooding et al., 2011; Guralnick, 2001, 2005, 2011; Iverson et al., 2003; King, Rosenbaum, & King, 1995; King et at., 1998; McWilliam & Scott, 2001; Moeller et al., 2013; Murphy et al., 1992; Sandall, McLean, & Smith, 2000; Shannon, 2004; Shelton, Jeppson, & Johnson, 1987; Walter & Petr, 2000; Zhang, Bennett, & Dahl, 1999)*
- Respect families from diverse cultural, linguistic, and ethnic backgrounds *(Kuo et al., 2012; Mandell & Murray, 2009; Moeller et al., 2013; Odom & Wolery, 2004; Paul & Roth, 2011; Sandall, McLean, & Smith, 2000; Walter & Petr, 2000)*

DEMOGRAPIC QUESTIONS

What is your professional background? *(Bailey, Palsha, & Simmeonsson, 1991; King et al., 2003; Woodside et al., 2001)*
- Special Education
- Early Childhood Education (without Special Education)
- Infant and Parent Development
- Early Intervention
- Educational Administration/Supervision
- Social Work
- School Psychology
- Clinical Psychology
- Speech/ Language Pathology
- Occupational Therapy
- Physical Therapy
- Business
- Other (please specify):

Do you have a New York State Department of Education School Leadership and Administration certificate? (Either a School Building Leader (SBL), formerly a School Administrator/Supervisor (SAS), or a School District Leader (SDL), formerly a School District Administrator (SDA), certification)? *(Fayol, 1916/1949; Johnson et al., 1992; Sandall, McLean, & Smith, 2000)*
- Yes
- No

What is the highest educational degree that you currently hold? *(Burton, 1992; Humphry & Geissinger, 1993)*
- Bachelor's
- Master's
- Doctorate

How many years have you been an administrator in an NYC EI Program? *(Dempsey & Carruthers, 1997; King et al., 2003; Roush, Harrison, & Palsha, 1991; Tang et al., 2011)*

How many years have you worked in Early Intervention? *(Dempsey & Carruthers, 1997; King et al., 2003; Roush, Harrison, & Palsha, 1991; Tang et al., 2011)*

Where did you receive your training in family-centered care? *(Murray & Curran, 2008; Mandell & Murray, 2009; Murray & Mandell, 2006; Sawyer & Campbell, 2009; Roush, Harrison, & Palsha, 1991; Rupiper & Marvin, 2004; Sewell, 2012)*
- College coursework
- Professional development workshops
- Intensive certificate-based training programs
- Work experience
- Personal/life experience
- Other (please specify):

To how many New York City families does your site (the location you oversee) provide Early Intervention services annually?   Your agency (all locations in total)?

#	Site	Agency
>50		
51 to 100		
101 to 250		
251 to 500		
501 to 750		
751 to 1,000		
1,001 to 1,250		
1,251 to 1,500		
N/A	----	

How many Early Intervention direct service providers (Special Instructor, Occupational Therapist, Physical Therapist, Service Coordinator, Speech Therapist, etc.) are employed on a full-time or part-time basis?

#	Full-Time basis at your site?	Part-Time basis at your site?	Full-Time basis with your Agency	Part-Time basis with your Agency
>10				
11 to 25				
26 to 40				
41 to 60				
61 to 75				
76 to 90				
91+				
N/A	------------------	-------------------		

What is your rate of staff retention (staff who return to work at your agency the following year)?

What types of Early Intervention services does your Early Intervention site provide?

- Evaluations
- Service Coordination
- Facility-based Services (where the child attends separately from his or her family/ caregiver)
- Home/Community-based Services

Is your organization:

- For-profit
- Not-for-profit

Does your agency provide services other than Early Intervention?

- Yes
- No

How many sites does your agency have that offer Early Intervention services to the families of New York City?

Does your site hold any of the following: *(Campbell & Sawyer, 2007; Dinnebeil, Hale, & Rule, 1999; Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; Epley et al., 2010; Fleming, Sawyer, & Campbell, 2011; King et al., 2003; McWilliam, Tocci, & Harbin, 1998; Moeller et al., 2013; Odom, 2009)*

Frequency	Case Conference (other than Family Team Meetings mandated on IFSP's)	Staff Meetings (separate from Case Conferences & Professional Development)	In-service training & professional development for staff
No			
Once a week			
Once a month			
Quarterly			
Twice a Year			
Annually			
As needed/ when mandated			

Does your program routinely pay for staff to attend workshops and trainings off site? *(Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; King et al., 2003; Moeller et al., 2013)*

- Yes
- No

How many times per year are your EI direct service providers observed during sessions? *(Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; Moeller et al., 2013; Odom, 2009)*

Frequency	Center-Based Staff	Home-Based Staff
Once a month		
Quarterly		
Every 6 months		
Annually		
As needed, or when there is a problem		
N/A		

Does your program offer clinical supervision for all EI direct service providers? *(Dunst & Raab, 2010; Dunst, Trivette, & Deal, 2011; Moeller et al., 2013; Odom, 2009)*

- Yes
- No

APPENDIX B

EMAIL OF INVITATION

Dear Early Intervention Site Administrator,

My name is Jen Longley, and I am a doctoral candidate currently enrolled in Seton Hall University's College of Education and Human Services, the Department of Education Leadership, Management and Policy. I am writing to ask for your assistance with the research I am conducting in relation to my dissertation.

I am interested in understanding how New York City Early Intervention program administrators define and perceive the purpose of, as well as implement, family-centered care. There are three aspects to my project. First, I seek to understand how you define and view the purpose of family-centered care. Second, I aim to identify the practices and policies of your program. Last, I intend to determine what barriers you face in implementing family-centered care. It is my hope that my research can shed light on how to improve the universal delivery of high quality family-centered care in all Early Intervention programs.

I recognize the time constraints you are under, but I am humbly hoping you can find 15 minutes to complete my web-based questionnaire.

This online questionnaire consists of 4 sections. In the first section, there are 2 questions regarding how you define family-centered care and its purpose in Early Intervention. In the second part, there are 3 questions concerning your program's practices and policies. In the third section, there are 3 questions about what barriers you encounter delivering family-centered care, as well as what practices constitute ideal family-centered care. The final section is a series of general demographic questions.

Participating in this questionnaire is, of course, entirely voluntary on your part.

The questionnaire is hosted through a secured, dedicated Seton Hall University web server, and the results are collected by a protected program called ASSET. This questionnaire is completed anonymously and will be used for the purpose of my research only. Because no information specifically identifying participants will be asked, it will not be possible for the responses of any individual participant to be connected to him or her in any way. Anonymity is assured. Responses from the questions will not be shared with, or distributed to, anyone. Results from the questionnaires will be secured on a USB memory data stick, which will be locked in my home office for a period of three years. The data will be maintained under the strictest levels of confidentiality.

Please allow me to express my profound gratitude, in advance, for your time and input. The web address for the questionnaire is
http://assettltc.shu.edu:80/servlets/assetAssetSurvey?surveyid=6009 .

(To access the site, you may need to highlight the address, paste it into your address bar, or highlight the address then right click the address and click "go to" from the pop-up menu that appears). The *password* for the survey is *nycei*. If you agree to assist me with my research, please complete the questionnaire by August 16, 2013.

With deepest appreciation,

Jen Longley

Doctoral Candidate, Seton Hall University

APPENDIX C

TELEPHONE CALL SCRIPT

All calls were conducted by a Research Assistant, hired specifically for this purpose.

Hi, I'm calling on behalf of Jen Longley, a doctoral student at Seton Hall University. She recently emailed you a research questionnaire, and I am following up to be sure you received the email. Jen apologizes if there were any problems with the email. Thank you very much for taking the time to complete the questionnaire! Your effort and feedback are greatly appreciated! If you have any questions or concerns, you can contact Jen at Jenifer dot Longley at student dot shu dot edu. That's J-E-N-N-I-F-E-R dot L-O-N-G-L-E-Y at S-T-U-D-E-N-T dot S-H-U dot E-D-U. Thanks again!

Dear Early Intervention Site Administrator,

My name is Jen Longley, and I am a doctoral candidate currently enrolled in Seton Hall University's College of Education and Human Services, the Department of Education Leadership, Management and Policy. Please allow me the opportunity to thank you very much for your time and insights if you have already completed my questionnaire.

In the event that you did not receive my previous email, or experienced any difficulty completing the questionnaire, please accept my most sincere apology. I am writing to request your assistance with the research I am conducting in relation to my dissertation. Consequently, I am forwarding you my questionnaire again, if you did not receive my prior email or were not able to complete the questionnaire.

With my doctoral study, I am interested in understanding how New York City Early Intervention program administrators define and perceive the purpose of, as well as implement, family-centered care. There are three aspects to my project. First, I seek to understand how you define and view the purpose of family-centered care. Second, I aim to identify how your program implements family-centered care. Last, I intend to determine what barriers you face in implementing family-centered care. It is my hope that my research can shed light on how to improve the delivery of family-centered care in all Early Intervention programs universally.

I recognize the time constraints you are under, but I am humbly hoping you can find 15 minutes to complete my web-based questionnaire.

This online questionnaire consists of 4 sections. In the first section, there are 2 questions regarding how you define family-centered care and its purpose in Early Intervention. In the second part, there are 3 questions concerning your program's practices and policies. In the third section, there are 3 questions about what barriers you encounter delivering family-centered care, as well as what practices constitute ideal family-centered care. The final section is a series of general demographic questions.

Participating in this questionnaire is, of course, entirely voluntary on your part.

The questionnaire is hosted through a secured, dedicated Seton Hall University web server, and the results are collected by a protected program called ASSET. This questionnaire is completed anonymously and will be used for the purpose of my research only. Because no information specifically identifying participants will be asked, it will not be possible for the responses of any individual participant to be connected to him or her in any way. Anonymity is assured. Responses from the questions will not be shared

218

with, or distributed to, anyone. Results from the questionnaires will be secured on a USB memory data stick, which will be locked in my home office for a period of three years. The data will be maintained under the strictest levels of confidentiality.

Please allow me to express my profound gratitude, in advance, for your time and input. The web address for the questionnaire is:
http://assettltc.shu.edu/servlets/assetAssetSurvey?surveyid=6009

(To access the site, you may need to highlight the address, paste it into your address bar, or highlight the address, then right click the address and click "go to"/ "open hyperlink" from the pop-up menu that appears). The *password* for the survey is *nycei*. If you agree to assist me with my research, please complete the questionnaire by August 16, 2013.

With deepest appreciation,
Jen Longley
Doctoral Candidate, Seton Hall University

APPENDIX E

SETON HALL UNIVERSITY INSTITUTIONAL
REVIEW BOARD APPROVAL F

REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR
RELATED ACTIVITIES INVOLVING HUMAN SUBJECTS

All material must be typed.

PROJECT TITLE: How do administrators of New York City Early Intervention programs conceptualize and implement family centered care?

CERTIFICATION STATEMENT:

In making this application, I(we) certify that I(we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.

Jennifer M Longley Jennifer M Longley 10. June 2013
RESEARCHER(S) OR PROJECT DIRECTOR(S)   DATE

**Please print or type out names of all researchers below signature.
Use separate sheet of paper, if necessary.**

My signature indicates that I have reviewed the attached materials and consider them to meet IRB standards.

J. Caulfield, C. Tienken, E. Walker 6/12/13
RESEARCHER'S ADVISOR OR DEPARTMENTAL SUPERVISOR   DATE

Please print or type out name below signature

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research at the _12 June 2013_ meeting.

The application was approved ✓ not approved ___ by the Committee. Special conditions were _____ were not ✓ set by the IRB. (Any special conditions are described on the reverse side.)

Mary F. Ruzicka, Ph.D. 6/12/13
DIRECTOR,   DATE
SETON HALL UNIVERSITY INSTITUTIONAL
REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH