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DePaul University
College of Education

FATHERS' EXPERIENCES IN EARLY INTERVENTION:
MAROONED IN THE KITCHEN OR MEMBER OF THE TEAM

A Dissertation

With a Concentration in Early Childhood Education

By

Megan Schumaker-Murphy

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Submitted in Partial Fulfillment

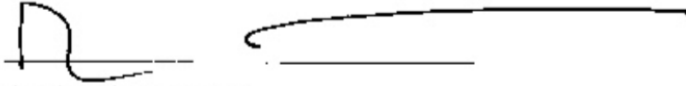
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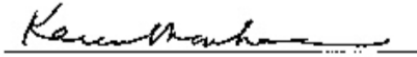
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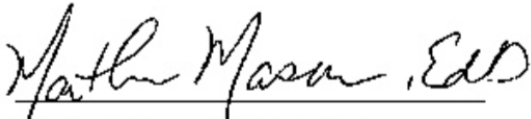
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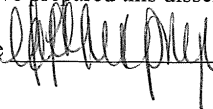


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ABSTRACT

Little research about fathers with young children with developmental disabilities or delays and their participation in early intervention/Part C programs is available. This study adds to existing scholarship through a narrative inquiry into the experiences of six fathers with children who have participated in early intervention services. Emergent themes within and across fathers' narratives include high levels of father engagement prior to entering early intervention, overall positive feelings about early intervention due to children's developmental progress, feelings of stress and frustration throughout participation in early intervention, varied relationship quality between fathers and early intervention service providers, an overall lack of understanding of the early intervention process, and varied levels of father capacity to help their children make developmental progress after early intervention ends. These themes are analyzed in the context of Bronfenbrenner's bioecological systems model. This study provides insight into how fathers perceive their experiences in early intervention programs and how those experiences impacted them.

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CHAPTER ONE: Introduction

It is universally acknowledged that the efficacy of service delivery in early intervention/Part C programs (EI) is largely dependent upon family engagement and participation (Bruder, 2000; Trivette, Dunst, & Hamby, 2010; Raver & Childress, 2015). Increased family quality of life is a valued outcome of EI programs (Bailey et al., 2006; Epley, Summers & Turbull, 2011). A significant number of studies have explored parents' experiences with EI. However, most of the participants in the existing research have been mothers. The paucity of research addressing fathers outdates federal law establishing EI. Budd and O'Brien (1982) first identified the lack of research addressing father involvement in parent education programs for families with children with disabilities in 1982, four years before Part C of the Individuals with Disabilities Act was passed. Even in families without children with disabilities, the discourse lacks attention to fathers.

Lack of research related to fathers of children with disabilities reflects American societal views of fatherhood. Mothers continue to be perceived as primary caregivers for young children. Until the 1970s, the perception of American fathers' roles primarily consisted of "breadwinning," providing emotional support to mothers (Pleck, 2004), and serving as a gender role model for sons (Lamb, 1981). A cultural shift toward more involved fathering in middle-class white families occurred throughout the 1970s, 1980s, and 1990s as more women with children joined the workforce and American couples began to shift toward more egalitarian gender roles within marriages. U.S. Census data reflects these changes. In 1988, only 19% of fathers provided care for their children while their mothers worked. In 2011, 32% of fathers provided care for their children, and 20% of American families with preschool age children reported that fathers were the primary caregivers (United States Census Bureau, 2013).

As modern fathers continue to take on a more active role in parenting children with and without disabilities, the field must develop an understanding of fathers' experiences parenting their children with disabilities. This information will aid practitioners in learning how to best engage them in family centered EI practices. The evidence base informing EI's family-centered framework is now more than 30 years old; thus, it reflects outdated societal expectations about how mothers should be the focus and target of routines-based interventions. As an evidence base that reflects today's cultural shift toward co-parenting emerges, early interventionists will need to shift their tried and true methods of encouraging engagement when working with families, specifically fathers.

As an EI service provider, I witnessed firsthand this cultural shift to more involved fatherhood. When I began my career in EI in 2008, it was relatively rare for me to interact with children's fathers outside of once or twice a year during official Individualized Family Service Plan review meetings. Gradually, the number of families asking for an appointment later in the day so that both parents could be present increased. As I transitioned to working with families within Chicago city limits as opposed to the Chicago suburbs, I noticed a considerable increase in shared parenting responsibility, even in families with stay-at-home moms. Increasingly more dads were present either in person or via technology during therapy sessions. In 2015, I found myself working with three stay-at-home dads for the first time in my career. None of the stay-at-home dads intended to be full-time stay-at-home parents when their children were born, but the need for full-time care for the child with the disability called for one parent to be at home. Each of these fathers made less money and/or did not carry the family's insurance coverage, therefore it made the best financial sense for these families to have a stay-at-home dad rather than the "traditional" stay-at-home mom. Each of these dads eventually returned to work either full- or

part-time once their child's health stabilized, but each continued to be the child's primary caregiver when both parents were at home. I noticed that dads engaged with me and their children in ways that differed from moms. Two of them were slower to confide challenges to me, and each of the three was significantly more likely to make caregiving routines playful. Overall, I noticed that fathers tended to focus on very specific outcomes like the number of spoken words in their child's vocabulary, or when their child reached a specific motor milestone such as cruising along furniture. Looking to improve my own practice and respond to these dad's needs for social support, I searched for existing scholarship and other resources, including professional development courses and practitioner books, but found very little information. As for social support networks for new and special needs dads, there were not any programs available in my area. My goal in completing this research is to advance the ability of early childhood special educators to understand the experiences of fathers with young children in EI so that we can better provide family-centered services for their families.

Bioecological systems perspective (Bronfenbrenner, 1986) heavily influences the field (Raver and Childress, 2015) and best practices for service delivery (Division of Early Childhood, 2014), yet there exists very little research aimed at helping practitioners gain insight into the experiences of fathers with infants and toddlers with disabilities (Flippin & Crais, 2011). Through a narrative inquiry research approach, this study seeks to develop an in-depth understanding of the experiences of fathers participating in EI with their child(ren). Specifically, what is the experience of a father participating in the Illinois Early Intervention Program? How does participation in EI impact fathers? Based on these fathers' experiences, what can EI providers do to better meet the needs of dads?

CHAPTER TWO: Review of Relevant Literature

This literature review will provide an overview of the EI system and present bioecological systems theory and family systems perspective as conceptual frameworks for understanding fathers' importance in families with children with disabilities. This review will also present an overview of the changing paternal role in America and fathers' impact on general child development, and it will review existing literature about fathers' experiences in EI and with disability parenting.

Early Intervention Overview

Currently, approximately one in six American children between the ages of three and 17 have a diagnosed disability or developmental delay (Boyle et al., 2011). Many of these children are identified as having a developmental delay or disability either shortly before or after birth or during infancy or toddler years. Prior to World War II, most people in the United States with disabilities were housed and cared for in asylums under a medical model of disability (Brown & Percy, 2007). The medical model viewed disability as something in need of curing or remediation. Overcrowding and inadequate care for persons with disabilities plagued asylums. High profile scandals involving the abuse of institutionalized people with disabilities in the United States became publicized concurrent with the World Health Organization and the United Nations advocacy for human rights following the discovery of Nazi concentration camps.

A move to deinstitutionalize people with disabilities soon followed (Brown and Brown, 2003). In 1966, Burton Blatt began advocating for the deinstitutionalization of people with intellectual disabilities with the publication of a photo exposé (Blatt, Kaplan, & Kaplan, 1966). In 1969, Blatt and Garfunkel published a study that demonstrated the importance of the home environment on the development of preschoolers with developmental disabilities. By the 1970s,

most children with disabilities remained at home with their families. Although no longer housed in institutions, people with disabilities lacked protection under civil rights laws and the guarantee of a public education.

Pioneers in the field of special education included Sam Kirk and Merle Karnes, who first coined the term “learning disability” in 1963. Karnes and Kirk’s work during the 1940s and 1950s established that some children with developmental disabilities improved when provided with targeted interventions at a young age (Kirk, 1977). Another researcher and advocate for children with disabilities, Dorothy Sievers, concurrently found similar results in her work with young children with disabilities (Bricker, Xie, & Bohjanen, 2018). Kirk went on to become an advocate for laws that provided educational access for children with disabilities (Thomas, 1996).

The first significant law related to research and training of people with disabilities passed in 1964. The Mental Retardation and Community Mental Health Centers Construction Act of 1973 appropriated funds for the creation of research and community-based facilities for people with cognitive impairments. Shortly after, in 1968, congress passed the Handicapped Children’s Early Education Program as a part of the Handicapped Children’s Early Assistance Act (PL 91-230). This act provided funds and a dissemination plan for findings related to the education of preschool-aged children with developmental disabilities (then referred to as Handicaps or mental retardation). Also in the 1960s, home visiting was beginning to show positive impacts on children’s developmental progress (Gray & Klaus, 1966).

In 1972, two landmark court cases, *PARC v. Commonwealth of Pennsylvania* and *Mills v. Board of Education of the District of Columbia*, judges ruled that children with cognitive disabilities aged 6-21 are entitled to a free and appropriate education. Shortly after, in 1975, the United States government passed The Education for all Handicapped Children Act. This law is

the foundation of the United States Special Education system. The current iteration of this law is currently known as The Individuals with Disabilities Education Act (IDEA).

The Education for All Handicapped Children Act of 1975 demanded that school age children with disabilities must be provided a public education and that the education take place in the least restrictive environment (LRE). Current LRE statute reads:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Individuals with Disabilities Education Act, 2004)

Once a legal foundation was established, the federal government began to support programs preparing educators focused on working with children with disabilities. Special education teacher preparation programs sprung up at universities around the country (Bricker & Widerstrom, 1996). The Division for Early Childhood (DEC), an arm of the Council for Exceptional Children, formed in 1973 (Bricker, Xie, & Bohjanen, 2018). This professional organization sets current professional standards and recommended practices for early childhood special educators. In the 1970s, members of DEC worked together to disseminate research among early childhood special education scholars in order to further the success of the relative new field of study. In the late 1980s, scholars found that the most successful interventions for children with disabilities were woven into the natural flow of children's daily routines (Bricker, 1989).

In 1986, Part C of The Handicap Children's Protection Act extended educational access for children with disabilities to include services for children ages birth to five years, effectively creating "early intervention." IDEA Part C provides publicly funded special education services for infants and toddlers with disabilities. The expansion of federal special education law helped to further legitimize the early childhood special education field (Bricker, Xie, & Bohjanen, 2018). Throughout this paper, special education services created under Part C will be referred to as early intervention or EI.

EI serves as the government response to widespread need for services to improve the lifetime outcomes of families with children with developmental delays and disabilities and the newly (for the time) realized importance of learning in the earliest years of life. Early childhood special education scholars presented a solid case for the success of children who lived at home and participated in community-based programs that set the expectation of developmental progress (Tjossem, 1976). Part C of the Individuals with Disabilities Act states EI services must be delivered in collaboration with parents and, whenever possible, occur in natural environments rather than hospital and clinical settings. IDEA (2004) defines natural environments as settings that children without disabilities typically occupy: homes, child care, public playgrounds, grocery stores, and other community settings. Nationwide, 88.7% of EI services occur in the family home (Office of Special Education Programs, 2017).

Each child enrolled in EI receives an Individualized Family Service Plan (IFSP). This is a legal document that outlines what services each family is entitled to and what outcomes the IFSP team is working toward attaining with the family. The IFSP is similar to the Individualized Education Plan (IEP) utilized in public school based special education services. EI service providers must tailor their services to meet the specific needs of the child and their family and

must include service coordination. Other services provided under EI include speech therapy, physical therapy, occupational therapy, special education instruction, social work, psychological services, medical diagnostic evaluations, family training, health services, vision services, assistive technology, and transportation to and from services (Individuals with Disabilities Education Improvement Act, 2004).

In compliance with federal regulations for EI services, a family-centered practice framework for service provision emerged via The Council for Exceptional Children Division of Early Childhood's Recommended Practices document in 1991. In 2000, the proposed Developmental Disabilities Assistance and Bill of Rights Act of 2000 stated:

It is the policy of the United States that all programs, projects, and activities funded under this title shall be family-centered and family-directed and shall be provided in a manner consistent with the goal of providing families of children with disabilities with the support the families need to raise their children at home.

While this bill died in congress, family-centered practice is widely accepted as the standard in EI (Raver & Childress, 2015). Updated in 2014, the current Division for Early Childhood Recommended Practices define family-centered practices as:

Practices that treat families with dignity and respect; are individualized, flexible, and responsive to each family's unique circumstances; provide family members complete and unbiased information to make informed decisions; and involve family members in acting on choice to strengthen child, parent and family functioning. (Division for Early Childhood, 2014, p.10)

Family-centered practice understands that children develop within a family context and leverages family strengths to empower families to provide the best care for their children with

developmental delays and disabilities. Family-centered practice is predicated on the principle that “all families, with the necessary supports and resources, can enhance their children’s learning and development” (Office of Special Education Programs TA Community of Practice, 2008). This support consists of a combination of the service provider’s direct therapeutic interactions with the child as well as the provision of routines-based intervention coaching for the family. Routines-based interventions are therapeutic events that take place during everyday caregiving routines including bathing, feeding, housecleaning, play, and any other event that naturally occurs in the family’s daily routine (McWilliam, 2010). Family-centered practice is contingent upon strong family-service provider relationships. The desired outcomes of family-centered practice are increased self-efficacy and caregiving skills in the child’s parents as well as increased individual functioning for the child. Formal data on whether families know their rights, can communicate effectively about their children’s development needs, and feel capable of helping their children make development progress are collected at annual IFSP meetings and submitted to the Office of Special Education Programs (OSEP).

EI services are grounded by an IFSP. This document describes the child’s current level of function and outlines a series of goals and strategies for meeting those goals that apply to the family unit rather than only the individual child. For example, an IFSP may outline goals and strategies that address strengthening relationships between the child and members of her family, facilitating the family’s access to resources related to the child’s disability or delay, and building a social support network for the family (Raver & Childress, 2015). OSEP requires that states report not only on child outcomes but also on the percentage of families who report that their participation in EI aided them to know their rights, communicate effectively about their child’s needs, and improve their ability to help their child develop and learn. In 2006, EI stakeholders

proposed that EI programs adopt a set of five family outcomes (Bailey, et al., 2006). Included are an understanding of their child's needs and abilities, awareness and understanding of their rights so they can affectively advocate for their children, the ability to help their children make developmental progress, identify and utilize support systems, and be able to access needed services in their community. While these outcomes are not all accounted for national data collection, they are considered best practice for EI practitioners and are reflected in the Division for Early Childhood's Recommended Practices in EI/Early Childhood Special Education (2014).

From the inception of EI to the present, the field of early childhood special education has aligned research on child and family outcomes with the tenets of family-centered practices. Myriad studies have focused on family quality of life (Summers et al., 2005; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Brown, Shalock, & Brown, 2009), parental satisfaction with EI service provision (Bruder & Dunst 2015; Khetani, Cohn, Orsmond, Law, & Coster, 2013; Upshur, 1991), and parent-service provider relationships (Broggi & Sabatelli, 2010; Minke & Scott, 1995; Dinnebeil, Hale, & Rule, 1996). Unfortunately, little of this research focuses on fathers, their experience in EI and with EI providers, or even their experiences parenting children with disabilities, especially in journals aimed specifically for EI practitioners.

Theoretical Framework

The family centeredness of EI was born from Bronfenbrenner's bioecological systems theory (1979, 1998, 2001). This theory serves as part of the conceptual framework of the study outlined. The bioecological systems theory provides a foundation for unpacking the intricacy of factors impacting human development. Family systems perspective (Seligman & Darling, 2007; Turnbull & Turnbull, 1996; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015:) fits into the micro- and mesosystem levels of bioecological systems theory. The marriage of bioecological

systems theory and family systems perspective provide a solid conceptual foundation for early interventionists engaged in family-centered practice.

Bioecological Systems Theory

Sometimes called the social ecology model or ecological model, bioecological systems theory addresses the ways that children do not exist and develop in isolation; rather, a child develops within the context of systems: the microsystem, the exosystem, the mesosystem, the macrosystem, and the chronosystem (Bronfenbrenner, 1979, 2001).

Bronfenbrenner introduced Bioecological Systems Theory in 1979 with the publication of *The Ecology of Human Development: Experiments by Nature and Design*. He stated:

The ecology of human development involves the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings and by the larger contexts in which the settings are embedded. (Bronfenbrenner, 1979, p.21)

Bioecological systems theory discounts the notion that human beings are blank slates that develop in isolation. When first proposed as ecological systems theory in 1979, the theory focused primarily on human development during childhood. In 2001, Bronfenbrenner expanded the theory to include the proposition that behavior and development of children impact the development of their parents. While many bioecological systems theory models position children at the center of the bioecological model, this study positions fathers of children with disabilities as the focus.

Bioecological systems theory provides a framework for understanding the complexity of human development. Bioecological systems theory is a Process-Person-Context-Time Model

(PPCT) (Lerner, 2005). Lerner (2005) defines the PPCT model as the intersection of four main components of Bronfenbrenner's bioecological systems theory. The first, Process, consists of the individual's development occurring within their context. The Person component describes the individual's own internal characteristics: biological, cognitive, emotional, and behavioral. The person component is called out in the "bio" of bioecological systems theory. Next, the Context component speaks to the context in which development occurs. This is represented by the ecology in the model, the nested micro-, meso-, exo- and macrosystems. Visual representations of this model often consist of concentric circles with the developing person in the center, the closest circle representing the microsystem, the next circle as the mesosystem, then the exosystem, and the macrosystem existing in the outermost circle. Lastly, Time is defined as both the time that takes place within the individual and family lifespans development and historical time. Bronfenbrenner positioned time in the chronosystem. It is often represented in visual models as an overlay to the concentric circles depicting the model's other systems.

At the center of the bioecological systems theory is the individual. Each human being presents with their own unique biology, cognition, emotional, and behavioral characteristics. Bronfenbrenner and Morris (1998) proposed that these characteristics appear twice in the model. First as influencers of development and second as products of development. For example, a father with an easy temperament and optimal mental health will likely experience more pleasant interactions with the EI professionals in the microsystem. Through repeated, positive interactions with EI professionals, the father will develop knowledge and skills that produce effective fathering behaviors. Conversely, a father experiencing high levels of external stress due to financial concerns and/or immense worry about their child's developmental differences may exhibit behaviors that inhibit positive reciprocal interactions with EI therapists; thus,

preventing the acquisition of new knowledge and skills related to parenting a child with a disability.

Positioned immediately outside the person at the center of the bioecological model is the microsystem. The settings a person most directly and consistently interacts with make up the microsystem. Human development occurs as a direct result of the interactions between the person at the center of the bioecological model and their microsystem. The microsystem comprises the system of people and relationships closest to the person in the center of the bioecological model. For someone to exist within another person's microsystem, the person at the center of the bioecological model must interact with them regularly and maintain an interpersonal relationship with them. If the father of a child with a disability is positioned at the center of the model, the father's microsystem includes the settings of his home, work, and peer relationships. For example, a father's microsystem may include his romantic partner and co-parent (this may be the same person), his children, the children's caregivers, the children's EI providers and medical professionals, his own friends, coworkers, and any others that he interacts with regularly. This may include the father's parents and siblings, physicians, or any other person with whom the father maintains an interpersonal relationship. Bronfenbrenner posits that when one member of a dyad within a microsystem undergoes a developmental change, the other member of the dyad will experience a change as well. For example, as a father becomes more competent in managing the behaviors of a child with a disability, the child will then become more capable of participating in interactions at the microsystem level that consist of positive behaviors.

Situated outside of the microsystem lies the mesosystem. The mesosystem is "a system of microsystems" (Bronfenbrenner, 1979, p. 25). The relationships among a father's

microsystems make up his mesosystem. For example, the interrelationship between his work setting and his home, the relationship between his children and their daily caregivers, or the relationship between his partner and the EI team each exist within the mesosystems. The relationships within the mesosystem impact human development and can mitigate or exacerbate stressors that exist in a person's environment. At the mesosystem level of the bioecological model, the person at the center maintains interactions with each "system of microsystems" and may impact the relationships that make up the system.

Outside of the person's direct interactions sits the exosystem. Bronfenbrenner defines the exosystem as settings that the person at the center of the model doesn't interact with directly but that nonetheless impact that person's development. When a father of a child with a disability is the developing person at the center of a bioecological model, his exosystem includes the state level policies that drive EI eligibility, the fringe benefits package offered by his partner's employer, and/or the media's portrayal of both fathers and people with disabilities. Individual fathers are not able to impact any of these settings nor do they have direct interactions with them, however, each of the settings within the exosystem impact the father's development.

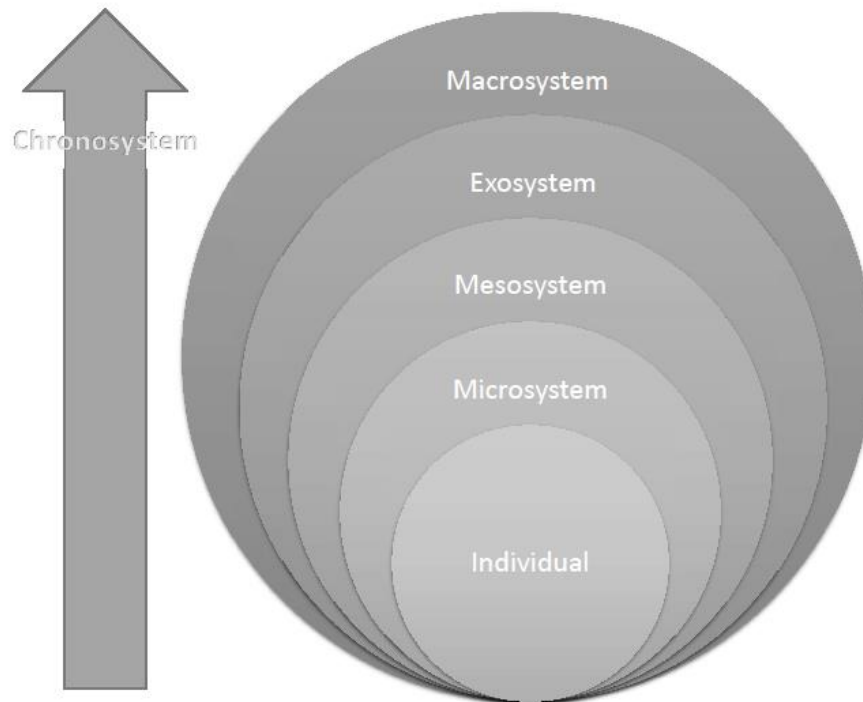
At the outside of the bioecological model is the macrosystem. This system encompasses all the other systems and includes the cultural ideologies upon which the other systems are built. Within the macrosystem lies the cultural beliefs about masculinity, fatherhood, family, and disability. The prevailing cultural attitudes about each have impacted the fathers' own development as a child as well as his development as the father of child with a disability. In the United States, the father of child with autism likely conceptualizes autism very differently than a father of a child with autism living and developing in the Ivory Coast of Africa due to the different macrosystems they inhabit (Bayat, 2015).

The chronosystem contains the shifting cultural ideologies and bodies of knowledge that shape a macrosystem over time as well as the major life events that impact a person's development. Bronfenbrenner added the chronosystem to incorporate the impact that these events have on development. The shifting perception of what it means to be a father in the United States is a prime example of the way the chronosystem impacts development. A father of a child diagnosed with a severe disability in the 1950s would likely have been encouraged to place that child in an institution (Brown & Percy, 2007) and not experience the same changes in psychological development that a modern father who engages in the daily caregiving of a child with a disability living at home would experience. Additionally, life events like the birth of a child and the diagnosis of the child's disability can impact fathers' development.

Close examination of the bioecological models of fathers with children with disabilities requires nuanced understanding of how a father interacts within the settings of the microsystem. Family systems perspective gives insight into the potential impacts of microsystem-level interactions on the development of fathers and the other members of their immediate family.

Figure 1 Bioecological Systems Model

(adapted from Bronfenbrenner & Morris, 1998)



Family Systems Perspective

Family systems perspective views the family as a dynamic unit; thus, whatever happens to one member of the family, impacts all members of the family (Seligman & Darling, 2007; Turnbull & Turnbull, 1986; Turnbull, Summers, & Brotherson, 1984; Turnbull & Turnbull 1996, Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). This position aligns with bioecological systems proposition VIII which states that children influence their parents' development as powerfully as parents influence their children's development (Lerner, 2005). Within the model of family systems perspective, these influences occur through family characteristics, family interactions, and family functions as they occur throughout the family life cycle (Seligman & Darling, 2007; Turnbull, et. Al, 2015). A family's ability to derive joy through their interactions

with one another and successfully navigate family functions results in the family's overall quality of life (Zuna, Summers, Turnbull, Hu, & Xu, 2010). Improved family quality of life is a desired outcome of family participation in EI services (Bailey et al., 2006; Bhojti, Brown, & Lentin, 2016).

In the spirit of providing inclusive family-centered practice, this study defines a family as any two or more people that define themselves as a family and work together to achieve family functions (Turnbull et al., 2015). Consistent with this definition of family, fathers in this study are identified as any male-identifying person who takes on the role of fathering and identifies within his family unit as the child(ren)'s father. Characteristics of families and fathers vary greatly from home to home and are influenced by the size and form of the family, cultural background of the members, family culture of the family unit, socioeconomic status, geographic location, and other unique circumstances including but not limited to disability status, homelessness, family mental illness, teen parenthood, and divorce.

Family systems perspective as a conceptual framework was initially introduced in the field of family therapy (Bowen, 1966) and later applied as a conceptual framework for working with families with children with development disabilities (Garbarino, 1992; Goldenberg & Goldenberg, 2003; Seligman & Darling, 2007). In family systems perspective, mesosystem relationships make up family subsystems (Turnbull et al., 2015). Family interactions are the relationships and social exchanges between family members and subsystems. Cohesion and adaptability are the main descriptors of these interactions within family systems perspective (Seligman & Darling, 2007; Turnbull et al., 2015).

Family cohesion describes each family's emotional bonds and the boundaries between the members' subsystems and between the family and individuals, such as EI professionals,

positioned outside the family unit. Family cohesion exists on a continuum (Seligman & Darling, 2007; Turnbull et al., 2015). On one end is enmeshment and on the other, disengagement. Enmeshment occurs when one or more members of the family sublimate their own needs or overlook the needs of one member in favor of another (Minuchin & Fishman, 1981). In a family with a child with a disability, this could mean that one parent focuses solely on the care of that child to the detriment of their spouse, other children in the family, or themselves. Enmeshment at this level negatively impacts the development of all family members.

Conversely, disengagement exists on the opposite end of the continuum and occurs when families have such a low level of cohesion they withdraw from interactions and relationships within subsystems (Seligman & Darling, 2007; Turnbull et al., 2015). In families with a high level of disengagement, families may grant each other excessive privacy, fail to consult each other when making decisions, and may neglect each other's emotional needs. For families with a child with a disability, disengagement may occur subsequent to denial or lack of acceptance of the disability. Just as excessive levels of cohesion arrests development so can disengagement.

Levels of family cohesion impact the relationships between family members and EI professionals (Turnbull et al., 2015), which exist in the mesosystem of the father of a child with a disability. The level of family cohesion determines the level of boundaries between the family and outsiders, including EI professionals. For family-centered practice to occur within EI services, family cohesion levels must be such that the family allows the EI professionals to build trusting and collaborative relationships with family members, especially the parent-child subsystem. Family-centered practice occurs only when EI professionals and family members work together to improve the knowledge, skills, and caregiving practices of the family (McWilliam, 2010; Raver & Childress, 2015).

Exo-, macro-, and chronosystems play an influential role in expectations of appropriate levels of family cohesion. For example, American families tend to place a high value on independence; therefore, they may display a lower level of family cohesion than a family coming from a collectivist culture that values interdependence (Turnbull et al., 2015). Families who experience a harmony of cohesion, that is, when family subsystems agree on and achieve the level of cohesion desired by all members, experience more positive outcomes than families without family cohesion equilibrium (Gavidia-Payne & Stoneman, 1997; Keller & Honig, 2007).

The second feature of family interactions in family systems perspective is family adaptability. Adaptability refers to families' ability to change in response to stress or crisis (Seligman & Darling, 2007; Turnbull et al., 2015). For many families, the diagnosis of child's disability is viewed as a time of crisis (Walsh, 2003). Even in families that do not view disability as a crisis, all parents of children with disabilities must adapt their perceptions of what parenthood and their child would be to the reality of what parenthood and their child are (Galinsky, 1987). The level of family adaptability greatly impacts a family's ability to balance coping strategies with the stress of parenting a child with a disability (Turnbull et al., 2015). Families with strict roles and hierarchies have difficulty adapting to new situations. These families often experience high levels of difficulty achieving family functions when presented with the stress that may accompany the birth and caregiving of a child with a disability. Equally, families with very high adaptability struggle to cope with the family stress brought on by caring for a child with a disability (Turnbull Et al., 2015). Families with an extremely high level of adaptability lack structure, often do not respect promises and commitments, and lack a family leader. Much like cohesion levels, families function best with moderate levels of adaptability. A

family's inability to adapt appropriately to caring for a child with a disability hinders their ability to complete essential family functions, potentially resulting in decreased family quality of life.

Adaptability in the face of family stress is a process, rather than a static characteristic (Walsh, 2003; Turnbull et al., 2015). For example, a family with a child in the Neonatal Intensive Care Unit (NICU) may need to restructure their plan for family leave following the birth of a premature infant. Some families decide to return to work during the day while the child is in the NICU and cared for around the clock by medical staff and then take maternity and/or paternity leave once the child has been discharged home. Other families may need to rethink their gender roles if one parent is needed to stay at home and care for a medically complex child. Family-centered practice supports families in gaining knowledge, skills, and caregiving practices that can impact the process of family adaptability.

Levels of family cohesion and adaptability ultimately determine a family's ability to accomplish family functions. Family functions are the day-to-day actions that need to occur to meet the needs of the family. Seligman & Darling (2007) state there are eight family functions: affection, daily care, self-esteem, spirituality, economics, socialization, recreation, and education.

The first family function, affection, describes the exchange of physical and verbal affection between family members and the exchange of unconditional love (Summers et al., 2005). Affection contributes to strong attachments between parents and children (Bowlby, 1953; Bronfenbrenner, 1979). Affectionate displays vary from one family culture to another but may include smiles, hugs, kisses, physical proximity, kind words, and permissiveness. Some families are more overt with affectionate exchanges than others (Turnbull et al., 2015).

Family-centered practice can facilitate strong, affectionate relationships between parents and their children by building the capacity of parents to care for their children (Raver & Childress, 2015) and adopting a strengths-based approach to describing children and their disabilities (Steiner, 2011). It is within strong, affectionate relationships that positive developmental outcomes occur for children and parents (Bronfenbrenner, 1979; 2005). All levels of the bioecological model deeply impact familial displays of affection. For example, a father with an affect disorder at the biological level and a father who comes from a macrosystem that values strict gender roles may fail to show their sons physical affection. Their behavioral outcomes are same, despite varying contexts.

The second family function is spirituality. The family systems perspective definition of spirituality centers on the meaning that people derive from their lives (Turnbull et al., 2015). For some families, this happens through the practice of an organized religion and for others, it manifests in the meaning making of life events. Families with children with disabilities often increase their levels of spirituality (Bayat, 2007), and positive meaning making is a factor in developing family resilience (Walsh, 2003; Patterson, 2002). In my work as a practitioner, I've observed this in many different ways depending on the family belief system. For example, a deeply religious parent may view the birth of a child with a disability as either a gift from God or a punishment for past misdeeds. A spiritual but not religious parent may assign positive personal outcomes, such as increased value of government-funded early childhood programs, to the experience of parenting a child with a disability. At the same time, caregiving for a child with a disability may disrupt spirituality functioning for some religious families if the caregiving inhibits participation in religious worship services or rituals such as the observation of Shabbat.

The third family function is economics (Seligman & Darling, 2007). All families need to access economic resources to fulfill basic needs. For almost all families, this means work-generated income. Families raising children with disabilities incur additional costs beyond the cost of raising a child who is typically developing. These costs include insurance co-pays, special diets, medical costs, adaptive toys and equipment, specialized services and therapy, and mobility devices (Parish, Rose, Dababnah, Yoo, & Cassiman, 2012). Depending on the severity of the child's disability, American families with one child with a disability can expect to pay between \$20,000 and \$60,000 in disability-related costs per year (Stabile & Allen, 2012). Low-income families and families living in states without robust Medicaid coverage face higher out-of-pocket costs than families with higher incomes or those living in states with high levels of Medicaid (Parish et al., 2012). Twenty percent of low-income families reported at least one parent leaving their job to care for their child full time (Parish et al., 2012), which inevitably results in lost income and surely impacts economic family functions. It may not seem that EI professionals need to focus on the economic family function as EI services are subsidized by federal funding (IDEA, 2004), however, economic family functioning impacts the external resources that families access. For many families, family income is more predictive of family quality of life than disability severity (Wang et al., 2004). Additionally, there is some evidence to show that EI providers perceive low-income families, especially those with single mothers, as less committed to their children's progress than families with higher income levels (McHatton, 2007). Exosystem factors that influence state Medicaid policy and macrosystem factors influencing societal perception of low-income families likely impact the relationship between parents and EI providers at both micro- and mesosystem levels.

Seligman & Darling (2007) identified daily care as the fourth family function. For families with typically developing children, these activities include everyday tasks: laundry, cleaning, meal preparation, grocery shopping, bathing, dressing, transportation, and accessing health care. Daily care is one of the most time consuming of the family functions for all families (Turnbull et al., 2015). In families with children with disabilities, daily care activities may present added challenges. For many children with disabilities, daily care tasks involve participating in therapy and medical appointments. Tasks like bathing may require adaptive equipment. Many families with children with disabilities report that their children have disturbances in eating and sleeping (Hogan, 2012). Many families with children with disabilities, such as autism, report additional stress associated with the daily task of managing child behavior (Davis & Gavidia-Payne, 2009).

Daily care routines are often targeted as learning opportunities within the family-centered practice model. One method of family-centered practice is routines-based intervention (McWilliam, 2010). The routines-based intervention model requires EI professionals to inventory daily care routines and embed opportunities to build parent capacity by teaching skills and caregiving practices in the moment. These microsystem-level interactions are highly effective. Families who worked directly with EI providers that provided routines-based interventions reported high levels of satisfaction with EI services (Murphy, 2013) and were more likely to engage in skill building tasks with their children between EI visits (McWilliam, 2010, 2012). Building parent capacity to successfully complete the family functions of daily care is highly correlated with increased satisfaction with family quality of life (Dunst, Bruder, Trivette, & Hamby, 2006).

After daily care routines, the family functions of socialization and recreation are vital to family quality of life (Seligman & Darling, 2007; Turnbull et al., 2015). Socialization creates friendships and extends a person's microsystem. Recreation includes sports, games, hobbies, and play (Turnbull et al., 2015). Families with children with disabilities report challenges with accomplishing these family functions. Socialization may be difficult because of a child's disability symptoms. For example, children with Autism have challenges with social communication (American Psychological Association, 2013), children with down syndrome face motor and communication delays (Skallerup, 2012), and children with spina bifida or cerebral palsy may not be able to access public spaces due to their lack of wheelchair accessibility. Mothers of children with disabilities also struggle with meeting the family functions of socialization and recreation for themselves. Lack of time was often cited as a major impediment to family socialization and recreation (Bayat, 2005; Benson, Karlof, & Siperstein, 2008).

Even in families that find time for socialization and recreation, it can be difficult to find other families who relate to parenting a child with a disability. One father tried and failed to find opportunities to connect with other fathers with children with and without disabilities. He became so frustrated by his lack of socialization opportunities and social support, he self-published a book of essays detailing the experiences of fathers with children with disabilities (Dietz, 2014). According to Bronfenbrenner (1979, 2005), socialization is a key factor in positive human development. This development may occur in either direction between parents and children (Lerner, 2005) or between peers. Family-centered EI professionals can support families by integrating opportunities for socialization and recreation into their therapeutic interactions with families.

The last family function within the family systems perspective is formal education (Seligman & Darling, 2007; Turnbull et al., 2015). Formal education takes place primarily in public and private school. Macrosystem-level influences in the United States place a high level of emphasis on education as a pathway to success. This cultural value is evident in the exosystem-level discourse about school quality and macro- and exosystem policies like the No Child Left Behind Act (2001) and, for children with disabilities, the Individuals with Disabilities Act (2004). EI was born from the need to provide educational services for young children with disabilities for the purpose of improving developmental outcomes for children and improving overall family quality of life. EI professionals are uniquely positioned to affect the family function of education in two generations. EI professionals improve the knowledge and skills of children and parents. Additionally, EI professionals stimulate adaptive changes to caregiving practices and teach parents how to navigate the special education system. Parents of children with disabilities are legally required to participate in their children's educational goal setting and service provision planning. Parents frequently describe this process as overwhelming or frustrating (Hogan, 2012; Lovett, & Haring, 2003), but EI providers have the power to mitigate the stress brought on by this process by providing support to families as they transition into school-based special education (Lovett & Haring, 2003) and by engaging families in collaborative goal setting (Rodger, O'Keefe, Cook, & Jones, 2012).

The family life cycle provides context for family systems perspective. Differences exist in families' abilities to complete family functions and adapt to changing needs of the family to achieve the eight family functions. Within family systems perspective, the life cycles stages correlate to the developmental stages of the family's children and include the birth and early years of their child(ren), their childhood, adolescence, and adulthood (Turnbull et al., 2015).

Bronfenbrenner positioned these family life cycle events in the chronosystem (Bronfenbrenner, 2001). According to family systems perspective, the most stressful times of the family life cycle are the transitions from one stage to another. One such transition is the welcoming of a new baby into the family system. This stress may influence human development via its influence on the micro- and mesosystems of the bioecological model. Clearly defined but flexible family roles and expectations reduce the stress often associated with life cycle transitions as does the timing of the transition within the typical timeframe as dictated by family culture (Turnbull et al., 2015).

Family systems perspective is widely accepted within the early childhood special education system and is taught in early childhood special educator preparation programs (Turnbull et al., 2015; DEC 2014; Raver & Childress, 2015). EI is predicated upon the acceptance of a framework that supports family-centered practices. As such, a combination of bioecological systems theory and family systems perspective undergird this research.

The Changing Paternal Role in the United States

Developing a firm understanding of father involvement in EI requires the unpacking of the macro- and chronosystem influences on the paternal role in two-parent families in the United States. In 2016, about 70% of all children lived in two-parent households (U.S. Census Bureau, 2016). Over the last 40 years, the idealized role of the father in two-parent American families has evolved from one of breadwinner to that of a more active participant in childrearing and domestic tasks (Lamb, 2013). In literature prior to 1970, fathers were defined by their status as the male head of household rather than by a relationship with their children. In fact, John Bowlby, a prominent theorist in early childhood, stated in 1953 that a father's usefulness in infancy was solely to provide financial and emotional support for mothers. Fathers were not

even included in the National Family Growth Survey until 2002 (Jones & Mosher, 2013). From the period of Bowlby's research through the beginning of the 1980s, time-use surveys showed that when fathers did engage with their children, it was largely play rather than any kind of caregiving activity (Kotelchuck, 1976). In fact, fathers spent approximately three times the number of minutes in play with their children than mothers did daily, 73 minutes versus 24 minutes (Kotelchuck, 1976).

Beginning as early as 1924 and continuing through today, time-use studies focused on middle class white families demonstrate a slow increase in the amount of father caregiving activities (Fuligni & Brooks-Gunn, 2004; Lamb, 2013; Craig & Mullen, 2011; Jones & Mosher, 2013), with father caregiving reaching its highest levels in the 1990s and 2000s. Lamb (2013) attributed this relatively recent change in fatherhood as the evolutionary result of feminism's impact on American society, citing an increase in the number of working mothers and changes in societal norms about gender roles within heteronormative couples with children. In 2015, 60% of American families had two working parents (Bureau of Labor Statistics, 2015). This figure starkly contrasts the pre-World War II rate, when 13.8% of married women worked outside the home (Eisenmann, 2006). This increased number of families with two working parents caused a shift in American thinking about the role of fathers, as families needed to adapt to new divisions of labor to achieve family functions. In modern families, mothers' full-time work schedules predict more equitable divisions of infant caregiving. Working mothers need assistance with childrearing and domestic tasks and men are no longer sole breadwinners, although, notably, fathers that have high socioeconomic statuses participate in lower levels of caregiving of children with disabilities than fathers with lower SES levels (Dyer, McBride, Santos, & Jeans, 2009).

Since the 1980s, shared responsibility for caregiving between mothers and fathers became more widely accepted in homes with both highly educated parents (Craig & Mullen, 2011) and those whose lower income qualifies their children for Head Start Programs (Vogel, Boller, Faerber, Shannon, & Tamis-Lemanda, 2003). Investigations of father caregiving often compare fathers' levels of caregiving with mothers' levels of caregiving (Fuligni & Brooks-Gunn, 2004; Hofferth, Pleck, Goldschneider, Curtain, & Hrapczynski, 2013). Comparative studies have consistently shown that mothers maintain higher levels of daily caregiving than fathers, while fathers engage in higher levels of play with their children than mothers. These numbers can be misleading and may impact early interventionists beliefs and practices with fathers. EI providers often feel that fathers are not good targets for EI because men are not caregivers (McBride et al., 2017). Time-use and self-report studies show this assumption is false.

According to a federal report of 3,928 fathers of varied educational and racial backgrounds, 72% of residential fathers ate meals with and/or fed their children daily (Jones & Mosher, 2013). Fifty-eight percent of residential fathers engaged in daily bathing, dressing and/or diapering, with 90% of fathers participating in these daily care family functions several times per week. Consistent with time-use surveys from earlier decades, 81% of residential fathers engaged in daily play with their children. Twenty-nine percent of residential fathers reported daily reading to their children. These statistics of father involvement demonstrate a higher level of father caregiving between 2006-2010 than EI professionals perceive (McBride et al., 2017). It is notable that fathers in this survey reporting high levels of daily caregiving were likely to rate themselves either good or very good fathers.

An earlier report conducted with fathers of typically developing newborns in Early Head Start programs also found high levels of father involvement in daily care (Vogel et al., 2003). One hundred and eight fathers participated in self-report and videotaped interactions with their infants. Fathers were partnered and residing with their child's mother at the time of the study. Their average age in 2003 was 27. All families met the low-income requirements of Early Head Start. The sample was 70% black or Hispanic and 30% white. The majority of fathers, 90%, reported spending an hour or more engaged in daily interactions with their infants. Videotaped interactions of the fathers and their infants at ages six months and fourteen months demonstrated high levels of positive affect, responsiveness, and flexibility and low levels of teasing. This study demonstrates that modern fathers interact differently with their children than fathers observed in the 1970s and 1980s. Research conducted pre-1990 found that fathers engaged with their children mainly through teasing and rough and tumble play (Vogel et al., 2003). These changes in the type of father interaction with children throughout the late 20th century is consistent with the data from time-use surveys that show an increase in father caregiving during that same time period (Fuligni & Brooks-Gunn, 2004). U.S. Census data (2013) have shown similar increases in the level of father caregiving. In 2011, 32% of fathers provided care for children while their mothers were at work, whereas in 1988, only 19% of fathers cared for children while their mothers were at work. Currently, 20% of two-parent families reported that the father was the primary caregiver for children.

Most available literature on modern fatherhood and father engagement in daily caregiving focuses on fathers of typically developing children (Vogel et al., 2003; Lamb & Lewis, 2010; Manning & Brown, 2013; Jones & Mosher, 2013). A paucity of research related to the amount of post-1990 father engagement in daily caregiving for children with disabilities

presents a challenge for researchers (Dyer, McBride, Santos, & Jeans, 2009). One examination of data from the Early Childhood Longitudinal Study – Birth Cohort (ECLS-B) found no difference in the level of overall father involvement spent with their children with or without disabilities born in 2001 (Dyer et al., 2009). Interestingly, fathers of typically developing children showed a lower level of daily caregiving with daughters than sons. No such difference occurred among fathers of daughters with disabilities. More research is needed, but this may indicate that the presence of a disability negates father caregiving differences between sons and daughters.

The ECLS-B data also indicated that fathers with higher socioeconomic statuses engaged in less daily caregiving than fathers with lower socioeconomic statuses. While this is consistent with the high levels of father caregiving among Early Head Start fathers, more research is needed before developing a robust understanding of father caregiving in families with children with disabilities. Interestingly, in less educated, lower SES families with children with disabilities, fathers are more likely to work while mothers stay at home with the child with the disability (Hogan, 2012). Overall, in families with children with disabilities, fathers are 19% more likely to be employed than in the general population of married fathers. More data about shared caregiving in families with children with disabilities are needed before EI professionals and policy makers can draw conclusions about father caregiving in these families.

Impact of Father Involvement on Child Development

Once researchers noted the shift in the paternal role in American families, a slowly increasing amount of research on the impact of father involvement emerged, peaking in 2000 with 20% of articles in prominent peer-reviewed journals attending to fathers and fathering

(Goldberg, Tan, & Thorsen, 2009). Currently, no more than 15% of journal space focuses on fathers. More scholarly attention is called for, especially for fathers of children with disabilities.

Father involvement research began by looking at the adverse impacts of not having a father present. In 1954, *Father Relations of War-Born Children* compared the behavior and development of children with absent fathers to children with fathers in the home. The children with absent fathers were found to have more negative behaviors than their peers with coresidential fathers, but Stoltz did not examine the actions of residential fathers. The sentiment that fatherless children fared poorly in the areas of school performance, social-emotional skill development and behavior management continued through the early 1990s (Lamb, 2010), concurrent with studies focused on the gender identity development of fatherless boys (Lamb, 1981). A focus on the value added by involved fathers emerged in the 1980s (see Lamb, 2010 for a review).

Contemporary researchers began to pursue father involvement research that looked at the additive value of father involvement for typically developing children across developmental domains of social-emotional development and behavioral regulation (Leidy, Schofield, & Parke, 2013; Bagner, 2013), language acquisition (Tamis-leMonda, Baumwell, & Cabrera, 2013), math ability (Cook, Roggman, & Boyce, 2012), sense of humor and attention span (Brazleton & Sparrow, 2006), and comfort with healthy risk taking (Hagan & Kuebli, 2007).

For example, contemporary researchers found that the important characteristics of paternal behavior are warmth, commitment, and sensitivity, and that the quality of a child's attachment to their fathers has just as much impact on their development as their attachment to their mothers (Lamb, 2013; Shannon et al., 2002). Strong father-child attachments built through responsive father caregiving can buffer the impact of maternal depression on children's

behavioral regulation (Mezulis & Perry- Jenkins, 2010). Increased father caregiving during infancy increases the quality of attachment between father and child which in turn can positively impact a child's development, especially in terms of social-emotional development, IQ, sense of humor, and attention span (Brazleton & Sparrow, 2006).

Fathers' involvement offers additional opportunities to shape their child's language development. Fathers tend to use a more varied vocabulary with children than mothers (Pancsofar & Vernon-Feagans, 2006). In general, fathers use more directives and wh- questions, and request more clarification than mothers (Tamis-LeMonda, Baumwell, & Cabrera, 2013). These types of back-and-forth exchanges with young children increase language comprehension (National Association for the Education of Young Children, 1998). Overall, fathers' supportiveness during play better predicted language abilities at 24 and 36 months than father education level, family income, or mothers' supportiveness (Tamis-LeMonda, Baumwell, & Cabera, 2013).

When observing the impact of father involvement on children with disabilities, one study found that when fathers of children with challenging behaviors (tantrums, noncompliance, physical outbursts) participated in a behavioral parent training, their children showed significantly fewer challenging behaviors and more compliance after the intervention than children whose fathers did not attend (Bagner, 2013). Two-parent families without father involvement in the parent training were twice as likely to drop out of the intervention than those with participating fathers. Children whose fathers participated actively in behavioral treatment programs have shown better outcomes at one-year post intervention (Webster-Stratton, 1985) and maintained those outcomes at four years post outcome (Bagner & Eyberg, 2003).

Impact of Father Involvement on Their Own Development

Father involvement and caregiving is also advantageous for the personal development of fathers. Fathers who report higher levels of interactions with their children and more caregiving activities rate themselves good or very good parents (Jones & Mosher, 2013). Fathers of children with disabilities who actively participate in EI services with their children report a high level of satisfaction with the services and an increase in their efficacy as fathers (Murphy, 2013; Donaldson, Elder, Self, & Christie, 2011; Salinas, Smith, & Armstrong, 2011).

One such study surveyed 135 Tennessee fathers of children with disabilities after their children aged out of EI services (Fox, Nordquist, Billen, & Savoc, 2015). Fathers reporting a high level of empowerment on the Family Empowerment Scale felt higher levels of role salience and parenting satisfaction. Empowerment and efficacy mitigated any impact of income or disability severity on role salience and parenting salience. Fathers who felt efficacious in their parenting spent more time with their children across play and caregiving. This supports Bronfenbrenner's (2005) proposal that the act of parenting impacts the psychological development of parents. The body of research on impact of father empowerment, role salience and parenting satisfaction as an outcome of EI participation is emergent, and the field will benefit by a more robust body of evidence.

Fathers' Participation and Experiences in EI

Overall, research investigating parents' experiences with EI is largely positive (Dunst, Trivette, & Hamby, 2007; McWilliam et al., 1995). The program has proven to be highly cost effective and to have an overall positive outcome for families over the course of their lifetimes including an increased family quality of life. The vast amount of literature relating to families' experiences in EI focuses on mothers' experiences parenting children with developmental delays

and disabilities (Bagner, 2013; Flippin & Crais, 2011). Little research has been done that directly addresses fathers' experiences in EI. One literature review of interventions specifically targeting families with a child with autism, found only two studies published between 1990-2010 that directly addressed fathers (Flippin & Crais, 2011). Other studies relating to family quality of life and disability parenting listed participants as either mothers or parents without specifying gender (McFelea & Raver, 2012).

Often, research collected about mothers' experiences, perceptions, and desired outcomes in EI is generalized to "parents" and some studies do not disclose whether participants were mothers, fathers, or both (Flippin & Crais, 2011). This line of thinking is faulty based on a variety of factors, not the least of which are what we know about the ways in which fathers' interaction with children differs from the ways in which mothers interact with children (Tamis-LeMonda, Bamwell, & Cabrera, 2013; Labrell, 1996; Pleck & Masciadrelli, 2004). Additionally, a discontinuity exists in the reported causes of stress and perceived levels of family quality of life among mothers and fathers of children with disabilities (Wang et al., 2004). For mothers, an increase in family quality of life is correlated with higher SES. The is factor did not correlate with higher levels of reported family quality of life for fathers. Overall, fathers of children with disabilities rated their family quality of life as higher than mothers (Wang et al., 2004). Based on these differences, it is reasonable to believe that fathers and mothers experience parenting children with disabilities differently.

A qualitative study of 20 fathers with children enrolled in special education programs for older children (ages 3-21) found that the fathers shared a common experience of feeling like the "odd man out." One father stated, "We're definitely on the outside looking in... I think the role, the idea of not being the primary caregiver still holds true across this..." (Mueller & Buckley,

2014, p.43). A study of British fathers with children with disabilities echoed this sentiment as fathers in this study felt invisible to special education service providers (Carpenter & Towers, 2008). These fathers' feelings of being left out are consistent with the self-reported views and actions of EI professionals. McBride and his team (2017) found that while most EI providers surveyed stated they believed father involvement is important, the same providers continued to express very old-fashioned gendered notions about the roles of fatherhood. This group of providers reported that fathers are not good targets for intervention and spent little or no time working to engage fathers (McBride et al., 2017). There is a clear disconnect between fathers' desire for involvement and the actions of their EI providers to involve fathers during therapeutic interventions with families.

When fathers are engaged in EI, they report a high level of satisfaction with the services and attribute positive family and personal outcomes to their participation (Murphy, 2013; Fox, Nordquist, Billen, & Savoca, 2015; Upshur, 1991). One qualitative study found that Latino parents of both genders rate EI programs highly, and parental satisfaction with EI programs is linked to developmental progress (Murphy, 2013). The fathers interviewed have clearly articulated in detail what EI strategies helped their children or helped them to parent their children. Fathers in this study also reported that they valued gaining information about their child's development and being given specific strategies to use with their child. They also reported that they valued working with EI providers that communicated clearly, were punctual, and had a high level of expertise in the field.

Another small-scale study found that although 10 fathers reported initial skepticism and uncertainty about participating in EI programs, they were active participants in the program and came to feel supported and informed (Baden, 2012). These results were based on fathers' own

perceptions and failed to qualify what active participation looked like in these cases. Lastly, an exploratory study of 16 mothers and 16 fathers provided a training for one member of the family related to understanding disability, disability-related problem solving, coping strategies, addressing problem behaviors, and effective family and educational communication. It reported increases in family satisfaction and the level of support provided. However, it was not specified which parent attended the training (Soresi, Nota, & Ferrari, 2007), so it is impossible to parse the exact experiences of fathers in the intervention.

It is well established that the involvement of fathers of children with disabilities in EI and other interventions has myriad positive impacts on children's developmental, social-emotional and behavioral outcomes (MacDonald & Hastings, 2010; Bagner, 2013; McBride et al., 2014). Unfortunately, many fathers still feel that providers are not working to fully engage them in the intervention process (Mueller & Buckley, 2014; Carpenter & Towers, 2008). Overall, while there has been a move in the right direction, little research has been done that specifically addresses the experiences of fathers in EI. In the small body of research that does exist, clear themes emerged. Primarily, American fathering has changed in the last fifty years but presumptions about low levels of father caregiving prevail. Next, fathers feel left out of special education services, and service providers continue to work harder to engage with mothers due to antiquated ideas about the role of fathers in the everyday care of children with disabilities.

CHAPTER THREE: Methodology

This study sought to further the understanding of the ways in which fathers experience EI services, including the way participation impacted them as individuals, their relationships with and perceptions of their children with and without developmental differences, and their family unit.

Research Design

This study used a qualitative, narrative inquiry approach. Qualitative research is most appropriate for researchers seeking to gain an understanding of people's unique experiences and how they construct meaning around those experiences (Ravitch & Carl, 2016). The purpose of this research was to develop a nuanced understanding of what fathers experienced in EI programs. This goal is aligned with qualitative narrative inquiry. Considering the paucity of research about fathers in EI, a research methodology focused on collecting and examining fathers' unique experiences is appropriate.

Narrative Inquiry

Narrative inquiry is the collection, examination, and sharing of individual's stories (Webster & Mertova, 2007). For this research, narrative inquiry's positioning in people's stories provided a set of data that "[addressed] the complexities and subtleties" of fathers' experiences and how they constructed meaning from those experiences (Webster & Mertova, 2007, p. 1).

Narrative inquiry researchers "investigate the way humans experience the world depicted through their stories" (Webster & Mertova, 2007, p. 1) as a vehicle to "[honor] lived experience as a source of important knowledge and understanding" (Clandinin, 2013, p. 17).

Due to this study's goals of developing a nuanced understanding of fathers' experiences in EI and EI's focus on individualizing family services, narrative inquiry is a natural fit.

Listening to and collecting narratives of fathers' experiences allowed for the in-depth exploration of each father's unique experience. This approach is well aligned with special education law and service provision. Special education law establishing EI is predicated upon the notion that special education services for very young children must be individualized to meet the needs of the entire family system and take place within family homes and natural environments (Individuals with Disabilities Act, 2004). Each father's narrative has the potential to show the field of EI how participation in the program impacts fathers' development.

This research is rooted in bioecological systems theory (Bronfenbrenner, 1979; 2005). Narratives about one's experiences "do not merely describe what someone does in the world but what the world does to that someone" (Mattingly, 1998 p.8). Clandinin (2013) maintains that to develop an understanding of an individual's experiences, researchers must understand "the social, cultural, familial, linguistic, and institutional narratives that shape, and are shaped by, the individual (p. 33). These statements perfectly capture the intention of this study and its grounding in bioecological systems theory.

In special education, there is no single "typical" experience. This is evidenced by the need for IFSPs. In addition to each family's child presenting with different developmental needs, in Illinois alone, more than 22,000 families participated in EI in FY2018 (Illinois Department of Human Services, 2018). These families represented a variety of linguistic, socioeconomic and racial/ethnic backgrounds. Each of these factors has the potential to create a variance in how fathers' in these families conceptualize their child's developmental needs, interact with home-based service providers, and how they experience their participation in EI. Additionally, each child who qualifies for services presents with different developmental needs. A child's specific developmental difference and the severity of developmental and medical needs

has the potential to alter a family's quality of life (Wang et al., 2004; Bayat, 2005; Brown et al., 2010;). Collecting detailed narratives of fathers' experiences across contexts allowed this researcher the ability to find themes consistent to the experience of participating in EI that transcend categories of child's developmental difference and severity, income, age, and EI provider, as well as other potentially unknown factors.

Pilot Study

A pilot study added credibility to this research project. Piloting is an important part of the qualitative research process. Piloting helps develop research questions, refine interview protocols, and assist researchers in becoming more adept interviewers (Ravitch & Carl, 2016).

Prior to this dissertation research project, I conducted a pilot case study with a father, who experienced EI services with two of his children. Data gathered from the pilot case study informed the theoretical frameworks and interview protocol for this research. This pilot presented several themes that informed the addition of questions and prompts to the interview protocol. Main themes across Jacob's experiences included an unidentifiable (to him) quality in therapists that facilitated rapport relationship building and contributed to positive meaning making.

Based on the pilot study, it became clear that demographic questions about the family structure, child's current disability status, father education, etc. stilted narrative telling. The answers to these questions peppered themselves through the father's telling of his story, making the initial ask unnecessary. The amended interview protocol allowed for the initial omission of demographic questions with the option of asking clarifying questions throughout the interview or during the follow-up as needed. Open-ended questions that directly address the rapport between the father and service provider were another addition to the protocol after the initial pilot study.

The opening prompt, “Tell me about your experience in early intervention” worked well as a conversation starter and remains in the revised protocol.

Participants

When I proposed this research, I aimed to collect and analyze the narratives of four to 10 fathers who participated in home-based, EI services with at least one child for a minimum of six months. More than ten participants, I thought, would create an overflow of data. Less than four participants would not allow for the rigor needed to find themes across narratives. I sought fathers with at least six months of EI participation to ensure that each father spent enough time in the program to build relationships with services providers. Ultimately, six fathers participated. This number of participants provided ample opportunities for theming within each father’s narrative as well across narratives. Six participants is consistent with the numbers of participants in other narrative inquiry studies related to parenting children with disabilities (Philpott, 2003; Smith, 2008).

An additional inclusion parameter was the family’s discharge from EI services between 2014 and 2017. Families are discharged from EI when one of three possible situations occur. The first, and most common in my experience as a practitioner, is that their child turns three and transitions from EI to school-based special education services. The second possible reason for discharge is that the child attains age appropriate development. The third and last possibility that results in discharge from EI is the family’s decision to opt out of the program. The purpose of the inclusion parameter of discharge between 2014-2017 was threefold. First, for many families, initial diagnosis of development differences and/or disabilities is a stressful time (Walsh, 2003). Partaking in the qualitative interview process would add another time requirement to a population of families who report struggling with finding adequate time to complete daily tasks

and manage family functions effectively (Summers et al., 2005; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Brown, Shalock, & Brown, 2009). Secondly, separation from service providers for a short yet significant amount of time of between one and three years positions fathers to reflect on their experiences while they are still relatively fresh in their minds but not ongoing. Lastly, special education policy and the body of research that has established best practices did not change significantly between 2014 and 2017, ensuring that that socio-cultural aspects of each father's chronosystem were similar.

Participants were recruited through posts on various social media sites and groups that families with children with disabilities or developmental differences can opt into joining. The recruitment posts specified the need for participants to assist in dissertation research. Posts stated inclusion criteria of being English speaking, over 18 years old, and identifying as the father of child that participated in EI services for a least six months. The recruitment posts sought volunteers whose children were discharged from EI between 2014-2017.

No fathers volunteered as a result of posting in social media groups for parents of children with special needs. Ultimately, all participants were recruited as a result of the sharing of the recruitment post on my own social media page. Two participants, Sathi and Tom, are my former EI clients. They volunteered for the study after their wives saw the recruitment post on my own social media page and shared it with them.

Once verbal consent was established, all eight fathers were asked a set of screening questions to establish they met the inclusion criteria. Each of the eight men did meet the criteria, verbally consented to participation, and scheduled initial interviews based on their time, location, and communication preferences. Fathers were given the option of in person or FaceTime/Skype Interviews. Two of the fathers canceled their scheduled meetings repeatedly and as a result were

not interviewed. The remaining six fathers participated in one or two interviews. Interviews lasted between 40 and 90 minutes.

Interviews

Semi-structured interviews provided the primary source of data collection. To establish a richness of data, in-depth interviews were scheduled with each participant. Initial interviews lasted between 40 and 90 minutes depending on the participant's time constraints and/or narrative flow. Five of the six participants participated in a 20-60 minute follow up interview. The structure of the second interview varied depending on the level of detail participants gave during their first interview. Follow-up questions were customized for each father after I reviewed their interview transcript. One father, Sathi, participated in one ninety-minute interview rather than two interviews to accommodate his travel schedule.

In-depth interviewing affords opportunity for participants to share thick and rich descriptions of their experiences and perceptions about their experiences (Seidman, 2013). A semi-structured interview format established guardrails for the conversations while permitting me the liberty to ask questions phrased in the format and order that made the most sense for each individual participant as it related to his specific lived experience and the flow of our conversation (Merriam & Tisdall, 2016). Some fathers proceeded to tell their stories in a large amount of detail and needed very little additional prompting or initial follow-up questions while others' interviews followed the interview protocol more closely.

A pilot case study informed the semi-structured interview protocol for this research. The initial interview protocol used in the pilot study asked direct questions about the reason for the child's referral to EI, current disability status, and other demographic questions to provide questions. Feedback from the pilot study participant indicated that parents of children with

different abilities are asked these questions quite frequently and that they are often seen as cumbersome. Each interview began with me saying “Tell me about how you came to be involved in EI.” Full interview protocol can be found in Appendices C and D.

Data Analysis

Interview transcriptions were coded for themes both within and across narratives. Coding was completed first using themes that arose in the pilot study. Another round of open coding occurred to see what additional themes emerged. In the findings chapter, each father’s experience is described in its own context as well as in conjunction with the experiences of the other fathers. In the discussion chapter, each father’s narrative is examined using the theoretical frameworks.

Thematic analysis in narrative inquiry is influenced by the researcher’s theoretical grounding and prior experiences and the purpose of the research (Riessman, 2008). As such, it is essential to the trustworthiness of this research to share my own positionality and how my development as a researcher is impacted by my interactions with macro-, exo-, meso-, and microsystem level factors.

Trustworthiness

Data from each participant’s first interview was transcribed and reviewed prior to each participant’s second interview. Member checking was completed during the second interview in the form of clarifying and follow up questions. A second round of member checking occurred with Dan and Adam as data were interpreted during the writing of this dissertation. This practice of asking the interviewees to check and clarify narratives and initial findings adds to the trustworthiness of the study by eliminating the possibility to misunderstand the participants’ statements (Maxwell, 2013; Merriam & Tisdall, 2018). Additional rigor was established via

dialogic engagement with an EI peer, a peer familiar with qualitative educational research, and members of my dissertation committee. All dialogic engagement partners complete CITI human subjects training. Dialogic engagement is a commonly accepted strategy to ensure increase credibility within qualitative research (Ravitch & Carl, 2016).

Ethical Considerations

This research was conducted with the best interests of participants in mind. The DePaul University Institutional Review Board approved the study. A copy of the IRB approval is available in Appendix A.

Prior to asking any asking screening questions or scheduling of interviews, verbal consent from each participant was obtained using the IRB approved protocol. Records of verbal consent are stored with transcription files on a HIPAA and FERPA compliant cloud drive. None of the information shared during the interviews falls into these categories, but I felt that storing the data in this way helped to ensure confidentiality for participants.

Each interview was digitally audio recorded and then transcribed. Audio and transcription files are stored on a HIPAA and FERPA compliant cloud drive to ensure privacy for the participants. Pseudonyms, mostly chosen by the participants themselves, are utilized for participants, their children, family members, service providers, medical facilities, and doctors. Their children's disabilities are named specifically but no identifying symptomology is shared. These strategies were put into place to ensure ethical research practices and establish a level of trustworthiness for this data (Creswell & Poth, 2018).

Other ethical considerations include the omission of identifiable details such as exact details of children's developmental delays or disabilities.

In-person interviews took place in private spaces without additional people present. For interviews conducted via technology, I was alone in a room with a closed door. I recommended to participants that they do the same.

Audio files and interview transcriptions are stored in a HIPAA and FERPA compliant cloud drive. The Illinois Early Intervention program allows IFSP documents and session notes to be stored on HIPAA and FERPA compliant cloud drives. While data collected for this research is not protected by either HIPAA or FERPA, I felt confident that these safeguards would ensure participant confidentiality as I had used them to maintain privacy of client files when I was an EI provider.

Researcher Positionality

As stated previously, I worked as an EI provider for nine years and currently teach university courses related to EI methods. I experienced the phenomenon of being a part of the EI process as a service provider, not a parent. Therefore, I developed a deep understanding of the system through the lens of a practitioner rather than a parent of child with a developmental disability. This position is advantageous as it allows me an insider's understanding of the lexicon of special education and medical complexity and provided adequate reference to aid in choosing an appropriate theoretical framework. My own lived experience as an EI provider was disclosed to all participants. Two participants were former clients. It's possible that knowing my position as a former provider influenced what parts of their experiences they chose to share during interviews. Each of these fathers worked with EI teams with EI providers other than myself and I was careful not to include any statements made by fathers that related directly to their experiences with me as an EI provider. My work experience certainly impacts my thematic analysis of fathers' narratives as it cultivated my interest in the topic and influenced the selection

of theoretical frameworks. According to Reissman (2008), data from narrative inquiry is analyzed in light of the researcher's own experiences, the theoretical frameworks, the purpose of the study, and the data itself, rather than despite those factors.

When I began my work in EI, I had very little training in the best practice of home-based service provision. I took a bag of toys and individualized lesson plans into each home, sat on living room floors with children and did one-on-one activities with them as their parents observed. Several years into my career a father was observing me interact with his son and said, "Wow, you're like a magical sorceress. I can't ever get him to do those things with me!" In that moment, I realized that while children were making developmental progress as a result of my interactions with the families, I was not at all addressing the capacities of children's caregivers. Through coaching interactions with a speech therapist firmly rooted in family-centered practice, reading up on evidence-based practices, and attending trainings on family-centered intervention, I transitioned into a more family-centered service provider. My sessions with families no longer consisted of me bringing specialized materials to work one-on-one with children while family members observed. Instead, I became more of a coach to caregivers. I modeled strategies to embed in daily caregiving routines and worked in tandem with caregivers to determine how to best address their family functions of daily care and education.

CHAPTER FOUR: Introducing the Participants

In keeping with the spirit of narrative inquiry, it was my goal to tell each father's story of his time in EI first, then describe themes that emerged within and across fathers' narratives. To maintain a narrative flow, research pertaining to each research theme is interspersed throughout this section.

Dan

The first father I interviewed was Dan. Dan invited me to conduct the first interview in his classroom at the public school where he teaches. The second interview was conducted via FaceTime at Dan's request.

Dan is a teacher in his late thirties. He lives and teaches in a large midwestern city. He and his wife, Greta, have two children, Felix and Duncan. At the time of his interview, Felix, who has cerebral palsy, was six and Duncan was two. Dan's son, Felix, received EI services for about two years, from just after his first birthday until he turned three and aged out of the program.

Felix is Dan and Greta's first born. When Felix was born, both Dan and Greta intended to continue working full time outside of the house. Felix was born in the spring. Dan's schedule as a teacher allowed him to stay at home with Felix as his primary caregiver for a couple of months after Greta returned to work. Dan describes himself as a very involved dad participating fully in daily care routines with both his sons. Dan takes on the primary role as homework support now that Felix is in school.

Dan's family came to interact with EI services when Felix was an about a year old. When Felix was about nine months old, Dan and Greta noticed that he "only used his left hand." They brought it up to Felix's pediatrician who said that Felix was too young for them to know

whether he is left-handed. Shortly after they noticed the hand preference, Dan and Greta's family went on a vacation with Greta's brother and his family. Dan and Greta noticed that Felix wasn't developing motor milestones as quickly as his cousins. One of Felix's cousins "who is six months older than Felix was running around and climbing on things, and Felix was not even cruising yet." When they returned home, Greta called EI to set up an evaluation. Both Greta and Dan were present for the initial evaluation. Felix was found to have a gross motor delay more than 30%. A service coordinator connected the family with Lily, their first physical therapist. Felix began twice weekly, home-based physical therapy sessions shortly after his first birthday.

The beginning of EI services happened to coincide with Dan's summer vacation. Dan was present at all sessions that summer. He "wanted to be as involved as possible" in EI even though he "really [didn't] want his son to have to be doing this." Dan initially assumed that physical therapists were going to come in and work with Felix for a while until he caught up on his motor milestones. He said, "So, we're gonna do some PT and then he's gonna be fine, normal, whatever you wanna call it — age appropriate." Before Dan realized the permanence of Felix's developmental differences, he said that EI sessions "were mostly me sitting there helping, making sure that [Felix] was participating in the thing that the [therapists] were doing."

Dan was fixated on Felix's motor challenges being "fixed" by EI. He said, "My brother had, you know, those Forest Gump-like braces where it connects to the hip [and he doesn't need them now] so I think that maybe in my head it was just like that." Dan was certain that "we're gonna correct this and it's gonna be fine and then [Felix] will just be normal."

After Felix started physical therapy, both occupational and speech therapy were added to Felix's IFSP. It slowly became evident to Dan that Felix's motor differences weren't going to be "fixed." The family started to seek medical opinions about the root cause of Felix's delays.

Felix was diagnosed with cerebral palsy when he was two. After Felix's diagnosis, Dan and Greta decided that Greta would quit her job to stay at home with Felix. Greta's primary objective in staying at home was coordinating Felix's therapy and doctor appointments and addressing his developmental needs.

During the two years Felix was enrolled in EI, the family worked with two different physical therapists, Lily and Joanna. The family also worked with one occupational therapist (OT), and two speech therapists whose names Dan had difficulty recalling. Of the OT, Dan said, "I can't even remember what she looked like."

Dan, Greta, and Felix switched out their physical and speech therapists at some point during their two years in the program. Greta fired the family's first speech therapist because she did not like the way that the therapist interacted with Felix. Dan and Greta were aware that their rights in the program included the ability to change EI providers for any reason. Greta called their service coordinator to manage the transition. The family did not have to speak to the therapist directly about removing her from the IFSP team or find a new therapist to replace her. Dan remembers that the service coordinator made things easier for the family by coming to them, calling them to check in, and managing the transition from one speech therapist to another. As Dan recalled the service coordinator's role in EI, he was deeply appreciative. When talking about how the service coordinator handled all the details and conversations about firing the first speech therapist, Dan said, "We probably didn't even think about it at the time, about how much easier that made our life. I think that it probably did make a significant difference." This was an extremely stressful time in the family's life and the service coordinator helped to take on some of the responsibility for managing Felix's IFSP team.

Dan's family also had to transition from away from working with Lily. Dan had great relationship with Lily. She was "in the trenches" with him and Greta. Dan isn't sure exactly when Lily transitioned out due to her own medical concerns, but he is certain that it was after Felix was diagnosed with CP. The service coordinator also orchestrated this transition and matched the family with Joanna. Dan was able to quickly develop a positive working relationship with Joanna.

Dan remembers both physical therapists fondly. He feels that Lily "was in trenches" with the family during the early phases of learning about Felix's developmental differences. Dan said that Lily was instrumental in making sure the family got the medical care needed to get a correct diagnosis for Felix. Dan thinks that Lily suspected Felix had cerebral palsy immediately after she met the family. Making a CP diagnosis is beyond the scope of an early interventionist's practice, so Lily couldn't give the diagnosis herself. "At one point, Lily — this is why we think she knew — she kind of said get a ... brain scan, an MRI." Based on Lily's recommendation, the family sought a professional opinion. Their first doctor told the family, "Oh, he's fine, you just need to take him home and love him." Dan and Greta didn't really understand what this meant. When Lily heard this, she encouraged Dan and Greta to get a second opinion. The second neurologist noticed a "huge bruise" on Felix's brain and diagnosed him with cerebral palsy. Dan is grateful that Lily was forthright with him about her concerns. Dan still carries "unbelievable amounts of anger at ... medical professionals who just kicked the can down the road so that they didn't have to be the bearer of bad news."

Once Dan and Greta received the news that Felix has CP, they were temporarily "wrecked" by it. For about a year, Dan and Greta expended all of their energy coping with and adjusting to Felix's diagnosis. Dan said that during this time, he and Greta operated like

roommates. He didn't go into explicit detail but did convey that it was an incredibly stressful and sad time in his life and in his marriage.

Lily and Joanna were a source of support for Dan during this stressful time. Both Lily and Joanna spoke simply and directly to Dan. Conversely, Dan said that "I listened and talked with the speech [therapist] and the OT but I didn't feel exactly like I knew what to do afterwards." Dan identifies himself as a very literal person. He appreciated that Lily and Joanna were very direct in what the next goal was in Felix's developmental progression and that they shared those details with the family very explicitly. Dan feels that he connected with the clear-cut nature of addressing gross motor skills. For example, one strategy that Lily gave the family was to hold desired objects to right of midline so that Felix would be encouraged to reach for them with his weaker hand. This was a simple strategy that Lily clearly connected to Felix's developmental needs. Dan understood what he was supposed to do and how the activity would further Felix's development.

Based on Lily's clear communication that Dan should work on ways to get Felix up onto his feet, Dan recalls that he worked one-on-one with Felix for several weeks while Lily was on vacation to come up with up as many ways as he could to get Felix standing and cruising throughout the day. When Lily returned, Felix mastered cruising along the furniture. Lily commented on the progress Felix made while she was away. Dan began to tear again as he shared that when Lily acknowledged those developmental changes, he began to cry because "he and I had that [together], and it can be so hard but that's mine. I did that thing [with Felix]." Dan feels that these early experiences with Felix's physical therapy brought him closer to Felix while he was still a very young child.

Unlike the consistent communication Dan engaged in with Lily and then Joanna, the speech and occupational therapists generally communicated only to Greta. This was in large part due to Greta being a stay-at-home mom, although it happened when while Greta was still working full-time as well. When the speech and occupational therapists did communicate with Dan, they were friendly, but he felt they did not communicate as concretely as Lily and Joanna. Dan recalls that interactions with them were awkward. The speech and occupational therapists were both quite a bit younger than Dan and both women. Dan felt that “gender and sex dynamics” contributed to their less fruitful relationships. Dan remembers that one of the therapists was “twenty-three, twenty-four, really, like, fresh out of school.” At the time, Dan felt that those therapists’ ages, lack of experience, and gender lead them to communicate less confidently and directly with him than Lily and Joanna did. Lily was “around [Dan’s] age, maybe a year older ... or a year younger” and Joanna was about ten years older than Dan.

A major impediment to effectively communicate with Dan were the speech and occupational therapists’ approach to making recommendations. Rather than explicitly state the next steps in Felix’s development and what they wanted Dan to follow through on at home, they would make general statements and suggestions that were more like questions such as, “Maybe you would like to work on.... Or maybe you try....” Dan found this kind of communication frustrating and lacking in the directness he needed to make sense of what they were asking him to do.

Dan attributes some of this mismatch of communication skills to gender dynamics. He felt there was an assumption that Greta would be the “caring mother.” Dan felt the speech and occupational therapists were unsure what role the dad played in their family. Dan also

acknowledged that he can be perceived as intimidating because he is very tall, has a deep voice, and “pointy eyebrows that can look angry.”

Possibly related to their lack of ability to communicate effectively with each other, Dan’s experiences with the speech and occupational therapists were not as positive as those with the physical therapists. He found those sessions to be challenging to get through and would “find any reason to step out.” Dan remembers that when he was present for speech and occupational sessions, the therapists often told him that his presence was distracting for Felix. They asked him to step out of the room for long periods of their sessions. Dan trusted the therapists with Felix but had mixed feelings about his own exclusion from sessions. While Dan didn’t find the sessions with speech and occupational therapists particularly enjoyable for himself, he wanted to be a part of what happened with his son. During the school year, speech and occupational therapy sessions took place while Dan was at work. Dan does not remember the names of either the speech therapist or the occupational therapists that worked with their family. He ran into one of them during a family outing. Dan didn’t recognize her until Greta reminded him who she was and how the family knew her.

Overall, Dan feels that his “family was well served by [EI].” He calls his time in EI “a guided entry into this world of having a child with special needs.” When he and Greta didn’t understand something, they felt comfortable asking their IFSP team about it. Dan preferred to ask one of the physical therapists, while Greta was able to communicate effectively with all members of the IFSP team. When Dan expressed a concern or asked a question, one of the physical therapists would explain it or model how to use a strategy they’d given. When Felix got older, Joanna helped the family access an organization that provided assistive technology for Felix free of charge.

Dan's relationships with Lily and Joanna remain positive. He can recall small details about their personal lives when he speaks about them. Dan volunteered for this study after Joanna shared the recruitment posting with him.

Currently, Felix can walk independently. His prognosis is no longer as nebulous as it was when he was first diagnosed. He continues to participate in physical and occupational therapy sessions through clinic-based, private providers. Dan remains focused on supporting Felix's development but no longer feels as lost as he did when he first learned about Felix's delays and isn't focused on "fixing" Felix's motor skills any longer.

Ryk

Ryk was the second father I interviewed. After seeing my social media post soliciting participants, Ryk's wife Jane asked Ryk if he'd like to be interviewed. He agreed. Ryk's first interview took place in person at his home. The second interview was scheduled to be conducted in person, but due to a snowstorm, was rescheduled and conducted via FaceTime.

Ryk and Jane have two children. At the time of the first interview, Eleanor was five and Ned was two. Ryk is a stay-at-home dad in his late thirties. He is fully engaged in caregiving for his children. Jane is an EI occupational therapist who works long hours outside of the home. Ryk is a cancer survivor. While Eleanor was in EI, Ryk was completing intensive cancer treatments. Jane's family helped to care for Eleanor when Ryk was at the hospital or other medical appointments.

Ryk became involved in EI when Jane developed some concerns about Eleanor's motor skills and balance. When Eleanor was two, Jane and Ryk noticed that Eleanor "was not as physically capable" as expected and every time the family went "for a walk to the park or, like, to the park or something ... she would trip and fall." Cassie, the physical therapist assigned to

work with Eleanor provided weekly home-based services for just under a year until Eleanor met all the goals in her IFSP shortly before her third birthday. When Eleanor got discharged from EI, she transitioned to clinic-based physical therapy. Eleanor's mild motor concerns would not qualify for school-based services.

Throughout Eleanor's time in physical therapy, the family faced many external stressors. Ryk was diagnosed with an aggressive cancer when Jane was pregnant with Eleanor. He remained in treatment for cancer until Eleanor was over three years old. Ryk is now in remission. While Eleanor was in EI, Ryk was "a stay-at-home dad but ... was still in cancer treatment" and underwent an invasive surgery to address damage caused by the cancer. During the year that the family was enrolled in EI, Jane worked long hours to meet the family's financial needs.

In response to concerns about Ryk's weakened immune system, Eleanor's contact with other people was limited. Ryk and Eleanor took almost daily trips to a local park and very occasionally visited with extended family. Ryk describes this time as very isolating for him and Eleanor. He felt that Cassie's weekly visits were an excellent opportunity for Eleanor to build a relationship with someone outside of their family. He said, "I think it was great for her to not just be with family one hundred percent of the time ... and I think that [interacting with Cassie] helped our relationship a little bit" because it gave her time to grow and develop outside of the confines of their very small nuclear family.

Ryk describes his role in Eleanor's therapy sessions as mostly that of a "very present observer." Ryk states that he "didn't have a lot of knowledge about physical therapy" or EI. Managing communication and decision making about Eleanor's development was largely Jane's role. Jane and Cassie shared a common jargon, and Ryk was managing his own health care at

the time, so it seemed to make sense for Jane to take on this role. Cassie communicated with Jane after sessions about Eleanor's progress rather than directly with Ryk who was present at most sessions. Ryk said that he got the feeling Cassie "felt more comfortable discussing the more medically intense, jargony-type stuff" with Jane due to their shared experience with EI. Ryk did not have the energy to question this communication pattern at the time.

Ryk remembers that Eleanor's early therapy sessions were greatly beneficial for them both. Often, Cassie and Ryk would take Eleanor to the park near their home to play. On the walk and at the park, Cassie explained different ways that Ryk could help Eleanor practice skills she needed on the playground equipment. Once the weather no longer allowed for park sessions, Cassie began to do therapy in the family living room. During sessions at the family home, Ryk felt that Cassie followed a set program that was repetitive and not tailored to Eleanor's needs. At first, Ryk found these sessions to be helpful in that they gave him new, specific activities to do with Eleanor at home. These activities didn't help Ryk to build a greater understanding of her needs or how each activity would further her progress. Eleanor was making developmental progress, so Ryk kept doing them. Several times, he mentioned an activity wherein Cassie asked Eleanor pick up marbles with her toes that was repeated for months during every session. Ryk followed through on this activity during the week but still has no idea how this activity was related to Eleanor's gross motor development or how it helped Eleanor to meet her goals.

Although Ryk didn't feel that he came to a greater understanding of Eleanor's developmental needs, he acknowledges that Eleanor made great progress in EI. Ryk is happy about that aspect of the services. He wishes Cassie did a better job of communicating with him. He did not feel comfortable initiating questions about therapy, especially about the repetitive nature of the therapy and the purpose of activities like picking up marbles with toes. Ryk felt

that maybe other parents would say, “Wow, you’re doing the marbles again?” or that “maybe other parents would feel comfortable saying something and I just didn’t.” At the time, Ryk wasn’t sure that there was supposed to be anything different about what was happening during Eleanor’s therapy sessions.

After Eleanor aged out of EI, she started going to clinic-based therapy. It was after interactions with Eleanor’s new therapist that Ryk realized how sessions with the clinic-based therapist felt more planned and intentional than most of Cassie’s sessions. Ryk got the impression that Cassie “was actually good but had personal stuff going on.” He based this opinion on the high quality of the initial sessions with Cassie. As a result of the personal things Cassie experienced, she wasn’t approaching Eleanor’s sessions as intentionally as Ryk felt she could have. Instead, Cassie would bring the same materials week after week. Ryk noticed that Eleanor seemed “to sort of have a plateau effect with the exercises and games she was doing.” Ryk often thought, “Huh. You’re doing that again? It’s not [that Eleanor] wasn’t getting anything from it, but you could try something new.”

After Ryk’s surgery, he received his own physical therapy. It was then that Ryk began to question Cassie’s effectiveness and her use of the same activities over and over. For example, during Ryk’s recovery, his PT would explain what she did and how it helped his recovery as well as other ways to target the same goal with objects that Ryk had at home. In EI, Cassie often brought in items like a wobble board that the family did not have at home, so Ryk was not able to follow through on those activities during the week between sessions.

Ryk was very reflective about how he didn’t initiate more communication with Cassie. He acknowledges that he was preoccupied with the stress of cancer treatments and a joint replacement. At the same time, Cassie was seemingly preoccupied with her own personal

struggles. The impact of both parties' external stressors was a lack of communication. In light of his own experience in EI, if Ryk could speak with a new class of graduating early interventionists, he would share how important it is to invite fathers and other caregivers into the therapy activities with them and the child to help fathers understand why they are doing what they are doing and to "teach some things that [fathers] can do."

If Ryk had another child go through EI, he would be more assertive in communicating with the EI providers. For example, when an activity like the marbles came out, Ryk would "say, like, 'Why are we doing this?'" instead of taking "a backseat because [PT] isn't in [his] wheelhouse."

Despite the plateau at the end of EI and the ongoing lack of open communication with Cassie, Ryk rates his time in EI positively because it helped Eleanor to meet her motor goals. At the time of this writing, Eleanor no longer needs physical therapy. Additionally, Ryk was reassured that "you can ask for help with your child, and you can get it, and it works." Ryk would "definitely recommend" EI to other parents.

Tom

Tom is the third participant. Tom and his family were my clients for about 18 months. After seeing my recruitment post, Tom expressed joy at the idea of sharing his experiences in an interview. Tom is the only father who volunteered to participate in this study who has a child with autism. Due to prevalence of children with autism in the United States, I felt it was important to include his experiences in this study.

Tom's son, Brandon, aged out of EI three years ago. Since that time, the family used Facebook to update me and other members of the EI team about Brandon's progress and accomplishments. Both Tom's interviews were conducted using Skype, at Tom's suggestion.

Tom is in his early fifties. He has three adult sons from a previous marriage. Brandon, who was six at the time of the interview, is his wife Susan's first and only child. Tom mostly works from home. Susan works outside the home. Tom chose his current job because it allows him to spend more time at home with his family. Tom describes himself as a very involved father.

Tom's family became involved in EI when Brandon was about eighteen months old. Brandon wasn't meeting milestones in the same way as Tom's older sons did. At fourteen months, Brandon wasn't walking. Tom and Susan shared their concerns with the pediatrician at Brandon's fourteen-month well baby visit. The pediatrician referred the family to EI. There were a few months between the initial referral, eligibility determination, and the beginning of home-based services. Brandon's IFSP team recommended speech/feeding, occupational, and physical therapies as well as special education services. I was the special educator on the team.

Tom describes his relationships with the IFSP team as quite good. Brandon aged out of EI in 2015, but Tom maintains contact with most members of the IFSP team through social media. He has "so many of that are now Facebook friends." Tom described the EI providers' weekly visits as:

More family than therapists coming the house.... They wanted to know how [Susan and I] were doing, not just how Brandon was doing. That's where more family came in, because it seemed like they were concerned not just with Brandon, how the family as a unit was doing with Brandon.

When the family started EI, Tom's main goal was "to see him develop so we could get him to the park ..., to walk around the park rather than have to push him everywhere and carry him." This family goal was honored by the IFSP team. The OT, Nicole, was instrumental

supporting the family to meet this goal of Brandon walking the park and navigating the equipment on his own. Tom spoke about Nicole's impact on the family's ability to enjoy trips to the park multiple times during both interviews. He feels strongly that Nicole's being with the family at the park instead of talking about what the family could do on their own when they went to the park was extremely helpful for them.

Just going to the park is obviously a normal family outing but the therapist being there — being there with the therapist there to say, you know, these are the ways you can encourage him to walk upstairs. These are the ways you can encourage him to go down slides. It was simple things like that, that without seeing the child interact with the therapist, I would think I already do that..., but [having] it modeled for me, [allowing] me to do it and if necessary, showing a different way... The interaction with Nicole has made a big headwind.

Tom feels that each of the family's therapists took time to really get to know and understand Brandon. Sessions felt individualized for their family. “[The therapists] learned Brandon. They came in and said, all right, let me meet Brandon and interact with Brandon and see what direction I am going.” This personalized approach helped Tom, Susan, and Brandon's older brothers to understand how to connect with Brandon during their interactions. Tom said that he learned new techniques to engage with Brandon he hadn't needed when he raised his older son's “because they didn't have autism.”

Tom credits IFSP team with helping Brandon learn social skills that promoted more interactions between him and his older brothers. Overall, the most significant outcome of EI for Tom was “reaching Brandon..., finding something, anything, even a small signal of anything [during social interactions].”

Tom, Susan, and Brandon's team noticed that Brandon exhibited symptoms of autism. Tom states that he remembers me and the other therapists giving a "gentle push" to have Brandon evaluated by a specialist. Tom felt that each of the therapists "very gradually and gently" communicated concerns that Brandon showed signs of autism. For example, "Brandon was hand flapping all the time..., his gross motor skills were very slow but his fine motor skills were off the charts." Brandon didn't speak in sentences but when asked what shape something was he answered specifically with "isosceles triangle, isosceles, parallelogram, rhombus." When Tom and the EI providers discussed these quirks, Tom felt validated in his feelings that something atypical was going on with Brandon. When Brandon was formally diagnosed with autism at age two, Tom wasn't surprised and felt relieved by the diagnosis. He recalls that "early intervention as a whole prepared me for that diagnosis."

Tom remembered that I referred the family to a neurodevelopmental pediatrician and worked with my contacts in the office to get Brandon moved up the waitlist. I remembered making the referral to a particular doctor but had forgotten that I was able to move up Brandon's appointment by several months. Tom describes feeling relief upon hearing the diagnosis. "Now I can find out how to help him," Tom said of his immediate reaction to the diagnosis. He added, "Shoot, I'm still trying to figure out how to help him to this day." Brandon is six years old and continues to receive specialized services through the school based special education system.

While Tom accepts Brandon's diagnosis and felt relief upon hearing it, he still remembers Brandon's time in EI as very frustrating and stressful for their family. Parenting Brandon during his toddler years was very difficult. Brandon's delays in social communication made meeting his needs challenging. Tom recalls that his main feeling during Brandon's toddler years was frustration.

When [Brandon] was hungry, he would scream, or point, but that could be anything. If there was something that he wanted [or] that was bothering him, screaming and pointing was what he did.... There were days Brandon — when just nothing works. And it's frustrating.... Frustrated you don't even know what to do anymore.

Tom appreciated having a group of people he trusted come into the house and interact with Brandon. Tom remembers being a part of the EI program often provided him with an outlet for that frustration. He said, “[The therapists] wanted to know how we were doing, not just how Brandon was doing.... They were concerned not just with Brandon but how the family as a unit was doing with Brandon.” Tom's feelings of being supported by the family's IFSP were a recurring theme in Tom's narrative. He stated that he feels grateful that his therapists prepared him and Susan for Brandon's eventual autism diagnosis by gently and directly communicating what they saw in Brandon's behavior and how some of the behaviors could be indicators of Autism.

Brandon was diagnosed with Autism shortly before his third birthday. By then, Tom was prepared to see the diagnosis not as something wrong with Brandon, but as a label that would help him to access the services Brandon needed.

Tom names the referral to this doctor as one of the most significant benefits of his family's participation in EI. He said, “Of course, the most wonderful thing that happened was we got great referrals to doctors.”

Tom vividly remembers several EI sessions that he and Brandon took part in. Nicole and Linda, the family's physical therapist used to meet at the family at home, then take short trips to the beach near the family home for their sessions. Many of Brandon's early goals were related to gross motor development, so Nicole and Linda incorporated therapeutic interventions during the

family routine of walking to the beach and going to the park. Both Nicole and Linda coached Tom through playful interactions with Brandon that helped him to build his motor skills. Tom recalled one session where he climbed into a tunnel at the play structure at the beach to encourage Brandon to crawl through. Tom remembers that he was in the tunnel encouraging Brandon, and the therapist was outside of the interaction, providing suggestions and cheering them on. Tom felt this was a very successful session.

Tom remembers only positive feelings about the EI team. I felt that our conversation had a reminiscent tone to it. Tom volunteered to be interviewed for my research because he carries strong positive feelings toward me and the EI programs. These positive feelings toward me certainly influenced the tone of the conversation and what Tom shared with me during the interviews; however, I think that it should be noted that these positive feelings were cultivated during service provision. Tom developed positive feelings about me because he feels the program led to successful outcomes for him and his family.

Care was taken to only include details that Tom shared with me during his interviews. I did not add any of my own memories to the narrative. Member checking was completed via email to ensure that Tom's narrative captures the essence of his experience, and not my own.

Brandon made an appearance during the skype interview to say hello. He greeted me and engaged me in a short conversation. Tom reported that Brandon is doing well overall, with some regression with self-feeding using utensils, a skill that he mastered while in EI and no longer uses. Brandon receives special education services in public school.

Sathi

Sathi is the fourth person I interviewed and another of my former clients. Sathi's interview took place via FaceTime.

I felt strongly that Sathi's experiences in EI should be included in this study. Sathi is the only person of color to volunteer for this research. He and his family are Southeast Asian American. Including the experiences of families outside of the dominant American culture in research is imperative to building an understanding of the ways that family culture impacts EI experiences. Sathi's narrative was rich in detail and peppered with Sathi's own reflections about how various external factors influenced his experiences in EI.

Sathi is in his mid-forties. He and Meena have one child, a son named Arin. Sathi is very involved in Arin's daily caregiving. Sathi travels frequently for work, but when he is not traveling, he is able to work from home. Meena primarily works from home. The family has a nanny who helps with Arin's care during the day. She was usually present for EI sessions. Since Sathi and Meena work from home, they engage with their son throughout the day during breaks from work.

Arin and his family entered EI shortly before his second birthday. Sathi and Meena discussed concerns with each other that Arin wasn't talking. They referred him to EI. Arin was found eligible to receive speech therapy and developmental therapy services. Occupational therapy services were added several months into the family's participation in the program. About nine months after beginning services, the family moved and transitioned out of EI. Arin is now four years old and his speech is age appropriate.

Sathi described his initial assumptions about EI as "this old doctor who would come out and poke and prod, scratch his chin — or her chin — and be like, 'Well, this my prognosis.'" Then, that stuffy old doctor would work one-on-one with Arin and "fix him" by getting him to talk and addressing behavioral concerns. Through participation in EI, Sathi recognized that "our

kid is not broken” so he didn’t need fixing. Sathi realized that is Arin is a “unique person who develops at his own pace, in his own way”.

Sathi is quick to point out that he didn’t have a working knowledge of child development prior to his participation in EI. Initially, Sathi participated in sessions as an observer and served as a reference “to [Arin’s] behavior when the therapists are not in the home.” As weeks progressed, Sathi interacted more with the therapists. Sathi feels that the therapists drew him into the process as a collaborator. Although he thought his role in EI sessions was “initially just very functional, to be there,” over time Sathi and the IFSP team

started to exchanged information. I started to see a different role for myself, which was more of a collaborator than an observer or a resource. And that came through just communication. And understanding..., understanding our expectations and what we need out of each other to make this thing work.

An example of this information sharing happened several weeks into working with their speech therapist, Julia. Julia struggled to build rapport with Arin. She shared concerns with Sathi and Meena that perhaps she wasn’t the right fit for their family. Sathi reassured Julia that it often took Arin a while to build relationships with people. He and Meena suggested that she lower the tone and volume of her voice when she interacted directly with Arin. This strategy was very successful. Sathi felt that as a result of the therapist’s direct communication, they became collaborators in the process.

Sathi states that his therapists were clear and effective communicators who were honest with him about the challenges raising Arin presented. He said, “When you know that someone cares and genuinely likes you, it’s easier to digest that information.” Sathi feels that all the therapists cared about their family and “genuinely liked our son.”

Sathi describes his relationships with me and the other therapists as “very warm and comforting.” Initially, Sathi felt unsure about the friendly nature of interaction between himself and the therapists. He was worried that the friendly chats he engaged in with the therapists would negatively impact Arin’s outcomes. After a while, Sathi said that he changed his mind. He now feels that getting to know the therapists as people and letting the therapists to know him a bit was how the team built a “very warm and comforting” relationship that well served the family.

When Sathi describes EI, he says it’s “not only therapy for the child but for us as well.” For Sathi, the benefits of EI reached beyond Arin learning to talk. Working with EI providers helped to shift the way Sathi viewed Arin’s developmental delays. Through EI, Sathi came to see that Arin wasn’t broken and didn’t need to be fixed. Working with EI therapists helped Sathi to reaffirm the idea that we need to be patient.... We need to keep trying things even though we may not be seeing results, there is something going on in his head, he’s slowly making connections. In many ways, it’s not just therapy for the child but also the parent at the same time.... Going back to the fix my kid thing, just knowing that our kid is not broken, they’re just growing. They’re simply growing up. When a kid is not reaching a milestone, you worry about, “Oh my god, they’re not going to perform in school. Oh my god, when they’re twenty-five, they’re not going to be able to process this information.” Like all these irrational thoughts start coming into your head, and I think a lot of our therapists just really, really helped up put perspective on things. I also think that if there was really something wrong with him, they would be forthright and say, look, this is something we need to address on a different level.

While Arin was in EI, his language delays often resulted in tantrums and interactions that were frustrating for him, his parents, and his nanny. During this time, parenting Arin was “wonderful and frustrating.” Sathi felt that through EI, he began to understand that the cause of so much of the frustration was “that kid is an autonomous, feeling little person who doesn’t know how to communicate that.” Sathi identified that gaining this understanding was a significant outcome for him. While Sathi was learning about child development and how to manage his expectations of a two-year-old, EI providers also helped Sathi and Arin to learn to play together. Arin played in a very particular way when he started EI. It was challenging for anyone to join him in play at first. Sathi felt that

having someone be like, “Oh look, this is what your kid is gravitating towards. This is what he does,” finding what he enjoys and he’s happy with — I think that was huge benefit for him, as opposed to me saying, “Look, I loved [building with] Legos® as a kid, Arin, you need to enjoy them, too.” Whereas his approach to Legos was instead of building something, he sorted all the blue bricks, then the green bricks, and then the yellow bricks and put them into piles as opposed to building something. Just that little extra perspective helped a lot and to find something that he really enjoyed [and we could do with him]. I think that was a tremendous benefit for him. Again, acknowledging that your kid is a complex emotional being, and him having people that he could trust to interact with is a big thing.

Finding joyful ways to interact in play with Arin was a key to the family’s success in EI. Each of the family’s EI providers, including myself, acknowledged that Arin was “a tough, challenging kid.” Sathi thinks that it was the therapists’ intention to show empathy and understanding for their family, but his initial reaction was, “Well, [expletive] therapy then. Why

are we doing this then?” As Sathi processed this information, he started to think about how “having blunt communication with people you trust is an important first step.” Sathi also thought about how the EI providers acknowledged that Arin was “a tough, challenging kid” and at the same time “actually all of our therapists genuinely liked our son.”

It’s important with parents to lead in with a compliment.... It’s a reminder that your kid is not Satan, he’s a good kid. [The EI team shared] that he did this little thing or anecdotes, he did this thing with his toy, he wanted me to do this, and then lowering the boom [laughed] ..., but that was always a great approach. I like to think that actually all of our therapists genuinely like our son and liked our family. We only get that by communicating outside the realm of therapy. When you know that someone cares and genuinely likes you, it’s easier to digest this information.

Participating in EI helped Sathi gain an understanding of child development, gave him specific strategies to use when engaging with Arin, helped him gain perspective that Arin was not the only child who tantrums in public spaces, and that Arin is “a complex emotional being.” Overall, Sathi named developing his own understanding of child development and finding new ways to play and engage with Arin as the outcomes of EI for him. For Arin, EI helped him to “find confidence in his own voice.”

Sathi is grateful for his family’s time in EI. The experience helped him come to a better understanding of his son as a person with complex emotions. At the time of the interview, Arin’s speech was age appropriate. He attends a play-based preschool where his family feels he is thriving. Sathi and Meena feel that their experience in EI helped them to choose a preschool that is a great fit for Arin. Sathi thinks that without EI, he and Meena would likely have gravitated toward a more academic preschool but as a result of their newfound perspective about

child development, they sought out and chose a school that meets Arin's social emotional learning needs as well as academic ones.

Jason

The fifth father I interviewed was Jason. Per Jason's preference, both his interviews were conducted via FaceTime. Jason's interviews were shorter than the other fathers' interviews. He made it known at the beginning of both interviews that he needed to stop at a certain time, about thirty minutes after the interviews began. Jason's story is not quite as detailed as some of the other narratives. I included it in the research because he and another father worked with the same speech therapists but told very different stories about their experiences with her.

Jason is in his thirties and is a teacher. He and his wife, Jenni have two children. Their oldest is a son, Travis. Their youngest is a daughter named Charlotte. Charlotte was born after Travis completed EI. At the time of Jason's interviews, Jenni was seven months pregnant with their third child.

Both Jason and Jenni work full time outside the home. Jason shares caregiving responsibility with Jenni. During the workweek, Travis and his sister, Charlotte go to a childcare center. Jason and his family came to EI when Travis was two. His childcare providers shared concerns about Travis's communication development and recommended that he be evaluated by EI. The IFSP team that completed the initial evaluation recommend that Travis receive both speech and occupational therapies. Emily and an occupational therapist began providing weekly sessions for the family.

During speech therapy sessions with Emily, Jason and Jenni sat with Emily and Travis on the floor. They watched as Emily modeled different strategies for them to use to help Travis develop his communication and play skills. Jason and Jenni were present for most of the speech

therapy sessions and “sitting there [while Emily] was explaining what she was seeing, what she was doing. She was constantly giving us feedback which is helpful.”

At first, Travis’s attention span was very short. Emily modeled specific strategies including how to use “nonverbals, [your] body to keep him in one place which helps to reinforce whatever skills he had.” Jason also remembered “the organizational piece that Emily had. She had these mesh bags with zippers to keep [all the pieces to a toy] in place, so we adopted those.” Seeing a model of how Emily used mesh laundry bags to store all the pieces of toys like puzzles and shape sorters together helped Jason and Jenni connect how it was easier for Travis to play meaningfully with toys when they were stored with all their pieces, rather than needing to stop the activity midway to look for missing pieces. Jason and Jenni still use this strategy to organize Travis and Charlotte’s toys.

Jason credits Emily with teaching him how to get down on the floor and play with Travis and Charlotte. Before early the family’s time in EI, Jason assumed that providing an environment rich with educational toys and materials was enough to foster development. He stated, “because my wife and I both work, we’re just like constantly working on the house, we were just always doing something and that gave Travis a lot of free time.” While Travis was nearby and supervised, he and Jenni didn’t spend a lot of time playing with him. During Jason’s interview, he talked about how Travis’s time in EI pushed him to be more involved in playing and doing academic tasks with his children. Jason says now, “we play a lot. We play with blocks and try and play with his dinosaurs and things like that.... I’m usually on the ground with him playing as much as I can be.” Jason feels that this change to more interactive play with his children will continue with the family’s new baby as well.

Working with Emily showed Jason the importance of playing with Travis rather than doing household projects nearby while Travis played alone. Working with Emily taught Jason and Jenni how to help Travis hold his attention to a task longer and how to organize the family's toys to optimize play and learning, and it helped Travis to reach speech milestones. Travis was able to exit EI before his third birthday because he attained age appropriate communication skills. Travis no longer needs special education services.

While Jason rates Emily's speech services quite highly, he felt that the occupational therapy was "kind of a waste of time." Throughout his narrative, Jason made it clear that the OT never established a positive relationship with him or Jenni. When asked for the occupational therapist's name, not only did Jason not remember it, but said that he "couldn't even pick her out of a line up."

Jason felt that the OT lacked competence. Jason said that the OT "was younger [and] didn't know what she was doing yet." During OT sessions, the therapist "didn't really give any tips and things to try out, so it felt like she was checking a box, essentially." Jason remembers that the occupational therapist asked a lot of questions about Travis but never offered any strategies to use when interacting with him. He's uncertain what the occupational therapy goals for Travis were.

During the interview, I asked Jason directly if he knew that the family could request a change in OT providers. He answered, "I know we didn't. I think we just felt like since it was a state-run program, we don't have a lot of choice. We probably should have asked." Jason and Jenni also didn't feel that they could opt of OT services, either. Jason recalled that "our assumption was that Travis had to do this in order to successfully get [EI] and be exited out of special ed services. So, we just went with the recommendation and just did all of it.... We

didn't really understand our options at the time." To Jason's knowledge, the EI service coordinator did not explain the family's rights to opt out of certain services or change providers.

The family endured their weekly "waste of time" sessions with the OT, not knowing the exact purpose of those visits. When the OT worked directly with Travis, he wasn't engaged and "he just had a really hard time.... He was never quite paying attention and it was just kind of a struggle." Jenni researched what occupational therapists typically did with toddlers online. She and Jason "started doing the occupational therapy stuff on [their] own." Their service coordinator did not reach out to check in on how services were going. Jason did not discuss his frustrations about occupational therapy with Emily. After several months, the IFSP team met to discuss Travis's progress. Travis had met all the goals in his IFSP and developmental assessments demonstrated that he was age appropriate. Travis was discharged from services. Travis is now in Kindergarten and his development continues to be age appropriate.

Sometimes, Jason runs into Emily around town when she is with her husband. He described Emily and her husband as "really nice people." Conversely, he says that he doesn't remember the occupational therapist's name and that he "couldn't even pick her out of a line up."

Jason rates his overall experience in EI as neutral. His interactions with Emily were very positive. He rated his experience with the occupational therapist as so negative that the net rating is neutral. Jason said he would recommend the program to another dad without hesitation and would make sure that dad knew they could switch therapists or opt out of services.

Adam

The last of the interviews was Adam. Emily was also Adam's family speech therapist. Adam's wife is a special educator, so he was excited to offer his participation to a dissertation related to his wife's field. Adam preferred his interviews to be conducted in person.

Adam is in his late thirties and works full-time outside the home. He and his wife, Bridget, have two children. Soren, their son, is the youngest. Soren has an older sister whom Adam referred to only as "my daughter" during the interviews. At the time of the interviews, Adam's daughter was in second grade and Soren was five.

Adam is very involved in the daily caregiving of his children. When each of Adam's children was born, he took paternity leave. Adam's wife was only able to take three months of maternity leave following the births of her children, while Adam was able to take four months of paid parental leave. Adam relished the "extra" month he was able to spend with his babies after his wife returned to work. He feels that "there was a ton more bonding" with his children than perhaps other dads have because he shared infant caregiving with his wife. That high level of involvement "is because from the first days as a dad, [Adam] was involved."

Now that his children are older, Adam manages the family's morning routine. Adam manages "everything in the morning, make them breakfast, get them dressed, brush my daughter's hair, which was a total learning experience." Adam proudly shared that he learned to braid and do hair so that he could successfully manage the morning routine for his family. He coaches his daughter's sports team and takes his son, who is a little too young for team sports, to gymnastics class. Adam really enjoys being a dad tries to "get as much time with [the kids] as possible."

Adam became involved in EI when his son Soren started to show signs of a communication delay. Bridget took the lead in making the referral to EI and scheduling an initial evaluation. Adam rearranged his work schedule to attend the evaluation. The IFSP team recommended speech and feeding therapy. Soren started with one speech therapist that Adam does not remember very well. When the first speech therapist left the EI program, Emily began working with the family once per week. Soren received services for about a year until he turned three and aged out of EI. During this time, Adam was able to be home for “maybe a quarter to half” of all of Soren’s sessions with Emily but would have preferred to be present in all of Soren’s sessions with Emily. He said, “That’s my kid and if he’s having struggles, I want to be there with him to help him get through them.” Unfortunately, it wasn’t possible for Adam to be at home for all the EI sessions due to his work schedule and the hours the speech therapist worked. To be home for the sessions that he did attend, Adam had to rearrange his work schedule or work from home.

Soren really liked engaging with Emily and “was very trusting of her.” Adam described a typical speech session as one where Emily would come into the family home, briefly greet Adam and Bridget while she removed her coat and took her shoes off, then set off to work independently with Soren. Greetings were a quick exchange of, “Hey Emily, nice to see you, Hey Soren, Miss Emily is here.” Once Emily settled in to work with Soren in the living room, he and Bridget were “marooned” to another room until the end of the session when Soren came to get them. While Emily was working with Soren, Adam would “peek around the corner and snoop a little” to see what was happening in real time.

At the end of each session Emily would give a short recap of the session along with that week’s homework which was usually “working on sounds.” Adam remembers the homework

being a list of seemingly random words that all contained a certain sound that Soren needed to practice. Adam incorporated Soren's word lists and flash cards into the time that his daughter completed her school homework.

In some sessions, Emily worked on feeding with Soren. During these sessions, Adam and Bridget tended to be more active observers rather than "marooned" in another part of the house. Adam remembers a couple of specific strategies that Emily used to help Soren chew and swallow more typically, including reminding him to have "chipmunk cheeks."

Adam's time in EI was stressful. He often felt like he wasn't exactly sure what happening and why. Adam felt hesitant to ask questions about the process because he viewed his wife and Emily as experts. Adam didn't want to ask what he felt were going to be perceived as "dumb questions." As a result, many of Adam and Bridget's conversations felt like, "it was a lot of asking Bridget the dumb questions I was afraid to ask the therapists."

During IFSP meetings, Adam felt that although he was physically present, the team focused on looking at and communicating only with Bridget. This compounded Adam's feelings of discomfort with asking questions or adding to the conversation. When Emily would email the family, she emailed the correspondence to Bridget and then Bridget would recap the email for Adam or forward him the email. Adam's lack of active participation was a source of conflict with Bridget. Adam and Bridget had a significant argument about his passive observation of the process. Bridget "wasn't too happy" with "the team and her having a conversation that [Adam] wasn't involved in at all." Adam told his wife that he felt his role on the IFSP team was "not a collaborator but an observer." Bridget responded that Adam essentially needed to "get your act together because this is your kid, too." Bridget encouraged him to do some of his own research so he could invite himself into the conversations with the special education team if they weren't

directly communicating with him. That was an important conversation for Adam, and he took Bridget's advice.

At Bridget's urging, Adam did some research online about speech delays. Researching gave Adam "more confidence to be more involved in the conversation." Now that he's had more experience with IFSP and IEP meetings, Adam feels confident asking questions. He has a better grasp on what kinds of questions to ask when he is unsure of something. Soren continues to have speech services through the school district and at a private speech therapy clinic. At Soren's last IEP meeting, Adam was proud that he was able to ask a very specific clarifying question about what the typical age range for skill mastery is.

Overall, Adam rates his time in EI as positive because it helped Soren to learn to communicate more effectively. For himself, he rates the experience of being in EI as neutral but the experience of parenting a child with a development difference as positive. Adam stated that he feels that having a child with language delays taught him to be more empathic in his interactions with others.

Table 1. Participants, Their Families, and Service Providers

<i>Father's Name</i>	<i>Wife's Name</i>	<i>Child and Diagnosis</i>	<i>Time in EI</i>	<i>Prognosis</i>
Dan	Greta	Felix Cerebral palsy	2 years	CP diagnosis has lifelong impact on motor development and skills
Ryk	Jane	Eleanor Gross motor delay	1 year	Occasional, minor concerns about motor coordination, no measurable developmental delay
Tom	Susan	Brandon Autism	About 18 months	Moderate autism with lifelong impacts on development across all developmental domains
Sathi	Meena	Arin Communication delay	9 months	No measurable developmental delay
Jason	Jenni	Travis Communication delay	About 1 year	No measurable delay
Adam	Bridget	Soren Communication delay	About 1 year	Speech and language delay that continues to impact articulation

CHAPTER FIVE: Findings

As narratives were coded, and codes were thematically categorized, several themes emerged within and across each fathers' EI narrative. These included high levels of engagement in parenting prior to EI, initial lack of understanding of the process and EI system and resulting need for an invitation to participate in EI sessions, varied levels of understanding about child's development or developmental needs, varied relationship quality with EI providers, feelings of stress and frustration, varied levels of comfort asking questions about the process or child development, the presence or absence of capacity building during EI, and positive feelings about child outcomes.

Once themes emerged, it became clear to me that most themes identified aligned with the federally mandated outcome categories and four of the family outcomes proposed by Bailey, et al.(2006). These outcomes are identifying and utilizing support systems, knowing family rights and advocating for family within those rights, understanding and communicating about their child's developmental needs, and helping their children make developmental progress. Only one theme, a high level of father caregiving prior to participation in EI, was not directly related to recommended family outcomes, but closely aligned with the outcome of helping children make developmental progress.

Table 2. Themes

<i>Themes</i>	<i>Desired Family Outcome</i>
High levels of engagement in parenting prior to EI	Helping children make developmental progress
Feelings of stress and frustration	Identifying and utilizing support systems
Varied relationship quality with EI provider	Identifying and utilizing support systems
Initial uncertainty about how EI works with varied understanding of the process and system during program	Knowing rights and advocating for the family
Waiting for an invitation from providers to participate	Knowing rights and advocating for the family
Varied understanding about child's development or developmental needs	Understanding and communicating about children's needs
Positive feelings about child outcomes despite varied levels of capacity building	Helping children make developmental progress

High Levels of Engagement in Parenting Prior to Early Intervention

Five of the fathers in this study, Ryk, Sathi, Dan, Adam, and Tom, identified themselves as very involved with the caregiving of their children prior to beginning EI. Jason, the sixth father, shared in daily caregiving but was not as engaged with his son prior to EI as he is now. Jason's increased level of engagement with Travis is directly related to his participation in the EI program.

Each father made statements about their level of involvement with their children throughout their narratives. Ryk is a stay-at-home dad who does the bulk of the daily caregiving

for his and Jane's children. Tom intentionally chose a job that allows him to work primarily from home so that he can be present for Brandon.

Although Sathi often travels for work, he works from home whenever possible and participates fully in Arin's caregiving when he is not traveling. Sathi described holding Arin as an infant skin-to-skin to promote a strong bond. Dan and Adam traced their strong relationships with their children and high levels of caregiving back to their children's infancies. Both were primary care providers for their children as infants after their wives returned to work. They both continue to participate in daily caregiving now that their children are older. Now that Felix is in school, he and Dan sit together each night and work on Felix's homework together. Dan clarified that it isn't that Greta "can't or won't, or that Felix won't do it with her, it's just Felix and I do homework together. Felix and I do this thing together."

Adam also helps his children with homework. Additionally, Adam manages all the family functions related to his children in the morning. He "takes care of everything in the morning, breakfast, gets them dressed, brushes hair." Adam also coaches his daughter's sports team and takes Soren to a gymnastics class. Adam tries "to get as much time with them as possible."

It is likely that the high levels of caregiving of each of the men influenced their openness in sharing their stories with me. Participants' value of high levels of engagement with their children was considered during coding and theming. Factors that likely contributed to the high levels of participant caregiving are examined in the discussion section.

Feelings of Stress and Frustration

Feeling stress and frustration throughout family involvement in EI was a theme that occurred across fathers' narratives. Each of the six fathers expressed feelings of stress and

frustration during their time in EI. The source of the stress and frustration varied for each father. Three of the fathers, Sathi, Tom, and Dan experienced stress and frustration related to parenting a child with developmental differences. Dan and Tom, whose children have the most significant disabilities, reported feelings of stress related to figuring out what was “wrong” with their sons and determining what the long-term prognoses for the boys would be. For Dan, Jason, Adam, and Ryk, participation in EI was stressful and frustrating at times due to poor relationships with EI providers. For Ryk, his cancer diagnosis and treatment caused significant stress for the family during Eleanor’s time in EI.

Sathi and Tom experienced frustration related to their sons’ behavioral challenges including tantrums. This is consistent with the experiences of other families with children whose developmental delays manifest in tantrums and challenging behaviors. A main predictor of family quality of life for families with children with disabilities is the presence or absence of challenging behaviors. For those families with children who exhibit high levels of tantrums and other challenging behaviors, family quality of life is rated as significantly lower than for families with children with disabilities who do not exhibit challenging behaviors (Brown & Brown, 2003; Davis & Gavidia-Payne, 2009; Brown et al., 2009).

Sathi describes parenting Arin as both wonderful and challenging. Arin’s inability to communicate verbally when he started EI often resulted in him throwing long and intense tantrums. When the family was first referred to EI, Sathi felt a lot of stress related to Arin’s behavior and tantrums.

When you take him out, he’s supposed to behave at a restaurant ... and when he doesn’t, that feeling that you are failing somehow and other people are succeeding.... [Meena] would bring up things like I don’t see any other kids doing this, it’s only our kid.... And

hearing stories from our therapists that hey, you guys are not alone, this is actually quite common.... So just knowing that other parents are going through it, that we're trying our best, the fact that he's going through therapy is a sign of love and care, those things helped us a lot.

Sathi's stress about parenting Arin was mitigated by his positive relationships with the family's EI providers. He added that, "If we had to go through it by ourselves, I think that both my wife and I would get immensely frustrated and probably would have taken it out on each other and our kid." Sathi also talked a lot about how the therapists provided support for the family by validating their feelings that their son could be hard to parent, while also reminding him and Meena that Arin is affectionate and sweet by using specific examples of anecdotes they had participated in or witnessed. When asked about what the overall impact of EI was on the family, Sathi named the ability to address stress and frustration when he responded, "It helped provide some explanation for our frustrations. We were able to vocalize with each other our frustrations and put it in into a context of what he's developing and not what's wrong with him."

Much like Sathi, Tom felt frustration related to parenting a child with developmental differences. Tom felt that the support of the therapists was helpful to mitigate the stress. When asked "once Brandon was in EI, what was your experience like?" Tom immediately answered, "frustration." Tom went on to clarify that his frustration was related to the challenges Brandon presented with eating and self-feeding, engaging with his family members, and his slow developmental progression. Tom stated that he felt more frustration about not knowing exactly how to help Brandon reach milestones like self-feeding. He said, "There would be days when nothing works [during interactions with Brandon] and it's frustrating.... You don't even know what to do anymore." Tom went on to say that sessions with the therapists provided him with a

“vent space” and that “early intervention was a major help and probably caused me to have less stress with [Brandon] not doing stuff yet.”

Much like Tom, a significant amount of the stress Dan experienced during EI was related to his son’s developmental delays. Dan identified the cause of the stress first by the unknown cause of Felix’s delays and the lack of clarity given by the first doctors and then by the Felix’s unknown prognosis. Dan recalled that he and his wife felt “wrecked” by the cerebral palsy diagnosis and Felix’s unknown prognosis. He remembered the year immediately following the diagnosis as one of “sadness about what life could be like for my son and worry.” During this time, Dan recalls that he and Greta felt more like roommates than a married couple because they were “too emotionally and physically tired to have anything left for each other.”

Even more stress came from the anger Dan felt at the first group of doctors who failed to diagnose Felix. Dan shared that he still carries a significant amount of anger at the first group of medical professionals that worked with the family. Upon viewing Felix’s medical records, the first doctor said to the family “just go home and love him” and did not give a diagnosis. Dan feels these doctors “kicked the can down the road so they didn’t have to be the bearer of bad news.” Unsurprisingly, parents of children with developmental disabilities generally react negatively when they feel professionals have withheld information from them (Baden, 2012).

When Dan described this time in the family’s life, he said that he felt that Lily was “in the trenches” with him and Greta. It was the family’s relationship with Lily that lead the family to the pursue a second opinion and helped Dan and Greta see short-term goals as moving toward understanding what Felix’s future would hold. For example, Dan focused on whether Felix would be able to play soccer someday, not because he “needed him to play soccer but because [he] was trying to get a framework. So once that question was answered, that became the

outcome — to be quote-unquote normal.” Lily helped the family temper these expectations while at the same time remaining positive about the possibility that Felix would be able to play soccer someday. She presented shorter-term goals for the family as the steps that Felix needed to accomplish along the way to playing soccer. Dan felt this approach was exactly what he needed at the time because it addressed Felix’s immediate developmental needs, like using the impacted side of his body consistently in daily activities like eating while also allowing Dan to get used what Felix’s physical limitations would be.

Varied Relationship Quality with Early Intervention Providers

Fathers described varied levels of relationship quality with their EI providers which seemed to either exacerbate or mitigate their levels of stress during family enrollment in EI. Sathi and Tom experienced strong, positive relationships with their EI providers. Dan and Jason had strong, positive relationships with some providers and negative, stressful relationships with others. Ryk and Adam’s relationships with their EI providers were largely negative.

Sathi, Tom, and Dan experienced what research focused on family quality of life define as strong family-professional partnerships (Summers et al., 2005). These partnerships are characterized by authentic, reciprocal family-provider interactions. Families and EI providers share common goals to meet the needs of the families and children. EI providers and families communicate effectively with each other and view each other as competent. When all these factors are present within family-EI therapist relationships, families report higher family quality of life. These relationships between the fathers and EI providers became a source of support for Sathi, Tom, and Dan. Accessing emotional support systems is a vital part of enhancing family quality of life (Bailey et al., 2006; Davis & Gavidia-Payne, 2009). Positive supports for fathers

are predictive of high levels of parenting competence at age three and as children age (Crossmon, 2015).

Sathi credits effort put forth by both the therapists, himself, and his wife in building such positive relationships. Sathi's family and the therapists were "all focused on this little person being the best version of themselves." He felt strongly that I and the other therapists really liked working with Arin. When asked what he felt contributed to the high-quality relationships his family formed with therapists, he credited this to:

An offering on both sides. If this therapist is going to be as honest and open about our child, we owe to them to be honest and open about how we're feeling and the environment of our home.... Being honest about things was important to us and I think that it mutually fed into us forming a deeper relationship with our therapists.... I like to think the therapists genuinely liked our son and liked our family and we only got there through communicating outside the realm of therapy. When you know that someone cares, and genuinely likes you, it's easier to digest information.

When Tom thinks back to developing the relationships with the family's therapy team, he remembered the therapists initiating relationships with him. He feels this happened through both general conversation and checking in with him to see how things related to parenting Brandon were going. Tom feels that the onus for initiating relationships with fathers falls on the service provider. Due to age and gender differences, Tom was concerned that the therapists would misconstrue friendliness as flirting and feel uncomfortable. Tom described relief that the therapists initiated relationships with him.

I felt that most of the therapists actually initiated their relationship toward us.

Considering that all the therapists were female until the very the end, this was helpful

because as a man trying to initiate a relationship with your child's therapist can be awkward, especially when they're all twenty years younger than you.

Although Sathi and Tom enjoyed getting to know a little bit about their therapists lives outside of work, Dan felt that the strongest relationships he had with therapists were with the therapists that communicated with him primarily about his son's therapy and physical development. Dan felt that both Lily and Joanna were very competent physical therapists. They communicated very directly and kindly about what they saw happening with Felix's development and Dan felt comforted by this style of communication.

Unlike Sathi and Tom's mainly supportive relationships with all their EI providers and Dan's relationships with physical therapists, Dan, Jason, Adam, and Ryk shared that their relationships with some EI providers served as stressors rather than support systems. Dan and Jason had mixed experiences. Some relationships with EI therapists provided a positive support system while others contributed to their feelings of stress due to poor communication and/or relationship quality.

Dan and Jason struggled with their relationships with occupational therapists. Dan felt he didn't relate well with the family speech therapists, either. Dan was very reflective in his assessment of these relationships. He remembered how difficult this time in his life was so that sitting and watching speech and occupational therapy sessions with Felix was unpleasant. Dan felt there was always a feeling pulling at him during the sessions with speech and occupational therapy so he would find a reason to step out of the session. When Felix got a little older, the therapists told him that he and Greta were distractions for Felix. The speech and occupational therapists recommended that Dan and Greta go into another room while Felix worked one-on-one them. At the end of the EI sessions, Dan would speak with and listen to what the therapists

had done with Felix that day but once they left the home, Dan didn't ever feel like he knew what to do with Felix afterwards. He felt the therapists were not communicating very directly with him. Instead, the speech and occupational therapists talked around what they meant or said things like, "Maybe you may want to do...." rather than giving direct instructions or asking direct questions about family priorities. Dan doesn't remember these therapists' names or what they looked like. He does remember that they were significantly younger than he is and fresh out of school. Dan acknowledges that he can be intimidating because of his physical stature and that Felix's time in EI was emotionally fraught for their family and that perhaps these factors contributed to stilted interactions with the speech and occupational therapists. He also specified that physical therapy felt more straightforward than occupational and speech therapy. Dan feels that all these factors culminated to create less than supportive relationships with the speech and occupational therapists.

Jason found the goals of occupational therapy to be unclear. He often felt like the home visit sessions with the occupational therapist consisted of her asking questions like she was "checking a box." Jason describes a typical session with the occupational therapist, whose name he does not remember, as the therapist asking a lot of questions about Travis without giving context to the questions or offering tips or activities to try out when they identified a concern. After spending most of the session having a conversation with Jason and Jenni about Travis, the occupational therapists would work one-on-one with him for about fifteen minutes. Jason and Jenni weren't sure why an occupational was assigned to work with Travis or what function the therapy was supposed to serve. Jason felt that the hour this therapist spent with the family each week was a waste of time. Jenni researched online what skills occupational therapists typically target with toddlers and set to work on those activities with Travis. Jason remembers that he and

Jenni focused on fine motor activities like stringing beads without understanding how these tasks related to Travis's communication delays. Jason and Jenni felt like they were "stuck" with a young and inexperienced occupational therapist but that working with Emily made up for having to endure occupational therapy sessions.

Adam and Ryk's families each worked with only one therapist during their time in EI. Adam worked with Emily, the same speech therapist that served Jason's family. Ryk's family worked with a physical therapist named Cassie. Neither father had the immediate experience of working with other therapists and didn't immediately process why their relationships with Emily and Cassie felt stressful until after their children completed EI. For Adam, this happened when his son began working with a private pay speech therapist. For Ryk, this was combination of working with his own physical therapist and clinic-based physical therapist for Eleanor.

Adam's experience working with Emily was very different than Jason's. While Jason describes his relationships with Emily as a partnership, Adam felt excluded from the process. Due to his work schedule, he was present in the home for between one quarter and half of the therapy sessions. Adam attended all the evaluations and IFSP meetings. When therapy sessions occurred at Soren's child care center or when Adam was at work, Emily communicated solely with Bridget about what was happening via email. After reading Emily's email about that day's session, Bridget would share what Emily said with Adam either verbally or by forwarding him the message from Emily. Bridget works in early childhood special education, so Adam felt that she and Emily shared a language and understanding. Adam never felt comfortable asking for Emily to communicate directly with him or to ask her questions about what she was doing or Soren's development for fear of asking what he feared would be perceived as a stupid question.

When Adam was at home for therapy sessions, he felt largely excluded. While telling his story, he used words like “allowed” and “marooned” to describe his involvement in sessions. For example, Adam said that when the family began EI, he and his wife were “allowed to be there because [Soren] wasn’t very comfortable.... As he got more comfortable, then we were sort of marooned to the other room.” Adam wanted to be present for sessions and would try to “peek around the corner and snoop a little” to see what Emily and Soren were doing but felt that he should stay out of the session because “that’s what the expert thinks is best ... and I’m okay with it if that’s the best way to do it.” Soren became comfortable with Emily very quickly. The family liked and trusted her because Soren responded well to her. After Soren became familiar with Emily, Adam and Bridget were no longer staying with Soren to observe therapy sessions. Adam doesn’t remember exactly what the reason was for his being sent into another room, but remembers he felt that if he stayed, his presence would be a distraction for Soren. Emily’s approach of interacting one-on-one with Soren is common in EI despite recommended practices that discourage this practice. More than half of time EI therapists spent in family homes was spent engaging with the children in one-on-one activities (Peterson, Luze, Eshbaugh, Jeon & Kantz, 2007).

At the end of each session, Soren would run into the kitchen to get his parents and then they would have a short conversation with Emily. She would give the family a list of words and sounds to work on during the week. Adam usually worked on getting Soren to say these words one after another while his sister was doing her homework.

Adam also felt excluded at IFSP team meetings. Adam felt IFSP therapists and the service coordinator directed their attention and eye contact only to Bridget. Unfortunately, Adam’s feelings of being left out of conversations are common among fathers with children in

special education programs. Fathers with school-age children in special education reported feelings of exclusion from the process (Mueller & Buckley, 2014). When surveyed about parent involvement, many EI providers said that dads weren't good targets for intervention because providers felt they were unlikely to involve themselves in therapeutic tasks or make decisions about their children's services (McBride et al., 2017).

Lack of direct communication with Emily and the lack of inclusion in IFSP conversations reinforced Adam's feelings of exclusion from the process. Adam believed this contributed to his becoming a passive participant who entrusted Soren's speech development to an expert (Emily). Adam says that he "asked Bridget the dumb questions he was afraid to ask the therapist." This caused significant stress in his relationship with Bridget. Eventually the couple had a disagreement about Adam's level of engagement in the process. Adam shared his feelings of exclusion and fear of seeming stupid with Bridget. Bridget encouraged Adam to do research on his own and to ask questions anyway. This interaction with Bridget was significant for Adam and he worked to change his behavior afterward. Adam has done some reading on his own. Now that Soren is enrolled in services at their local public school and in a private pay speech therapy clinic, Adam feels he knows more about communication development and his son's development. He proudly recounted asking a very specific question about when children should develop certain speech sounds during Soren's last IEP meeting with the school district.

When asked about the services, Adam maintains that while the experience was neutral for him, he greatly values the services because they were beneficial to Soren. He assesses EI as "positive for me because it was positive for him." Now that Adam has the opportunity to engage with another speech therapist at the clinic who engages Adam in the activities and explains what is happening and why during therapy, Adam realizes he would have liked more of

those kinds of interactions during Emily's sessions. Adam feels now that he would have preferred more resources about communication development and more time working in tandem with Emily. Many fathers share this desire with Adam. When asked how fathers wanted to be involved in EI, many reported that they wanted video and written resources related to their children's development (Hadadian & Merbler, 1995).

Like Adam's family, Ryk's family worked with only one therapist. Unlike Adam's family, Ryk's family experienced significant external stress during their time in EI related to Ryk's medical condition and treatments. Ryk felt that Cassie and Eleanor had a positive relationship and that his role in therapy was a present observer. Ryk's medical treatments prohibited Eleanor from engaging with many people outside the immediate family due to fears about Ryk contracting common illnesses like colds while he received chemotherapy. Due to Eleanor's limited social contacts, Ryk viewed her weekly time with Cassie as a great opportunity to engage in social interactions with someone other than her parents. Ryk remembers that he was often feeling sick or weak during sessions at the beginning of Eleanor's time in EI. He describes himself as a very present observer during therapy sessions.

When the weather cooperated, Cassie and Ryk took Eleanor to the park for therapy. These were the most positive sessions because Ryk remembers Cassie demonstrating and explaining strategies he could use during play time with Eleanor. After a while, therapy transitioned from the park to the family living room. During this time, Ryk became a more passive observer. He felt that Cassie brought the same toys and did the same materials with Eleanor each week. Once the therapy became more repetitive, Cassie's communication with Ryk "petered out." Ryk wasn't sure what the benefit was of many of these activities and often couldn't replicate them once Cassie left because she brought in materials that the family didn't

have. Ryk didn't feel comfortable enough in the relationship with Cassie to say anything about the change or communicate that he could see that Eleanor was getting bored. Ryk acknowledges that he and Jane were focused on his health at the time, so they didn't necessarily have the energy to speak to Cassie about the change in the quality of her services or ask for a new therapist. When Ryk looks back on the experience, he thinks that Cassie was likely a good therapist, as evidenced in the early days of the family's relationship with her, and that she likely had something going on in her own life that led to the decrease in the quality of therapy with Eleanor and communication with Ryk.

Although each family experienced different relationships with each therapist, the consistent themes within and across fathers' narratives were that fathers often deferred to therapists to set the tone of the relationships. Therapists that engaged in both strong relational and practical help-giving with fathers cultivated relationships in which fathers felt support. In relationships where therapists did not take the lead to engage fathers in the process of EI and communicate clearly about the process and child development, fathers' felt those relationships contributed to their feelings of stress.

Themes of feeling stress and frustration as well as varied relationship quality are under the umbrella outcome of identifying and utilizing support systems. Need for support stems from initial feelings of stress and frustration. Some families perceive the discovery that a child has a disability or developmental delay as a crisis (Walsh, 2003). Fathers in this study identified that positive relationships with EI providers served as a support system while neutral or negative relationships with EI providers added to feelings of stress and frustration. In their interviews, fathers often shared details of their feelings of stress and frustration along with how their EI

therapists supported them through that stress or conversely, were viewed as the cause of that stress.

EI providers help families to access or build these support systems through family-centered help-giving practices. Indicators of this outcome may be families reporting that they feel supported raising their children, maintaining friendships, ability to talk to others about their concerns and experiences parenting children with developmental concerns, meeting other people who are also parenting children with developmental concerns, and finding trusted individuals to care for children. Families whose EI providers engaged with them using relational help-giving (active listening, empathy, respect, and compassion) reported higher levels of personal well-being (Dunst, Trivette & Hamby, 2007). Conversely, the absence of these characteristics in interactions between EI providers and fathers led to feelings of awkwardness and discomfort (Baden, 2012).

Initial Uncertainty About How Early Intervention Works

In each fathers' narrative, they shared an initial lack of understanding about how EI works. For example, both Dan and Sathi felt that therapists were going to come into their home, work with their children one-on-one for bit and that through this process their children would be "fixed" by an EI expert. Adam said that he felt "like a deer in headlights" at the beginning of therapy. Ryk had some basic understanding of EI because his wife is an EI provider, but overall didn't know what to expect once the therapist was in the house. Jason works as a high school special education teacher and assumed that the process was the same, especially in terms of the ability to choose therapists.

Prior to having a child with a developmental delay, none of the participants had experience with EI programs and five of the six didn't know that the program existed prior to

their family's enrollment in it. None of the fathers knew what to expect from the process. One of the desired family outcomes for EI is for families to develop an understanding of their rights. Ideally, families quickly become oriented to EI and how it works and develop an understanding of their rights within the system. To accomplish this task, families are assigned a service coordinator whose job it is to make sure the family understands the program and knows their rights, and to assist the family in finding therapists to work each family. All the fathers but Ryk attended initial meetings with service coordinators and came away with varied levels of understanding of the EI recommended practices and their family's rights.

After his initial meetings with the family service coordinator, Adam's understanding of EI remained one of experts coming into the family home to work one-on-one with Soren. It was only through our conversations that Adam learned that family-centered practice is the recommended model for EI provision. When Emily suggested that he and Bridget were a distraction and they leave the room, Adam trusted her opinion as an expert even though he would have preferred to stay and be a part of the entire session. He didn't advocate for anything else because he wasn't aware there was another method of service delivery. When he learned of the family-centered practice modality, he said, "It would have been helpful to have someone say this is what [EI] is and here's what you should expect."

Much like Adam's right to be part of a more family-centered service provision, there were rights that Jason had he wasn't aware of during the family's time in EI. Once Jason conveyed his dissatisfaction with occupational therapy services during our conversation, I asked if he considered contacting the family service coordinator to either ask for a change in therapists or discontinue occupational therapy. Jason didn't know that either was an option, as in the school-based special education system, therapists are assigned to children based on geographic

area and there isn't a choice for families. Jason also assumed that to be a part of the EI program, his family had to accept all the services the initial evaluation team recommended or decline all services completely. Had Jason known that it was within his rights to switch occupational therapists he is confident he would have done so. This lack of knowledge reflects Jason's lack of broader understanding of the EI system.

Dan understood more about how the EI system functions. Greta knew that their family had the right to ask for a change in therapist. Greta did not like way the family's first speech therapist interacted with Felix. Greta shared this with the family service coordinator. The service coordinator contacted the therapist to let her know the family no longer wanted to work with her then found another speech therapist for their family based on Greta's preferences. Dan said this process was super easy for him and Greta and that the service coordinator took care of everything related to the service provider change.

Waiting for an Invitation to Participate

While none of the fathers expressly connected their initial lack of understanding of EI to waiting for an invitation to participate in therapy, it was theme that appeared throughout each fathers' retelling of their experiences.

It was clear through Adam's story and his choice of language that he felt he was on the outside looking in. For example, when Adam described a typical speech therapy session, he used the word "marooned" to convey how he felt being asked to go into another room because he and Bridget were distractions from therapy. Adam also talked about how he would try to "peek around the corner..., snoop a little" to see what Emily and Soren were doing. Adam wanted to be involved in Soren's sessions so much that he frequently rearranged his work schedule to be present when Emily was in the home despite knowing that he wouldn't be included in

therapeutic activities. Each time that Adam attended therapy sessions, he experienced the same feelings of isolation and exclusion and lack of expertise. This feeling of exclusion repeated itself during IFSP meetings when the team would discuss Soren's development and the family's needs. Adam felt that the team shared the language of special education with Bridget and focused their communication with her while Adam observed the meetings rather than fully participating. These feelings of isolation and exclusion reinforced Adam's resistance to insert himself into the process; he refrained from asking questions, afraid that the experts would perceive him as stupid. The one task that Adam felt invited into was doing flashcards and wordlists with Soren each week. At the end of her weekly sessions with Soren, Emily gave the family homework to work on between speech sessions. This homework usually consisted of flashcards and words lists. Adam faithfully made time in the daily family routine to complete this task with Soren and spoke about incorporating it into the nightly homework routine with his older daughter.

In addition to communication delays, Soren experienced some issues with eating. During sessions when Emily focused on feeding therapy, Adam was "allowed" to be a present to observe. He vividly recalled several strategies he learned watching Emily work with Soren while he chewed including using the cue "chipmunk cheeks" to remind Soren to chew a certain way although Adam isn't sure what the phrase cued Soren to do or why.

Consistent with Adam's experience with Emily, the speech therapists that worked with Dan's family also said that his presence was a distraction for Felix. They often suggested that Dan step out of the room. During sessions that he wasn't asked to step out, Dan often made up excuses to leave the room for periods of time. Speech and occupational therapy sessions were quite stressful for him. He described feeling "something pulling at me" during sessions and connecting that feeling to wanting to excuse himself from the room. Conversely, Dan did not

have these feelings during sessions with either Lily or Joanna, who included Dan into activities with Felix and communicated directly with him about what they wanted Felix to be doing and why. Lily and Joanna connected what they were doing to a larger goal, the possibility of Felix playing soccer. While Dan proudly recounted strategies he used to help Felix meet motor milestones, he spoke a lot about how he didn't fully understand what to do with Felix to support his speech and occupational therapy goals.

Jason's experience working with Emily was different from Adam's. Jason's initial invitation into the sessions was to serve as a behavior monitor and over time, his participation evolved to more of a partnership. Jason remembers sitting on the floor with Emily and Travis. He watched Emily model what she was doing with Travis and she narrated what she was doing and why. When Travis started therapy, he had a very short attention span and would get up to try and leave the interaction with Emily. Emily modeled how to use the position of her body to limit distractions and create a visual cue of where Travis should sit and play. This was an effective strategy. Jason used it to help keep Travis engaged in play with him in between sessions.

Unlike the family's sessions with Emily, Jason did not feel invited into the process with the occupational therapist. During those sessions, she divided time asking Jason a series of questions about Travis and then would engage with Travis one-on-one without inviting Jason into their interactions. Jason felt these sessions were "a waste of time."

Sathi and Tom held the same initial impressions of EI as Jason, Adam, Ryk, and Dan that the expert would come into the home and work one on one with their sons. Sathi and Tom reported that they become full collaborators with their therapists relatively quickly. Neither

Sathi nor Tom recalled one specific invitation into therapy, but rather a series of actions that involved them into the process.

Sathi spoke a lot about how his understanding of the EI process evolved over time. His initial inclination of EI was that it would be “an old doctor type that would come out, poke and prod, he’ll scratch his chin and give his prognosis.” The reality, instead, was that the therapists were “very warm and comforting,” and that while he at first felt that his role was just to be there and serve as a reference for Arin’s behavior, that over time he, Meena and the therapists “started to exchange information,” and that through this communication he “started to see a different role which was more of a collaborator than an observer.” Sathi described therapy sessions during which the therapists coached his interactions with Arin, asked Meena and Sathi’s opinions about things related to Arin’s development and therapy goals, and provided information about general toddler development and Arin’s specific developmental needs.

One example of an exchange of information was a session when Julia checked in with the family about how they felt therapy was going. It took a while for Arin to become comfortable with Julia, his speech therapist. Julia was concerned that perhaps Arin would relate better to another therapist and thus make more developmental progress. Sathi and Meena were unaware that they could request a change in therapist and were a little surprised when one day Julia came to them and said she was unsure if she was the right fit for Arin. During this conversation, Julia let Sathi and Meena know that they could request a therapist change at any time and asked if the family thought perhaps someone else may be a better fit for Arin. Sathi and Meena offered an observation that they thought Arin was reacting negatively to the tone, volume, and pitch of her voice. Julia, Sathi, and Meena decided to continue working together with Arin. Once Julia changed the volume and pitch of her voice, Arin was able to build a strong relationship with her.

Julia's respect for Sathi and Meena as the experts on their son throughout the process helped demonstrate to Sathi that he was a full partner in the EI process. It was through interactions like these that Sathi came to understand that EI isn't at all an old guy coming into their home to fix their son.

Tom holds similar feelings about being a full collaborator in EI. Tom recalled that the therapists always asked how he was doing and seemed interested not only in Brandon but by how the family as whole functioned. When Tom shared challenges with therapists, they included him in working with Brandon to address these challenges. A specific example Tom mentioned several times was going to the beach park near their home for therapy sessions. The therapists would meet Tom and Brandon at the family home, work together to get his shoes on and walk the three blocks to the beach together and then share interactions with Brandon while he navigated playground equipment or practiced walking on the myriad surfaces at the park. Shortly after the family started EI, Tom began to feel that it was "therapy not just for [Brandon], but for us, too."

Ryk's initial experiences with physical therapy took place at the park. In contrast to Tom's experience, Ryk never felt invited into the conversations about Eleanor's development and session-to-session progress. Cassie and Jane shared a language and set of experiences as EI therapists that he wasn't a part of. Ryk stated that this wasn't unusual for the couple. In their home, Ryk provides the daily caregiving for Eleanor and Ned while Jane handles things like doctor and dentist appointments. At the time Ryk, was focused on his cancer treatments and recovering from a joint replacement, so it made sense for the family to continue with the established division of labor. In the case of EI, this meant that Ryk was present for the weekly physical therapy sessions and Jane handled the scheduling and communication with the therapist.

Now that Ryk is in remission, he can reflect on how his illness impacted the family's participation in EI. It's unknown whether Cassie would have invited Ryk into more communications about Eleanor had he been well during the time Eleanor was enrolled in EI.

The second proposed family outcome for EI is knowing what the family's rights are and advocating for those rights. Both themes of fathers' initial lack of understanding of the process of EI and fathers' desire to be involved in the sessions but waiting to feel invited into the process fall under the umbrella of knowing the family's rights and being able to advocate for those rights. This is common among families new to the EI program (Baden, 2012) and consistent with research findings from other studies focused on father involvement. An exploratory study about father involvement in early education programs found that issuing a direct invitation to fathers increased the number of fathers that showed up for the intervention (Turbiville & Marquis, 2001). In situations that the therapists did not expressly convey they wanted the fathers to join in the activities, fathers in this study remained on the sidelines and viewed the therapists as the experts or just endured the hour of therapy each week.

Varied Understanding of Child's Development or Developmental Needs

Each of fathers in this study came from families that entered EI able to communicate, in at least a rudimentary way, about their children's developmental needs. This is evidenced by their family contacting EI to refer their child for services. This theme is correlated with the proposed outcome of the ability to understand and communicate about their children's strengths and developmental needs. A portion of this outcome, the ability to communicate about children's development needs, is collected by the federal government as a measure of EI program success. Like information about families knowing their rights, this data is collected

through family self-report of their own capacity during an IFSP meeting with their whole team present.

Fathers in this study had varying degrees of involvement in the initial referral process. Tom knew something was developmentally different about Brandon based on his prior experience parenting his older children and broached the subject with his wife and then the family pediatrician. Sathi and Meena discussed their concerns about Arin's speech delays with each other and then Meena called to make the referral. For Jason and Dan, someone outside of their nuclear families expressed concerns and then their wives called EI. Ryk and Adam's wives knew their children had developmental differences based on their work experience and after sharing concerns with their husbands, made the referrals to EI.

When I spoke with each of the fathers about the current status of their children's development and what their current strengths and development needs are, they were all capable of providing an answer with varying degrees of confidence. Due to the in-depth nature of our conversations, it became evident that while each father could communicate with experts about what their children can and cannot do, that they gained varying levels of understanding about development as a result of EI participation. Each fathers' understanding of his child's development seems to relate directly to the quality of their relationship with EI providers and level of engagement in EI sessions.

For example, during our interview, Dan updated me that Felix is walking independently and taking an art class to encourage fine motor development. Dan spoke at greater length about the gross motor milestones Felix reached thus far but shared only that he was in an art class regarding Felix's fine motor development. Dan did not mention any milestones or current developmental needs related to speech and communication. It is of note that Dan had excellent

relationships with the family's physical therapists, and strong positive memories of helping Felix reach motor milestones in partnership with Lily and Joanna. Lily and Joanna included Dan in interactions with Felix and communicated directly with him about Felix's gross motor needs. Dan was told that his presence in speech and occupational therapy sessions was distracting for Felix. Dan was often asked to leave speech and occupational therapy sessions or was so uncomfortable during these sessions that he excused himself. He maintained that "after talking with the speech or OT, I didn't feel exactly like I knew what to do afterward." Overall, Dan felt that his time participating in EI "was the early process of getting me where I need to be." It was foundational in helping Dan gain an understanding of early childhood special education. Especially through his interactions with Lily and Joanna, Dan learned the language of cerebral palsy and special education, a skill that he puts to use constantly when speaking to others about Felix.

When giving me an update about Brandon, Tom spoke at length about Brandon's social emotional accomplishments including his ability to engage in pretend play and to engage in back and forth conversations with others. He also articulated the family's frustration with Brandon's extreme picky eating and refusal to eat foods that require the use of utensils which he feels is a regression from the progress that Brandon made with self-feeding when was in EI. Tom made several comments about how Brandon's strengths and challenges are consistent or not with typical autism symptoms. Tom said that "early intervention as a whole prepared me for that diagnosis." When the doctor told Tom and Susan that he felt Brandon was on the autism spectrum, Tom remembers that the doctor started the diagnosis by apologizing. Tom says that because he had come to understand what autism meant and what Brandon's skills and needs were, that he responded, "I'm not sad. You know, at least I know what's wrong. Now I know

how to deal with something, and I can figure out how to help him.” For Tom, having the autism diagnosis helps him to contextualize Brandon’s development and to communicate with others about how autism symptoms manifest in Brandon. Without EI, Tom said that he “would have been googling everything in the world” trying to figure out how to understand what Brandon’s developmental needs were and the cause of the those needs.

Tom felt that building an understanding of autism through interactions with EI therapists was a huge benefit to him. Sathi shares the value of coming to an understanding of his son’s development as a result of EI. Perhaps the most significant shift in understanding for Sathi was “a huge perspective shift of not seeing my child as broken.... It’s opened my understanding of children..., managed my expectations [about what was typical for young children].” Sathi identified participation in EI as a key factor in his coming to understand that his son wasn’t throwing tantrums just to misbehave, but instead because he couldn’t communicate strong emotions another way. He said,

Just because kids can form words doesn’t mean that they’re not having complex thoughts and complex emotional battles.... EI kind of helped in the sense of understanding emotional states and what may be angering or frustrating a kid ... could have been building up over time.... Your kid is an autonomous, feeling little person who doesn’t know how to communicate with you.

Learning about typical toddler development and behavior helped Sathi shift his perspective about his son’s play, communication development, and behavior. He developed an understanding that “[developmental progress] is gonna take time” and that Arin will develop at his own pace. Sathi is “glad we did [EI].... It’s opened up my understanding of children.”

Sathi and Jason also talked about deepening their understanding of their role in their son's development. For Sathi this meant taking a calmer approach to interacting with Arin rather than presenting too many new words and experiences at one time. Before EI, Sathi said that "in effort to get him back on track as fast as possible, we were throwing a ton of stuff at him, and our therapists did say y'all need to cool your jets just a little bit." This interaction with the therapists paired with what they taught him about toddler development helped Sathi come to understand that Arin's development was a process that would occur over time.

Opposite of Sathi's approach, Jason said that before starting EI, he assumed that Travis would learn what he needed by virtue of having the right kinds of developmental toys in the home.

I feel like in the beginning, because my wife and I both work, we were constantly working on the house [on evenings and weekends]. We were always doing something and that gave Travis a lot of free time.... I was just being assumptive that he was getting what he needed by just having the toys and stuff around but that wasn't the case.

Jason said that through working side-by-side with Emily during her speech therapy sessions, he came to understand that Travis needed interactions with his parents to optimize his development.

Adam emerged from EI with the least knowledge about Soren's language development, which is not altogether surprising as he was rarely present throughout the sessions and didn't feel comfortable asking Emily questions about what was typical or what the family should expect in the next phase of Soren's speech development. He described initially feeling like a "deer in headlights" and that feeling remained throughout Soren's enrollment in EI. Adam said:

I don't know anything [about language development]. You know, I was a criminal justice major in undergrad, so I didn't take any educational classes or anything, so I

didn't even know what to ask like, what's typical.... I didn't know anything. I mean, I know very little about speech services and stuff now.

In retrospect, Adam wishes that Emily provided him with written resources about language development, since he was afraid to ask her for fear of being perceived as asking a "dumb question." Many fathers would prefer that EI providers gave them written information about their children's disabilities (Flippin & Crais, 2011).

Adam feels that he just let Bridget naturally take over the communication about Soren's development with Emily and the family service coordinator because she already understood early childhood development. He likens his thinking about it at the time to the fact that he works in finance, so he handled all communication when the couple got a mortgage to buy their home. Through Bridget's urging, Adam eventually learned more about Soren's development through talking with her and asking questions at his school IEP meetings, although he still feels like he knows "very little" about speech and language development.

Overall, fathers in this study exited the EI program with varied levels of understanding about their children's development. Each family unit can communicate to special education professionals that they have concerns about their children's development; however, most of the fathers in the study would not be able to articulate to professionals exactly what skills they wanted them to target within the area of concern.

Positive Feelings About Child Outcomes Despite Varied Levels of Capacity Building

All six fathers felt positively about their family's participation in EI because they unanimously felt that participating in the program helped to further their children's development. They saw their ability to recognize that their children needed developmental assistance and seek EI services as a way of helping their children make development progress.

Each of the six fathers acquired varied levels of capacity in helping their childr make developmental progress as a result of their participation in EI. This varied capacity building seemed directly connected to the quality of relationships fathers experienced with EI service providers. For example, Dan reported high-quality partnerships with Lily and Joanna and a high level of competence in helping Felix make progress with gross skills. Conversely, he reported poor relationships with the speech therapists and a low level of competence in helping Felix make progress in the area of communication.

Five of the six fathers in this study felt that participating in EI increased their capacity as parents. Dan's interactions with physical therapists helped to build his capacity to plan activities to help Felix master gross motor skills. Ryk learned strategies to help Eleanor refine her gross motor skills that he put into practice during daily trips to the park. Tom learned many new strategies to address Brandon's global development. Sathi learned to understand the complex emotions of children and how to engage with Arin in ways that were developmentally appropriate. Jason not only picked up strategies about how to organize toys and help Travis attend to tasks longer, but also internalized the importance of getting down on the floor to play with Travis. Each of these five fathers gave specific examples of strategies that their EI providers taught them. This is consistent with small existing body of research about fathers. Fathers report they appreciate specific, concrete strategies to use when engaging with their children with developmental differences (Murphy, 2013) and that successful implementation of these strategies increases fathers' feelings of efficacy (Fox, Nordquist, Billen, & Savoca, 2015). Research shows that parents who demonstrate competence caring for children with disabilities at age three show a continued increase in competence as their children age (Crossman, 2015).

It is of note that regardless of fathers' personal feelings about their relationships with EI providers or whether they enjoyed attending the therapy sessions, all six fathers reported strong positive feelings about EI. This is consistent with myriad research about generally high levels of family satisfaction with EI programs, although the respondents in most studies were mothers (Bailey, Hebbeler, Scarborough, Spiker & Mallik, 2004; McWilliam, Lang, Vandivire, Angell, Collins, and Underdown, 1995; Murphy, 2013).

Fathers in this study felt that the program was effective in helping their children reach milestones and make developmental progress. When asked about the overall impact of the program on themselves, each father referenced the developmental progress made by their children as a positive impact of the program, even though I meant the question to elicit answers about how the program impacted them rather than their children. For example, when speaking with Adam, who repeatedly talked about being "marooned" during his family's involvement in the program, he said:

[I'd rate EI] an eight or a nine [out of ten]. It obviously helped Soren a great deal. I don't care about me, I care about him, and I think that the thing that makes it positive for me was that it's positive for him.

Dan, who had mixed feelings about different therapists, also described feeling that the impact of EI was positive because "it helped our son.... We felt well served by early intervention.... When I think about early intervention, it is an overwhelmingly positive thought that I have about it.... If someone said something happened with their kid, I would enthusiastically recommend they use early intervention."

Tom, who like Dan, has a child with a permanent and significant developmental disability, feels strongly that enrolling Brandon in EI was key to helping him make

developmental progress. He affirms,” Brandon’s interaction with people to this day is way better and I’m sure it’s because of early intervention.”

Jason’s son attained age appropriate development and no longer receives special education services. Jason feels that this is because Travis got speech therapy early on and that “Emily did a really great job.... Travis met all his speech and goals. We’re all in agreement that he made significant gains and he’s age appropriate.... The overall experience was certainly positive.”

Ryk was the most explicit in making the connection that getting EI for Eleanor was evidence of his own ability to help her make developmental progress. The impact of EI for Ryk was “Eleanor experiencing success” and knowing that “you can ask for help with your child, you can get it, and it works.” The ability to access programs like EI assists families in feeling capable of meeting their children’s developmental needs.

CHAPTER SIX: Discussion

Narrative inquiry “contributes to research on teaching and learning through its ability to frame and study the human experience” (Webster & Mertova, 2007, p. 13). The goals of this research were to “frame and study” what fathers’ experienced when they participated in EI programs with their children. Through father’s narratives about their experiences, I gained insight into fathers’ experiences, how fathers framed their experiences, how the experiences impacted fathers’ development, and how ecological factors impacted fathers’ experiences.

It is true that qualitative research does not exist to generalize findings from one father’s experiences to the experiences of all fathers in EI; however, as a reflective practitioner, it is helpful for my own practice to take in the stories these fathers told and to learn from their experiences. As someone who teaches courses on EI methods, I hope to use the wisdom gleaned from their stories to better prepare those entering the field of EI.

In this chapter, I revisit bioecological systems theory. Each theme is presented within the context of bioecological systems theory. Factors at the individual, micro-, meso-, exo-, macro- and chronosystem levels are considered. Family systems perspective is nested within mesosystem level of the ecological systems model and is addressed as appropriate. After each theme is contextualized within bioecological systems theory, I offer implications for practitioners based upon what I learned from the fathers’ narratives. To maintain a flow consistent with the findings chapter, relevant scholarship is intermingled throughout the discussion. Lastly, a call for additional research is provided.

Positioning Themes within Bioecological Systems Theory

Themes in this study included high levels of father engagement prior to EI, fathers’ initial lack of understanding of the process and EI system and subsequent waiting for an invitation to

participate, varied levels of understanding about child's development or developmental needs, varied relationship quality with EI providers, feelings of stress and frustration during time in EI, varied levels of comfort asking questions about the process or child development, and positive feelings about child outcomes. In the findings section of this study a table presented themes and matched those themes to the desired family outcomes for EI. These outcome categories include identifying and utilizing support systems, knowing their rights and advocating for their families, understanding and communicating about their children's developmental needs and helping their children make developmental progress.

Factors at multiple levels of the bioecological system impacted how each father experienced and made meaning of themes. This section presents an in-depth examination of each theme by placing some of the fathers' narratives into the context of bioecological systems theory. When possible, sections for different systems are provided. In some themes, including fathers' overall positive feelings about EI, factors present themselves across several systems and are presented in light of that positioning across multiple system levels.

High Levels of Father Engagement Prior to Early Intervention

Each of the fathers in this study characterized themselves as highly involved fathers who spend a lot of time engaged in daily caregiving and play with their children. Five of the six fathers interviewed (Sathi, Tom, Ryk, Dan, and Adam) were highly involved with daily caregiving and play with their children prior to their involvement in EI. Jason became more involved in play and educational activities with his children as a result of his participation in EI. Already involved fathers, Sathi, Tom, Ryk, and Dan learned additional strategies through EI that built their individual capacities to further their children's development while they engaged in caregiving and play.

Individual System Level Factors that Impact Father Involvement in Caregiving

Multiple factors at the individual level of bioecological systems theory influence a high level of father engagement in caregiving. Bronfenbrenner and Morris (1998) maintain that individual level factors appear twice in systems models. First as influencers of fathers' development and then as products of development. For example, Tom entered EI as an experienced father of four with a high level of involvement in daily caregiving and play. Parenting his older sons developed Tom's sense of parenting efficacy and influenced the value he placed on high levels of involvement in parenting Brandon. Tom is gregarious, friendly, and open to seeking help from medical and educational professionals to help his family address challenges that arise. These characteristics influenced his willingness to participate in EI services. Tom's feelings of efficacy and openness to help from outside services providers were strengthened through his participation in EI. These individual characteristics exist in his systems model as products of his development as well as influences on his development as a father with a child with autism.

Prior research demonstrates that while father involvement is complex, several individual level factors contribute to high levels of father caregiving. One main factor is post-secondary education (Karre, 2016; Barba 2016). All fathers in this study obtained at least a bachelor's degree. Ryk completed an MFA. Other fathers may have additional education that they did not share as a part of their narratives. In quantitative research examining fathers' self-reported levels of involvement, fathers with post-secondary levels of education tended to maintain more egalitarian views about gender roles in families which correlated with higher levels of father caregiving (Karre, 2016). More educated fathers also report higher levels of joy derived from parenting than children than fathers with less education (Dunst & Dempsey, 2007). Feelings of

joy likely translate into more positive individual perceptions of their children and fatherhood. Fathers who reported positive feelings about their children and fatherhood were more engaged with their children than fathers who did not associate positive feelings with caring for their children (Hofferth, et al., 2013).

Another individual factor that seems to impact levels of father involvement is socioeconomic status. No direct questions about SES were asked during interviews, but it was apparent through other cues (educational level, work environment, home environment, references to family vacations, references to employer paid leave policies, access to internet and cell phone technology, etc.), that all fathers in this study were at least middle-class and likely upper middle-class. Fathers with lower and middle SES tend to spend more hours per week engaged in caregiving and play with their children than fathers with a high SES (Dyer et al., 2009) This is consistent with the level of daily caregiving and involvement reported by the middle- and upper middle-class fathers in this study.

Father's experiences with their own father can impact their levels of engagement with their own children (Lamb, 2013). There are coexisting theories that explain that men whose own dads were engaged with them as children exhibit high levels of engagement and caregiving with their children. For other men, having a father who was absent or disengaged from caregiving results in intentionally higher levels of involvement in parenting their own because those fathers understand how having a disengaged father impacted their own development (Guzzo, 2011; Cabrera, Fitzgerald, Bradley, & Roggman, 2014; Karre, 2016). Most participants in this study did not share their experiences with their own fathers, but Dan stated that "both Greta's dad and my father were as involved as they could be and still are. That was both of our models and so that's definitely what I wanted." Dan talked about how he knew before his son was born that he

“wanted to be as involved [in parenting] as possible” because his own father was “very hands on.” Dan’s individual history with his father’s high level of engagement provided a model and personal expectation that Dan would also be a very involved parent.

Microsystem Level Factors That Impact Father Involvement in Caregiving

At the Microsystem level, several factors impacted fathers’ high levels of caregiving. Microsystem level relationships between the adults in the family are where decisions about how family functions like daily child caregiving made. Both Dan and Adam communicated that their wives expected a high level of involvement from them in the parenting of their children. For Dan, this came in the form of his wife, Greta, having had a dad that was heavily involved in her upbringing and carrying that expectation into her marriage with Dan. For Adam, his wife Bridget, communicated to him that because both were home on parental leave, she expected him to share in the getting up in the middle of the night to help meet the baby’s needs. These expectations have changed slightly with the aging of their children and Greta’s current role as a stay-at-mother; however, both Dan and Adam continue to meet the expectations of involved fatherhood that exist within their microsystems.

At the onset of their involvement in EI, each of the six men had wives who worked. Ryk, Tom, Sathi, Adam, and Dan’s high level of caregiving aligns with research about fathers with working spouses. Residential fathers who have working wives are significantly more likely to be involved in daily caregiving than men whose wives stay-at-home full time (Karre, 2016; Hofferth, 2013; Meteyer & Perry-Jenkins, 2010). In families with two full-time working parents, mothers and fathers share caregiving more equally than in families in which the mother works part-time or stays at home. While having working spouses seems like a primarily microsystem level factor on father involvement levels, it also sits in the chronosystem. Contemporary fathers

are far more likely to have working wives than middle class fathers with children were prior to the 1980s.

Several of the fathers in this study provided the primary care for their infants for a least a short period of time. In the United States only about 20% of fathers care for their children while their wives are at work (United States Census Bureau, 2013). In Ryk's family, his wife worked long hours outside of the home while he was undergoing cancer treatments that rendered him unable to work due to a weakened immune system. Ryk and Jane adapted to the needs of their family (financial stability, child care for Eleanor, medical care for Ryk) by deciding it made the most sense for Ryk to become a stay-at-home dad while Jane worked outside the home. Much like Ryk and Jane, Dan and Greta and Adam and Bridget also made adaptations in their microsystems related to the family functions of economics and daily child caregiving. Dan and Adam both took on the care of their infant children for a short time when their wives' paid maternity leaves ended. Both men were able to take additional time off work to be with their babies without financial implications. Although Dan and Adam were the primary daily caregivers for children for a short time, both report one-on-one caregiving for their children as infants solidified microsystem level bonds with their children.

Exosystem Level Factors That Impact Father Involvement in Caregiving

Exosystem factors influenced Dan and Adam's decision and ability to become the primary caregiver for their newborn infants. Dan is a teacher. The school district set a nine-month work schedule that allowed him to be home with Felix through the summer months. Adam works for a large company that provides four months of paid paternity leave while his wife's company only provided three months of maternity leave. Tom works in an industry that is

highly conducive to working from home, an exosystem level factor that contributes to his ability to be available during the day to engage Brandon's caregiving.

Jason's work outside the home offers less flexibility than the other fathers. As a result, Jason felt that during the week, the family focused on getting to and from work and getting children to and from childcare. Time on the weekends became dedicated to chores and errands. The company Jason works for made exosystem-level decisions about his work schedule and the location of his work that impact Jason's availability to engage in daily caregiving with his children.

Another exosystem factor that impacts levels of father caregiving is the way in which our culture shares images and ideals of fatherhood in the media. Sathi referenced the mixed messages about father involvement in the media during his interview. He recalled "Piers Morgan did a thing about Daniel Craig carrying his kid in a papoose and he [Morgan] called it emasculating."

Sathi was referring the 2018 media coverage of Daniel Craig, an English actor who portrays James Bond, posted a photo of himself wearing his infant daughter in a baby carrier on his social media pages. This photo of Craig was publicly lauded by many and criticized by others, including Piers Morgan, a conservative commentator. Mixed messages about modern fatherhood continue to permeate television and film, advertisement, blogs, social media, and books (Troop & Kelly, 2015). While there remains a contingent of Americans that feel infant care is mothers' work, men in this study were in either the Generation X or older millennial age groups. Both generations tend toward more egalitarian ideas about parenting and gender roles than previous generations (Buetell & Behson, 2018). During their childhood and adolescent years, there was trend for the media to portray fathers as unknowing fools when it came to child

rearing (LaRossa, 2015). A move toward depictions of more competent, involved fathers in film and television started in the 2000s and continues today. Media representations of involved fathers are both a reflection of the change in expectations that exists in our current moment in history.

Macrosystem Level Factors That Impact Father Involvement in Caregiving

Sathi identified his culture as a Southeast Asian man as an impact on his initial thoughts about fatherhood. He spoke of how microsystem interactions with Arin mitigated the potential impact that the macrosystem may have had on his approach to fatherhood. Sathi described bonding with Arin as a small infant by holding him on his bare chest. He shared that he knew that many men, especially those who share his cultural background would see that as “just not what men do.” Sathi comes from “a South Asian community where machismo is very much an issue. There are things that men just don’t do, but those moments, having it be a positive thing, a reaffirmation of your bond with your kid, is a greater mark of fatherhood.”

Other fathers recognized that perceptions about the role fathers play in families are influenced by the culture but did not connect it to their own levels of father engagement, rather they referenced American cultural ideas about men and women as factors that influenced the occurrence of other themes, including their relationships with their EI providers.

Feelings of Stress and Frustration

Each of the six fathers conveyed high levels of stress and frustration during their time in EI. Myriad factors at multiple systems levels contributed to, exacerbated, or mitigated these feelings.

Individual Level Factors Related to Stress and Frustration

At the individual level of the systems model, all new parents exhibit some level of stress as they adjust to new parenthood and adjust their perceptions of what they envisioned parenthood would be and what their child would be like versus their reality of parenthood and who their child is (Galinsky, 1987). An adjustment period is a normal part of one's transition into parenthood. One's adjustment to parenthood is influenced by their personalities, belief systems, prior experiences with infants and children, and mental health status. Parents who conceptualized parenthood more closely to their actual experience parenting an infant experience less stress and frustration during this stage of parenthood than parents who visualized an unrealistic version of parenthood. Most parents-to-be do not imagine their children as having a disability or developmental difference; therefore, the introduction of a child's developmental difference often heightens the intensity of this process for individuals (Galinsky, 1987; Walsh, 2003). Neither Dan nor Sathi envisioned the child they would parent accurately. Dan did not imagine that Felix would have a disability while Sathi did not expect Arin to have such complex emotional reactions.

Dan shared that once he noticed that Felix wasn't developing typically, he became "fixated on it a bit." Once Dan learned that Felix's had cerebral palsy, he describes feeling "wrecked by it." For about a year after Felix was diagnosed with CP, Dan felt "lost a bit" as he struggled to make meaning out of Felix's diagnosis and determine what it meant for him as a dad, for Felix's future, and for their family as a unit. Dan remembers a prominent emotion during this time as "sadness about what life could be like for [his] son." This caused Dan very high levels of stress and anxiety during Felix's toddlerhood.

Microsystem level Factors Related to Stress and Frustration

At the microsystems level, Dan's personal level of stress and frustration impacted his feelings of connectedness to his wife. He describes feeling like he and Greta "were roommates who were too emotionally and physically tired to have anything left for each other." Dan felt a comradery with Lily, the family's physical therapist during this time. She was such a source of support that Dan referred to her as being "in the trenches" with him and Greta while they were processing Felix's motor delays. Dan's microsystem level relationships with Lily and Joanna provided practical supports for helping Felix's development along and validation for the work that Dan invested in helping Felix meet milestones such as cruising along furniture.

Sathi's son, Arin, does not have a lifelong disability like Felix, but parenting Arin was still not exactly what Sathi thought it would be. Sathi describes parenting Arin as both wonderful and incredibly challenging. Arin had big emotional reactions to everyday situations that resulted in very frequent and intense tantrums. Sathi did not expect such complex emotions from a young child. Sathi felt a lot of stress as a result of the mismatch of expectations versus reality. Sathi felt stress and frustrated as his primary emotional reaction to Arin's language delays and frequent tantrums. Additionally, Sathi identified exosystem-level factors that contributed to an overall feeling of anxiety. Sathi was enrolled in EI services during the 2016 presidential election. Sathi is very politically minded. He stated that the "political situation of our nation had [him] in a state of anxiety that affects the timbre of the home."

Sathi's feelings of stress and frustration were related to challenging interactions with Arin in their microsystem or between Arin and his mother or Arin and the nanny. The challenges present in Arin's microsystems with his mother and nanny existed in Sathi's mesosystem.

Increased stress in families with children with developmental delays who exhibit challenging behaviors such as tantrums, is common.

Both Dan and Sathi found their EI therapists as sources of support to mitigate stress brought on by these individual feelings. Sathi shared his feelings of stress, frustration, and anxiety within his microsystem relationships with EI therapists. Sathi felt that being open about things that were important to him and Meena “fed into forming a deeper relationship” with their EI providers that felt authentic. This level of authenticity and caring became a source of social support for Sathi. He reflected on how “it’s nice to have a caring person ... come to the home.” These strong, positive relationships helped Sathi to take in information about Arin that may have otherwise been more difficult to hear. He stated that “when you know someone cares and genuinely likes you, it’s easier to digest information [about your child].” Sathi’s feelings being supported by the IFSP team and stated level of satisfaction with the program are consistent with other studies. One quantitative study found that parents (not identified as fathers or mothers) reported interacting with EI providers who engaged in relational help-giving had higher levels of well-being (Dunst, Trivette, & Hamby, 2007).

Unfortunately, some of the stress and frustration fathers experienced was directly related to their microsystem level relationships with EI providers. For example, Adam felt that he and Emily had a very shallow relationship that left him out of the therapeutic process and left him feeling disempowered. Jason felt that his microsystem-level interactions with the family OT created stress and he referred to having to “endure” her weekly visits. These microsystem-level relationships between fathers and EI providers caused additional stress instead of mitigating it.

Poor relationship quality that Adam experienced in his microsystem with Emily created strife in his marital microsystem. Adam’s lack of comfort with Emily, the family speech

therapist, caused him to hold back from asking her questions about Soren's development. Instead, Adam expected his wife to manage communication with Emily and answer any questions he may have. Adam's individual reaction to his shallow relationship with Emily created a conflict within his microsystem with his wife, Bridget. Bridget felt that Adam wasn't living up to the norms of how they took equal responsibility for the family function of caregiving and education for their children. This conflict with Bridget added to Adam's overall feelings of stress and frustration during the family's time in EI.

Mesosystem Level Factors Related to Stress and Frustration

One father, Adam, specifically identified how mesosystem-level factors created stress for him. His wife Bridget and the family speech therapist Emily maintained a much more positive and communicative relationship with each other than the relationship between Adam and Emily. Bridget and Emily's relationship with each other existed in Adam's mesosystem. As described in Adam's narrative and in the findings sections, Bridget and Emily's relationship with each other felt exclusionary to Adam.

Ryk also felt that the mesosystem-level relationship between his wife Jane and the family's physical therapist was exclusionary of him, although he did not identify this relationship as a source of his stress and frustration.

Varied Relationship Quality with Early Intervention Providers

During the telling of their stories, fathers deconstructed their relationships with EI therapists. Fathers identified several factors that impacted relationships with EI providers. These factors exist in multiple levels of bioecological systems theory and include therapeutic approach, gender differences, therapist age, therapist experience level and communication styles

and methods. Individual level factors that impacted relationships were identified as warmth, friendliness, and investment in the family unit rather than a focus on the individual child.

Individual-Level Factors Contributing to Father-Provider Relationship Quality

Fathers were quick to identify individual-level characteristics that promoted or inhibited strong, positive relationships with them. Sathi and Dan identified characteristics in themselves that contributed to their relationship quality with therapists. Sathi spoke at length about how he and Meena greeted their therapists warmly and communicated openly and honestly about not only topics related to Arin, but current events, books, and politics as well. Dan stated that he's learned through microsystem interactions with coworkers and students that he can be perceived as intimidating due to his appearance. Dan acknowledged how much anxiety and stress he felt during his time in EI and his feelings of not wanting his son to have to need EI services. This likely impacted his interactions with the therapists in the home.

Adam's individual-level feelings of lack of efficacy related to Soren's speech development contributed to his poor relationship with Emily. Adam's lack of knowledge of and experience with speech and language disorders in young children contributed to Adam's lack of efficacy. This led to him opting out of asking direct questions of Emily and not questioning her methods because she was the expert.

An individual-level factor that pertained to the therapists rather than the fathers themselves was therapist demeanor and affect. Tom and Sathi identified that all their therapists presented with a warm demeanor. Tom and Sathi felt that their IFSP team members each demonstrated an investment in the family rather than only in the child. The presence of these characteristics in providers with whom fathers reported positive relationships is consistent with existing research (Baden, 2012; Murphy, 2013). Tom, Sathi, and Dan named their EI therapists'

abilities to communicate clearly, honestly, and directly with them as advantageous to their relationships. Conversely, Ryk and Adam, who rated their relationships with EI therapists as less than optimal, did not feel EI therapists communicated with them. One of the most significant predictors of father satisfaction with EI providers is respectful open, honest communication (Baden, 2012; Higgins, 2005; Melton, 2005; Pandit, 2008). Literature published as early as 1995 stressed the need for communication with fathers as a vehicle for engaging fathers in family-centered EI practices (Turbiville, Turnbull, & Turnbull, 1995; Hadadian & Merbler, 1995).

Ryk and Adam experienced challenges in communication with their EI providers at multiple systems levels which both contributed to and became a product of their poor relationship quality with EI providers. At the individual level, Ryk was experiencing cancer treatments. Most of his energy was consumed with his own treatment and Eleanor's daily caregiving. It did not occur to him at the time to discuss his concerns about the repetitive nature of Eleanor's therapy sessions at the time. Once Ryk noticed a decline in the customization of Eleanor's therapy sessions, he did not feel comfortable addressing the issues with the therapists. It was only upon his storytelling and reflection and Ryk realized that he would address his concerns with the physical therapist if he had to relive the experience.

Micro- and Mesosystem Level Factors Contributing to Father-Provider Relationship Quality

Fathers identified communication as a major contributing factor to their relationship quality with their EI providers. In addition to the individual factors listed in the previous section, there are several micro- and mesosystem-level factors that impacted father-provider communication.

The family functions division of labor in Adam and Bridget's microsystem placed the primary responsibility of managing EI and communicating with EI providers on Bridget because she had professional experience in early childhood special education. As a result, Bridget and Emily maintained communication in what Adam felt was a closed loop. Exosystem factors at Adam's place of employment dictated that he be present in the office when the bulk of therapy sessions occurred. This created more opportunities for Emily and Bridget to communicate with each other that Adam was not involved in. These factors at Adam's individual, micro-, meso-, and exosystem levels reinforced Adam's initial feelings of lack of efficacy, so he continued to defer to Emily as the expert.

Adam also felt that his wife did more of the communicating with therapists than he did. This was the result of Adam's individual reticence to ask questions for fear of appearing stupid; microsystem-level factors, related to Adam's relationships with both his wife Bridget and with Emily; and Emily and Bridget's relationship, which sits in Adam's mesosystem.

When Ryk's daughter, Eleanor, started EI services, the physical therapist would call Jane after sessions to discuss Eleanor's progress and what they did to target specific skills. Ryk felt that the physical therapist (PT) communicated mostly with Jane because they shared a common profession and jargon. The division of labor in Ryk and Jane's microsystem resulted in Jane forming a more communicative relationship with the physical therapist. Jane's relationship with the PT existed in Ryk's mesosystem. The high level of communication in this mesosystem limited the level of communication between Ryk and the PT, which ultimately served a barrier to a strong, positive microsystem consisting of Ryk and the PT. Like Jane and Bridget, many American women take on the emotional labor of communicating about their children with others and managing the logistics of their care (Hochschild, 2012).

Exo- and Macrosystem-Level Factors Contributing to Father-Provider Relationship Quality

Lack of direct communication between fathers and EI providers is consistently identified as barrier to high quality relationships (Mueller & Buckley, 2014; Melton, 2005). Many EI providers report communicating directly with mothers because they feel that mothers are more involved in daily caregiving and fathers are often not physically present during sessions (McBride et al., 2017; Melton, 2005; Turbiville, Turnbull, & Turnbull, 1995). Some fathers reported they felt that this tendency for EI therapists to direct communication primarily to mothers was a result of the gendered nature of EI services (Melton, 2005). Most EI providers are female. Mother-focused communication is a reflection and reinforcement of the macrosystem-level American cultural norm for mothers to perform the emotional labor of parenting (Hochschild, 2012). Cultural influences lie in the macrosystem level of the bioecological systems model and influence internal belief systems at the individual level of the model.

Tom and Dan each shared their feelings that gender impacted their relationships with EI providers. Tom stated that he would not have initiated relationships with the members of the IFSP team because they were all women who were younger than he is. He felt that “a man trying to initiate a relationship with your child’s therapist can be awkward, especially because they’re all twenty years younger.” Tom was concerned that the young women would feel uncomfortable with Tom’s friendliness and potentially misconstrue it as flirting. For this reason, Tom waited for the EI providers to take the lead in initiating a relationship.

Chronosystem Level Factors Contributing to Father-Provider Relationship Quality

Dan’s feelings about gender’s impact on relationships were different than Tom’s, but he also identified that relationships with the younger female therapists were different than

relationships with the older female therapists. Dan found it harder to communicate with the twenty-something occupational therapist than with Lily or Joanna who were in their late thirties and forties, respectively. The younger therapist tended to communicate less directly and to frame recommendations as “maybe you could work on...” statements or questions rather than directives like Lily and Joanna. Dan attributes this to “age and sex dynamics.” Dan reported excellent relationships with clear and direct communication with Lily and Joanna who were older and more professionally experienced than the occupational therapist. As an outside observer with experience as both a young and more seasoned EI provider, I suspect that while gendered and generational communication styles likely impacted the communication, that individual level factors within the therapists related to their own feelings of competence and confidence were also impacting communication in their microsystem relationships with Dan. The occupational therapist was not interviewed so it’s impossible to know what she was feeling or thinking. Parents who did not perceive their EI providers as emitting competence and confidence reported similar challenges in relationships to those Dan experienced (Dunst & Dempsey, 2007).

Dan admits to “conjecture” on his part, but he felt that the younger female therapists didn’t know what role he played in Felix’s daily care or in the family and assumed that Greta “is gonna be this caring mother.” While Dan identified perceived assumptions about how the speech therapists viewed gender roles in his own family, he acknowledged that as a man, he was not as friendly and relatable with the speech therapist as Greta was. Dan also feels that he can be intimidating to people due to his height, deep voice, and “pointy eyebrows” and that these individual level factors likely impacted a relationship between him and the younger, female therapists.

Factors at every level of the bioecological systems model impact the ways in which gender affected EI provider and father relationships. Cultural beliefs about the role of fathers exist in the macro- and chronosystems levels. Also at the macro- and chronosystems levels are the cultural influences on how men and women communicate with each other, generation communication patterns, and the kinds of interactions between an older man in his fifties and a young woman in her late twenties or early thirties that are perceived as appropriate. These macro- and chronosystem factors influence the individual factors of personal belief systems and communication styles in the individual. Exosystem level factors, including college coursework and Illinois EI training opportunities, both reflect and influence individual and macrosystem factors surrounding gender beliefs and practices. More research focused on gender and its impact on father-EI provider relationships is needed.

Varied Relationship Quality with the Same Early Intervention Provider

Jason and Adam worked with Emily during roughly the same time period. Jason's relationship with Emily was "side-by-side." Adam did not experience this level of partnership with Emily. Rather than being "side-by-side" with her, Adam was "marooned" in the kitchen during Emily's sessions with Soren. Factors at the individual, micro- and mesosystems levels contributed to two fathers' difference in experiences with the same EI provider.

Emily did not provide narratives of working with Adam and Jason, so all analysis is founded in the fathers' stories of their experiences with her. Based on Jason's narrative, Travis exhibited a general delay in communication with some behavioral challenges that Jason did not describe. He did state that initially, he was part of therapy sessions in case "Travis got out of sorts, we were there to intervene." Based on Jason's narrative it sounds as though the mesosystem of Emily and Travis's relationships created a need for Jason to be present for the

duration of EI sessions. During these early sessions with Travis, Emily modeled strategies for Jason and Jenni that Jason says helped them to increase Travis's attention span and organize their toys. Through microsystem interactions with Emily, Jason learned about the importance of engaging directly with Travis, a skill that he found so valuable he has carried into his interactions with his other children. Jason describes a typical session with Emily as sitting on the floor observing Emily model strategies to use when engaging with Travis, listening to Emily explain why she used each strategy. Jason also attended sessions to help with any challenging behaviors that arose during Travis's interactions with Emily. Jason was present for all or almost all of the sessions with Emily because the exosystem-level factor of his work schedule allowed for his presence at home during Emily's typical work hours.

Soren did not exhibit any challenging behaviors and adjusted to the routine of sessions with Emily quickly. Adam noted that his son, Soren, developed a trusting relationship with Emily very quickly and that "it was pretty telling that Soren enjoyed his interactions with Emily" when he maintained a distance from most women, including his own grandmother. Adam described Soren's primary developmental delay as an inability to get words out that other people could understand. Otherwise, Soren's development was typical. Adam was present for most of the initial sessions with Emily. After Soren became comfortable with Emily, she asked that Adam and Bridget step out of the room for the duration of the session with Soren. Emily and Soren's pleasant and easy-going relationship in Adam's mesosystem meant that Emily did not ask for additional assistance with Soren's behavior during sessions and thus did not ask for Adam to be present. In fact, Adam was "marooned" in another room during sessions. Adam was able to attend "maybe a quarter to a half" of speech therapy sessions due to conflicts with his work session. Adam's work schedule exists in the exosystem.

Comparing Jason and Adam's narratives, it is clear their sons had very different individual characteristics. These factors certainly impacted the children's microsystem interactions with Emily. Each of the children's microsystems with Emily sit within the fathers' mesosystems. From Adam and Jason's narratives, it appears that Soren's relationship with Emily was easy to manage one-on-one and that the therapy focused primarily on articulating words with a little work on chewing and swallowing. Emily and Soren established a therapy routine in Adam's absence because of Soren's individual characteristics and Adam's exosystem work hours. It's possible that because Adam only attended sessions occasionally the disruption in routine did create what Emily perceived as a distraction or change to how Soren behaved during interactions with Emily.

Jason described his son's developmental needs as spanning both communication and behavior. Early EI sessions with Emily established a routine in which Jason and Jenni were both present. This routine continued for the entirety of the family's involvement in EI. This routine was influenced by Travis's individual developmental needs and the exosystem-level school day schedule that allowed for Travis to be present at almost all of the speech therapy sessions.

Lastly, Jason and Adam are different people with differing personalities. It's possible that their individual personalities impacted the way they engaged with Emily which in turn impacted how Emily behaved within their microsystems. Factors at multiple levels of Jason and Adam's systems models influenced their extremely different narratives about EI experiences despite their family's shared speech therapist.

Lack of Understanding of the Early Intervention Program

Across narratives, each father shared an initial lack of understanding of EI programs and EI service delivery. In some cases, unfamiliarity with the process combined with the perception

that EI providers were all-knowing experts created situations wherein fathers often waited for an invitation to participate in EI sessions. Additionally, fathers' lack of understanding of their rights within the system, including the right to change providers or decline services, led to some less than optimal experiences. These themes were often presented together in fathers' narratives and will be examined together as they seem to be influenced by similar factors.

Individual Factors Influencing Understanding of Early Intervention Programs and Services

None of the fathers had previous personal histories with early childhood special education services or the Illinois Early Intervention Program. Each of the men had some experience related to special education which they generalized to their individual perceptions about the Illinois Early Intervention Program. Dan remembers that his brother had braces to correct a physical difference. Dan and Jason work in high school settings where special education services are governed by different parts of IDEA that require educators to focus on only academic outcomes for children rather than the family outcomes required in EI. This lack of personal history with EI at the individual level contributed to the overall lack of understanding of the process and family rights within that process.

Microsystem-Level Factors Influencing Understanding of Early Intervention Programs and Services

Parents who participate in family-centered EI service provision report higher levels of satisfaction with the program (Donaldson Elder, Self, & Christie, 2011; Melton, 2005). Tom and Sathi described family-centered interactions with providers that met the needs of their families. Tom and Sathi did not anticipate this approach to service provision, but both came to understand

their roles as collaborators in family-centered practice through microsystem level interactions with their EI providers.

Conversely, Adam had a mostly negative experience due to his individual level perceptions about EI and microsystem-level interactions with a provider that asked him to leave the room while she engaged in therapeutic interactions with Soren. Once Soren felt comfortable interacting with Emily, which Adam remembers happening quickly, Emily asked Adam and Bridget to leave the room during her sessions with Soren. Adam remembers that Emily informed him that his presence during EI sessions was distracting for Soren, so she suggested that he leave the room. Adam didn't feel comfortable with this recommendation, because he wanted to be a part of EI services but deferred to Emily as the expert. Adam appreciated that a positive relationship between Soren and Emily existed within his mesosystem, but Emily's perception of Adam as a distraction had a significant negative impact on their relationship and on Adam's own feelings of efficacy in addressing his son's language delays. Unaware that the best practice model of EI involves EI providers interacting directly with parents, Adam accepted that he wasn't "allowed" into sessions. He said:

As Soren got more comfortable with [Emily], we were sort of marooned to the other room.... I get why professionally it may not be a good idea for us to not be there to distract him.... If that's what an expert thinks is best, then I'm okay with it, if that's the best way to do it.

Adam didn't know until our first interview that family-centered practice was an option for service delivery. His lack of understanding of what the program could be left him feeling left out of the process. Adam stated that knowing what he knows now about EI, if he had the

opportunity to do it over, he thinks he would advocate to be more involved in sessions with Soren.

Exosystem Level Influencing Understanding of Early Intervention Programs and Services

Moreover, at an exosystem level, there is very little information about EI available for fathers. Some media related to older children or people with disabilities does exist. Dan cited an older movie, *Forest Gump* as his frame of reference for physical differences in young children. That movie does not portray any EI services. A current television program, *Speechless*, shows high school special education services and due process in detail. Only one television show that I am aware of offered representation of EI. *Teen Mom 2*, a reality show on the MTV network featured a young family with a daughter born with muscular dystrophy. There was one episode of the series that showed a several minute clip of home-based EI services.

The exosystem is mostly devoid of representations of EI except for a couple of television shows and some media coverage during the time fathers in this study participated in EI. In Illinois, there was a social media campaign and some state and national news coverage addressing the need to fully fund EI services during the 2015-2017 state budget impasse. This campaign may have increased awareness about the program but did not provide reference for the actual process of EI services.

Due to their lack of history with EI services and lack of representations of EI in the exosystem, none of the fathers knew what to expect when EI service providers began coming into their homes to work with their children. Generally, service coordinators, who exist in fathers' exosystems, provide information about the Illinois Early Intervention Program and inform families of their rights at initial and annual IFSP meetings. Families must sign a form

stating that the service coordinator informed them of their rights. This likely happened with each of the participants in this study as most of the fathers attended all IFSP meetings; however, only Dan and Ryk's families knew they had the rights to change therapists, decline services, or be involved in all therapy sessions. None of the fathers recalled learning about how the EI process works or learning about their rights or went into detail about the meetings. In fact, when asked about IFSP meetings, Dan said, "I forgot all about those." While none of the fathers described attending an IFSP meeting in detail, my own history participating in IFSP meetings certainly colors how I interpret findings related to this this outcome.

I participated in hundreds of IFSP meetings over nine years. During these meetings, EI professionals share their developmental assessments of children and work with families to set goals and determine therapy dosage with families. Often, service coordinators gave families written notice of their rights to sign and return to the service coordinator. It was common for mothers to sign the form while looking and listening to someone else speak about the child. The stack of paper presented to families during meetings was usually at least an inch thick.

While I was working as an EI provider, many families shared that these meetings are overwhelming. Families consistently asked for the same information I provided at the meeting again after the meetings or stated they did not remember everything that was said at meetings because of the bulk of emotionally charged information they receive during meetings.

EI service coordinators exist in fathers' exosystem level of the bioecological systems model. It is their job to explain the EI process and inform families of their rights within the EI system. Service coordinators do not regularly interact with families and in some parts of the country, carry caseloads significantly larger than is manageable (EI service coordinator, personal communication, 2017). Exosystem policies at the state level dictate that service coordinators are

responsible for sharing information about family rights and about the EI process being family centered. Most families only interact with service coordinators a few times when they schedule and attend IFSP meetings.

Understanding Early Intervention and Advocating for the Family

It is important to note that while each father's individual level of knowing his rights and advocating for his child while enrolled in EI varied, each family unit was aware that their families were entitled to EI services and accessed those services. Most of the awareness of EI programs came through microsystem-level relationships with children's primary care physicians. The action of making an initial referral to EI and accessing services for their children is a form of advocacy. In all families other than Tom's, mothers made the phone call to refer children to EI and acted as the primary contact for service coordinators and EI therapists. Although mothers made the bulk of actual phone calls, each father participated in microsystem level decision making about referring their children to EI.

Other than a general awareness of EI being available to their families, the fathers, apart from Ryk, whose wife works in the EI system, were unaware of their rights as EI participants. It is very difficult to advocate within a system you do not fully understand.

Dan, Tom, and Sathi engaged in small microsystem-level acts of advocacy for their children as a result of their interactions with EI providers. Adam and Jason did not know their rights as EI participants and did not advocate for those rights while in the EI program.

Understanding Early Intervention and Advocating at the Microsystem Level

Dan, Tom, and Sathi were empowered by their EI providers to advocate for their sons within their microsystems. Dan acted in tandem with his wife to find a doctor that could provide an appropriate diagnosis for Felix. Lily communicated her concerns to Dan and Greta about a

lack of conclusive diagnosis given by Felix's first neurologist and recommended a doctor for a second opinion. With Lily's urging and her provision of a recommendation, Dan and Greta sought out another opinion to advocate for the needs of their family. This seemingly small act of advocacy helped the family to deepen their understanding of Felix's developmental needs, access assistive technology, manage their expectations, and better plan. While Felix's Cerebral Palsy diagnosis initially added to Dan's levels and stress and frustration, ultimately, having the diagnosis has lessened Dan's stress over time.

Tom and his wife, Susan, were empowered through microsystem-level interactions with me and their other EI providers to advocate for their son by seeking a medical diagnostic exam. The resulting autism diagnosis empowered Tom to better understand some of Brandon's behaviors, especially related to eating habits and extreme reactions to bathing. Tom's individual-level understanding of why Brandon sometimes acts the way he does alleviated some of Tom's frustration related to parenting Brandon. Quantitative studies have shown that high levels of empowerment predict higher levels of parenting satisfaction in families with children with disabilities (Fox, Nordquist, Billen, & Savoca, 2015).

Tom and Susan's advocacy for Brandon continued after they transitioned from the EI system to the special education system when Brandon turned three. Tom and Susan worked together to advocate for adequate school services and classroom placement. Ultimately, Tom and Susan decided to move to another state with better state supported autism services as an act of advocacy for their son. These larger acts of advocacy happened after the family exited EI, but Tom identified obtaining Brandon's autism diagnosis during EI as an important catalyst for advocacy after Brandon turned three.

While Dan and Tom advocated for their families by accessing medical doctors, Sathi advocated for his son within Sathi's mesosystem and then later by choosing a preschool in which Arin would thrive. During the families first months in EI, Arin was not responsive to Julia, the family speech therapist. While Sathi wasn't aware that changing providers was an option, Julia approached the family at the beginning of an EI session and suggested that perhaps she was not the right fit for Arin. Sathi, Meena, and Julia had an honest conversation about Arin's response to Julia. Sathi let Julia know that Arin was very slow to warm to new people. He also suggested that Julia change the volume and tone of her voice when interacting with Arin. Sathi's positive and honest relationship with Julia as well his strong relationship with Arin were the microlevel factors that set Sathi up to advocate for Arin's needs. This seemingly small act of advocacy — communicating his son's temperament and preferred level of speech volume — made an immediate and significant impact in Arin and Julia's relationship. This conversation also informed Sathi of the family's right to change providers should they so desire.

Sathi shared another, larger act of advocacy on Arin's behalf that was influenced by his participation in EI. Prior to EI, Sathi and Meena assumed they would enroll Arin in an academic preschool as is the norm among their South Asian community. After learning more about child development and specifically Arin's developmental trajectory, Sathi and Meena decided that an academic preschool wasn't the right fit for Arin. Meena researched multiple preschool approaches to learning and preschools in their area. She and Sathi determined that Arin would thrive in one within one specific educational approach that focused on play and social emotional development in early childhood. Sathi and Meena enrolled Arin in this school. Sathi reports that Arin is thriving in play-based preschool.

Lack of Understanding of Early Intervention and Lack of Microsystem-Level Advocacy

Neither Jason nor Adam had occasion to advocate for a medical diagnosis or different method of direct engagement for their son while in EI; however, both men could have benefitted from advocating for themselves or their family units. For example, Jason's family would have benefitted from the knowledge they could change providers or decline services. Adam was not able to advocate for his desired level of participation in Soren's speech therapy sessions due to lack of knowledge of about family-centered practice and his family right to advocate for a preferred service modality.

Jason described that his interactions with the family's OT were something that he felt he had to "endure." Jason's personal history with high school special education led him to believe that the two systems were the same. Jason's experience with school-based OT services is that the OT is assigned to students by someone at the exosystem level based on location and that there is an OT shortage. This led Jason to believe that in EI, therapists were assigned the same way. Jason's "assumption was that Travis had to do [OT] in order to successfully get through EI and be exited out of the special ed services, so we just went with the recommendations and did all of it." Luckily, Jason's positive relationship and partnership with Emily mitigated the overall negative feelings created by Jason's interactions with the occupational therapist.

While Jason found his interactions with Emily to be positive, Adam's microsystem with Emily was disempowering. Adam wasn't aware of family-centered practice so he did not know that there was another option for which he could advocate, so he went along with Emily's recommendation that he not participate directly in EI sessions.

After a strong push from his wife Bridget, Adam did online research about speech and language development. During Soren's transition from EI to school-based services, he was able

to help Bridget advocate for a higher level of services for Soren than the school proposed. His and Bridget's advocacy efforts were successful. The positive outcome of Adam's newfound ability to help Bridget advocate for Soren is excellent. Adam's development in this area was indirectly influenced by his participation in EI in that it created a conflict within his microsystem with Bridget. Adam's individual investment in his marriage to Bridget and motivation to solve the conflict resulted in his learning more about Soren's development needs.

Understanding and Communicating About Children's Strengths and Developmental Needs

Each of the participants exited EI programs with varied understanding of and ability to communicate about their children's developmental needs and advocate for those needs. In my experience as an EI provider, many families with children with disabilities at the onset of their involvement in the program need some coaching to identify and internalize their child's strengths. Participation in EI builds family capacity to positively adjust to parenting a child with a disability (Hebbeler, Barton, & Mallik, 2008). Capacity building happens at fathers' individual, micro-, and mesosystem levels.

Individual Factors Associated With Understanding and Communicating About Children's Development

Every father in EI enters the program with a unique personal history and belief system about disability and child development (Bayat, 2005). Individual level factors contribute to how they process news of their children's disability, which for some parents is processed as a crisis (Walsh, 2003). Dan "fixated" on Felix's disability and focused on EI "correcting" Felix's physical delays so that "then he'll just be normal." Through interactions with Lily and Joanna, and the neurologist who diagnosed Felix's with CP, Dan came to a better understanding of what Felix's developmental trajectory would look like over the course of his life and what his gross

and fine motor developmental needs are. For example, Dan spoke about how currently, Felix is enrolled in an art class that combines his interests and addresses his fine motor needs. Through microsystem-level interactions with Felix, as well as microsystem level interactions with Lily and Joanna, Dan came to see their children's developmental trajectories more positively than at the beginning of EI. Dan considers his time in EI as "foundational" to his journey parenting Felix and learning about cerebral palsy and how it manifests in Felix.

Like Dan, Tom's son has a permanent disability that will impact his development over his lifetime. Tom maintains a positive view of autism and Brandon's autism diagnosis. When Tom started to interact with EI providers, he didn't know that Brandon's developmental delays and challenging behaviors were symptoms of autism. Tom had personal experience parenting three other children, from which he had internalized that parenting comes with many challenging and some rewarding moments. His microsystem interactions certainly caused frustration, especially on days when "nothing worked" and Brandon screamed and screamed, but Tom did find a high level of parental satisfaction in other interactions with Brandon. Tom learned about autism in the context of his interactions with his son and the family IFSP team. As a result, Tom feels that he came to an understanding of what autism is within the context of Brandon's developmental needs and how Brandon's symptoms of autism manifest. Tom is now able to communicate Brandon's strengths in pretend play and reading fluency alongside Brandon's autism-related challenges of social communication and sensory defensiveness.

Microsystem-Level Factors Associated with Understanding and Communicating About Children's Development

The capacity to understand long-term prognoses and communicate about their sons' strengths and developmental needs occurred within the context of their strong relationships with EI providers.

Not all EI provider-father relationships helped fathers to improve their understanding of and ability to communicate about their children's developmental needs. Ryk still does not understand why Eleanor was falling so frequently or how picking up marbles with her toys addressed the cause of the falling. Adam left EI feeling disempowered and not understanding the details of Soren's communication delay. Dan left almost all interactions with speech and occupational therapists unsure of what Felix's needs were and what he was supposed to do to address them. Jason maintains that he still isn't sure what the purpose of having Travis in OT was. Each of these skill gaps in understanding and ability to communicate about children's developmental needs coincides with fathers' perception of poor relationships with the EI providers who specialized in these areas of development. Contrary, the areas of development addressed by EI providers with whom fathers described having strong, supportive relationships with are the areas of development that fathers understand most. In each of the fathers' narratives, they tell stories of how their interactions with EI providers helped them to acquire this understanding. These stories are consistent with recommendations for providers to engage in coaching activities and family-centered practices (Raver & Childress, 2015).

Helping Children Make Developmental Progress

Related to understanding and communicating about children's developmental needs is the capacity to help children make developmental progress or meet developmental milestones.

Themes in this category include an overall positive rating of EI due to children's development progress and a varied level of capacity to help their children make developmental progress.

Overall Positive Ratings of Early Intervention

Each father in this study told stories that ended with their positive appraisal of EI and directly connected this positive rating to their children making developmental progress. Sathi said that he feels "grateful" that his family participated in EI. Dan said that his family "was well served by EI." Tom feels that EI "was a major help." Jason said that "the overall experience was definitely positive." Ryk said his feelings about EI were positive. Most parents connect their level of satisfaction with EI programs with their children's development progress (Murphy, 2013; Melton, 2005; Epley, Summers, & Turnbull, 2011). Father-child microsystems at this period in the family chronosystem seem to be enmeshed when it comes to evaluating outcomes. For example, Adam, who felt disempowered by EI, rated his personal experience as negative but said that was completely mitigated by Soren's developmental progress and positive communication outcomes.

Varied Levels of Capacity to Help Children Make Developmental Progress

Each of the six fathers attributed positive meaning to their experiences in EI based on their children's progress, despite varied levels of their own skill development in helping their children make developmental progress. Much like understanding and communicating about their children's developmental needs, the theme of varied levels of capacity to build coincided with the areas of specialization of the EI therapists with whom fathers had the strongest relationships.

This is most evident in the contrast between Jason and Adam's feelings of their own competence related to the skills Emily addressed with their family. Jason told a story of a positive relationship with Emily and feels competent in helping his children to learn new skills

through playing and providing an educational environment, two skills that Emily addressed explicitly with the family. Adam, who told a story of a relationship fraught with his own feelings of incompetence, exited EI without an understanding of Soren's needs or how to help him make developmental progress with his speech. For both dads, their own capacity was built or stagnated within the context of their microsystem relationships with EI providers.

Father-EI Provider Relationships are Significant Aspects of Their Narratives

The common thread woven through each fathers' EI story was their relationships with EI therapists. The importance of relationships between mothers and EI providers had been well established in research (Bruder, 2000; Trivette, Dunst, & Hamby, 2010; Bailey et al., 2006; Pandit, 2008; Murphy, 2013; Crossman, 2015). As more research about fathers emerges, the importance of EI providers cultivating strong relationships with fathers gains a stronger evidence base (Melton, 2005; Flippin & Crais, 2011). This and other research provide insight for practitioners who want to adjust their service provision to meet the needs of fathers of children with development differences.

CHAPTER SEVEN: Conclusion

The field of early childhood special education has made a significant shift in service delivery methodology since the mid-twentieth century when children with moderate to severe developmental disabilities were often placed in institutions to the current practice of coaching caregivers to incorporate learning activities into daily routines at home (Bricker, Xie, & Bohjanen, 2018). Burton Blatt's (1969) landmark study established the importance of the home environment on the development of children with disabilities and Sam Kirk, Merle Karnes, and Dorothy Sievers' work with young children with disabilities proved that with intervention, many children's developmental delays improved. Since that time, a solid evidence base and various strategies for family-centered practice and the importance of involving caregivers emerged (McCollum & Yates, 1998; McCollum, Gooler, Appl, & Yates, 2001; McWilliam, 2010; Division for Early Childhood, 2014). Much of scholarship related to family-centered practice and modern EI centers on mothers. The goal of this research was to gain a more nuanced understanding of what fathers experienced during their participation in early intervention programs and to learn from these experiences what EI providers can do to improve fathers' experiences in early intervention programs. Narratives shared by the fathers in this research demonstrated the inconsistency with which family-centered practices are applied to home-based EI services and the ways that the lack of family-centered practices impacts fathers' experiences in EI programs.

Returning the Research Question

The purpose of this study was to examine fathers' narratives of their experience in EI programs for the purpose of broadening the research base about fathers in EI with the hope of providing some practical implications for EI providers.

Through their stories, it became clear each father wanted to be active participants in the process and that the quality of their participation in the process was influenced by the ways in which early intervention providers engaged with them and their families. When EI providers invited fathers into sessions by asking them about their children, communicating honestly and directly with them about their children, and including fathers into therapeutic tasks, fathers reported their time in EI as transformative. Conversely, when fathers weren't invited into the process, told they were a distraction, or treated as passive observers, fathers recalled that participation in early intervention added additional stress to their family life and in some cases, reinforced feelings that only experts could understand and further their children's development. This research shone a light on the disconnect between what EI providers are doing and what parents, specifically fathers, need. Implications for practitioners working with fathers is discussed later in this section.

While this research provided important insight into some fathers' experiences in EI programs, more research is needed for the field to develop a nuanced understanding of how to meet the needs of fathers in EI.

Recommendations for Future Research

Most of the current research available about fathers or providers' beliefs and practices with fathers in EI exists in isolation from each other. A recommendation for future research is to complete a qualitative case study of an entire IFSP team including the parents, service coordinator and EI providers. The ability to analyze an entire case in EI will help the field to connect the dots between father and provider perceptions of EI. These connections between father and provider perceptions will help practitioners to deepen their understandings of how to best serve families in EI programs.

Implications for Practitioners

I was drawn to this research through my own desire to better serve fathers in intervention. By sharing narratives of their experiences in EI, participants in this research granted me, other EI providers, and policy makers an authentic opportunity to learn about what fathers' experience in EI. A former EI provider and current teacher of pre-service EI providers, I spent time reflecting on each individual narrative and the implications for my own practices. These include the need for self-reflection activities about the potential gaps in beliefs about the importance of father involvement in families and the actual practices we engage in as practitioners, the need to explicitly invite fathers into EI sessions due to their lack of familiarity with the EI process and family-centered practice, and a move toward more coaching activities and fewer therapist-child activities.

All EI programs require ongoing professional development. In Illinois, where I practiced, providers were required to meet with at least one other EI provider each month for ongoing professional development conversations. In my experience these conversations were typically informal and focused on specific children and families. These conversations could be an excellent opportunity for a peer discussion about what providers believe about father involvement and how their practices align or misalign with those beliefs. As shown by McBride et al.(2017), most EI providers surveyed feel that fathers are key to EI success, but their practices do not facilitate father involvement. For example, many providers who rated father involvement as important communicated solely with mothers to schedule appointments, seek information, or recommend therapeutic activities. Providers can reflect on who they communicate with and how those communications occur. For example, Adam's family, this communication often happened via email. A simple way to ensure fathers feel more included in the EI process is for providers to

ask for both parents email addresses or cell phone numbers and address all email and text communications to both parents.

One way for EI therapists to move toward more parent coaching during their EI sessions is the Routines-Based Interview, which is conducted in the first few sessions families work with therapists once they begin EI services. A standard template for this interview is included in the appendix of *Working with Families of Young Children with Special Needs* (McWilliam, 2010). In addition to the interview template, the author provides suggestions for how to talk with families about family-centered intervention during the interview process, which would help fathers in developing a clearer understanding of the EI process and their role in the process. The use of the Routines-Based Interview (McWilliam, 2010) has proven to be useful in helping EI providers to focus their interventions on family priorities and be more inclusive of parents and other caregivers during therapy sessions (Boavida, Aguiar, McWilliam & Carreira, 2016). Use of the information gathered about family caregiving routines, strengths, and concerns about their child's development often leads to more functional IFSP goals. Research in Portugal's EI program showed that IFSP goals centered around family routines and priorities led to more family-centered EI practices (Boavida et al., 2016). Implications for universities, EI training programs, professors, and trainers include incorporating more curriculum specifically addressing the needs of fathers in EI, making opportunities to plan for and practice direct communication about children's developmental needs, and establishing a grounding in the DEC (2014) recommended practices which provide a framework for authentic family-centered practice.

State level EI training programs, such as the Illinois Early Intervention Training Program (EITP) or Virginia Early Intervention Professional Development Center offer professional development training for EI providers. Recently, Bruns and LaRocco (2017) offered a set of

strategies for EI providers that “support parent’s confidence to pull up a chair” (p.38). These strategies are evidence-based and align with DEC recommended practices and proposed EI outcomes. They include employing autonomy-oriented help-giving, building respectful, productive relationships with families, supporting meaningful caregiver participation in EI sessions, creating an empowering therapeutic context, and enabling family advocacy. These topics would make excellent foci for professional development offerings, especially in a linked course or series of webinars.

Policy makers are encouraged to consider the different educational paths of EI providers and create structures for professionals entering EI from education, occupational therapy, speech therapy, and physical therapy graduate programs to learn about family-centered practices. Many higher education programs in occupational, physical, and speech therapy spend very limited time addressing the practice of EI (Campbell, Chairello, Wilcox, & Milbourne, 2009). Only one third of surveyed OT, PT, and SLPs responded that their professional education programs prepared them very well to work with infants and toddlers. Only 20% of respondents felt well prepared to work with families upon graduation. Collaboration between professional associations, EI policy makers, and higher education institutions is needed to address these gaps in curriculum.

Lastly, it would greatly benefit families and providers if higher education programs and professional development explicitly taught pre-service and practicing EI providers about adult learning theory. Many special educators in EI programs, including myself, underestimate the amount of time spent with adult caregivers as most of the curriculum in early childhood programs is focused on child development, lesson planning, and interacting with young children. The inclusion of adult learning theory would be highly beneficial for family-centered EI practices (Bruns & LaRocco, 2019; Boavida et al., 2016; Banskford et al., 2000; Trivette, Dunst,

Hamby, & O’Herin, 2009). In a small, preliminary study, researchers found that introducing concepts related to caregiving coaching during in-person professional development sessions with follow up coaching for the EI provider was particularly effective (Oborn & Johnson, 2015). After the in-person course, EI providers sent videos of themselves engaging in caregiver coaching to the facilitators. Facilitators reviewed the videos and gave EI providers written feedback via email. This process which engaged EI providers in a parallel coaching process with the caregivers they worked with was effective in increasing EI providers use of caregiver coaching during EI sessions.

Another method of providing professional development for EI providers was the implementation of a six-week online course: *Using Adult Learning Strategies to Support Caregivers during Early Intervention Visits* (Childress, 2017). Each of the nine EI providers reported increased knowledge of adult learning theory and increased implementation of four adult learning components with caregivers. These practices included reflective conversations between EI provider and caregiver, caregiver practice with EI provider feedback, joint planning, and collaborative problem solving. While more research is needed to add to an evidence base, this method of professional development is a promising practice in developing EI providers’ capacities to engage in more family-centered practices that would include more father engagement. As scholarship related to fathers of children with developmental disabilities expands, the field will benefit from a collaboration between researchers, policy-makers, pre-service educators, and practitioners to share strategies on how to ensure that the needs of all family members in EI programs are met.

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APPENDIX A: IRB Approval

DEPAUL UNIVERSITY



Office of Research Services
Institutional Review Board
1 East Jackson Boulevard
Chicago, Illinois 60604-2287
312-362-7593
Fax: 312-362-7574

Research Involving Human Subjects NOTICE OF INSTITUTIONAL REVIEW BOARD ACTION

To: Megan Murphy, ME, Graduate Student, College of Education

Date: September 26, 2018

Re: Research Protocol # MM081418EDU
"Fathers' Experiences in Early Intervention"

Please review the following important information about the review of your proposed research activity.

Review Details

This submission is an initial submission.

Your research project meets the criteria for Expedited review under 45 CFR 45 CFR 46.110 under the following categories:

"(6) Collection of data from voice, video, digital, or image recordings made for research purposes."

"(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies."

Approval Details

Your research was originally reviewed on August 30, 2018 and revisions were requested. The revisions you submitted on September 1, 2018 and September 6, 2018 were reviewed and approved on September 26, 2018.

Approval Period: September 26, 2018- September 25, 2019

Approved Consent, Parent/Guardian Permission, or Assent Materials:

- 1) Verbal informed consent script, version 9/26/2018 (attached)
 - a. Waiver of documentation of consent granted under 45 CFR 46.117 (c) 2

Other approved study documents:

- 1) Study advertisement for social media, version 9/26/2018 (attached)
- 2) Script for Pre-screening survey, version 9/26/2018 (attached)
- 3) Thank You letter and contact information, version 9/26/2018 (attached)
- 4) Phone Script for member checking, version 9/26/2018 (attached)
- 5) Email template for member checking, version 9/26/2018 (attached)

Number of approved participants: 50 Total

You should not exceed this total number of subjects without prospectively submitting an amendment to the IRB requesting an increase in subject number.

Funding Source: 1) PI self-funded (cost of Box etc.)

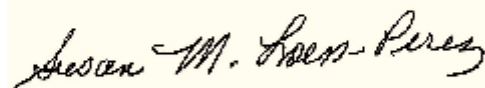
Approved Performance sites: 1) DePaul University

Reminders

- Only the most recent IRB-approved versions of consent, parent/legal guardian permission, or assent forms may be used in association with this project.
- Any changes to the funding source or funding status must be sent to the IRB as an amendment.
- Prior to implementing revisions to project materials or procedures, you must submit an amendment application detailing the changes to the IRB for review and receive notification of approval.
- You must promptly report any problems that have occurred involving research participants to the IRB in writing.
- If your project will continue beyond the approval period indicated above, you are responsible for submitting a continuing review report at least 3 weeks prior to the expiration date. The continuing review form can be downloaded from the IRB web page.
- **Once the research is completed, you must send a final closure report for the research to the IRB.**

The Board would like to thank you for your efforts and cooperation and wishes you the best of luck on your research. If you have any questions, please contact me by telephone at (312) 362-7593 or by email at sloesspe@depaul.edu.

For the Board,



Susan Loess-Perez, MS, CIP, CCRC
Director of Research Compliance
Office of Research Services

Cc: Karen Monkman, PhD, Faculty Sponsor, College of Education

APPENDIX B: Interview One Protocol

Opening: Thank you for taking the time to have an interview with me. The data collected from this first interview will help me understand the experiences that fathers have when their children receive early intervention services. Together with the data collected from your intake survey, this set of information will help formulate a manuscript that attempts to fill gaps in current scholarly literature related to the experiences of fathers. I ask you please be as descriptive as possible when responding to these questions so I may fully understand what the experience was like for you. You can opt not to answer any question or stop the interview at any time without penalty. This conversation is being audio recorded for research purposes. After the interview, the recorded conversation will be transcribed verbatim. Please let me know now if you do not agree to being recorded. Please remember, you may ask the recording to be stopped at any time. Please know that your identity and the identities of anyone you may mention will be kept confidential with the use of pseudonyms. If your child has a rare medical condition or a medical or developmental history that may be identifiable to you or them, I will omit the names of the condition and replace them with phrases like “rare medical condition,” or “complex birth and neonatal medical history” in effort to keep ensure you and your family’s privacy. There is a very small chance that your confidentiality will be breached, but we have put protections in place to prevent that from happening. This first interview focuses on you sharing your experiences participating in early intervention services with your child. If needed, a follow up interview will be scheduled so that you can continue to share the story of your full experience or I can ask follow-up questions that may arise. Are there any questions I can answer about this study or process before we begin?

Primary Question	Guides
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<p>Tell me about how your family came to refer your child to early intervention.</p>	<ul style="list-style-type: none"> • When did you first have concerns about your child's development? • What was the referral process like for you? • Who was the primary parent contact for making the referral and setting up appointments? • How did the referral process feel to you? • What were your initial thoughts about referring your child to early intervention?
<p>Once your child was referred to early intervention, what was your experience?</p>	<ul style="list-style-type: none"> • Where you physically present for the initial evaluation, IFSP team meetings, and/or therapy sessions? If not, why? • What services did your child receive? • How would you describe your relationship with the early intervention service providers (service coordinator and any therapists that worked with your family)? • What did your participation in your child's services look like? • How was information communicated to you?
<p>What outcomes did you hope for because of your participation in early intervention?</p>	<ul style="list-style-type: none"> • What outcomes were you hoping for your child? • What outcomes were you hoping for yourself? • What outcomes were you hoping for your family?

<p>What do you feel the impacts of your child's involvement were?</p>	<ul style="list-style-type: none"> • What was the impact of participation on you as a person and a father? • What was the impact for your child? • What was the impact for your family as a whole? • What was the impact for your relationship with your child?
<p>Is there anything that you wish were different about the experience?</p>	
<p>Is there anything else about your experiences in early that you would like for me to know?</p>	

Perform a check to ensure all questions were asked.

Before we conclude this interview, is there anything else you would like to add?

Closing: Thank you for spending time with me today. We've covered a lot of information. After I've had time to think about everything that we've talked about, I'm sure that I'll have some more questions. Are you open to meeting with me again to answer more questions about your experience? If the participant says no, thank them for their participation today and re-establish that they consent for this interview to be used in the study. If they say yes, thank them for participation and ask if they would like to schedule another interview time now or if they prefer to be contacted in a week or so to schedule the follow up interview. Ask if their preferred method of contact has changed.

APPENDIX C: Interview Two Protocol

Opening: Thank you for taking the time to have an interview with me. As you may recall, the data collected from this is the second and final interview will help me understand the experiences fathers have participating in early intervention services with their children. Together with the data collected from your intake and first interview, this set of information will help formulate a manuscript that attempts to fill gaps in current scholarly literature related to this phenomenon. I ask you please be as descriptive as possible I responding to these questions so I may fully understand your experiences in early intervention. You can opt not to answer any question or stop the interview at any time without penalty.

This conversation is being audio recorded for research purposes. After the interview, the recorded conversation will be transcribed verbatim. Please let me know now if you do not agree to being recorded. Please remember, you may ask the recording to be stopped at any time. Please know that your identity and the identities of anyone you may mention will be kept confidential with the use of pseudonyms. If your child has a rare medical condition or a medical or developmental history that may be identifiable to you or them, I will omit the names of the condition and replace them with phrases like “rare medical condition,” or “complex birth and neonatal medical history” in effort to keep ensure you and your family’s privacy. There is a very small chance that your confidentiality will be breached, but we have put protections in place to prevent that from happening. This second interview focuses on any details that you would like to add after our first interview and/or follow up or clarifying questions that I have about the information you shared with me in our first interview.

Are there any questions I can answer before we begin?

Primary Question
Is there anything else about your experience in with early intervention that came to mind between our first interview and today that you would like to share with me?
(Clarifying or follow up questions as needed after initial review of the transcript from the interview. All clarifying questions will relate to participant’s experience in early intervention. An example of a clarifying question would be “in the first interview you mentioned that you really liked the way your occupational therapist worked. What are some examples of things that she did that you liked?” Interview not to exceed 90 minutes.)

Perform a check to ensure all questions were asked.

Closing: Thank you for spending time with me today. Before we conclude this interview, is there anything else you would like to add?

If participant consented to member checking in informed consent: As I review our conversation, I may want to ask you just a few clarifying questions to make sure that I fully understand your experience. This will take less than 30 minutes and can be done via phone or email. Are you open to me contacting you with these kinds of questions? If yes, state their preferred contact method and confirm it has not changed. If no, thank the participant for their participation in the study.

If participant did not consent to member checking, thank the participant for their participation in the study.

Provide all participants with a written copy of the study thank you letter.