

PARENT/CAREGIVER EXPERIENCES OF RAISING A YOUNG CHILD WITH
MULTIPLE DISABILITIES

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In

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by

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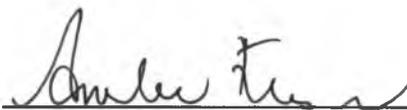
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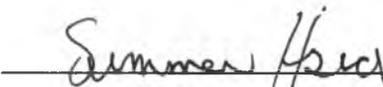
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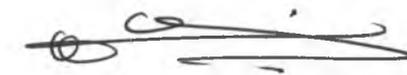
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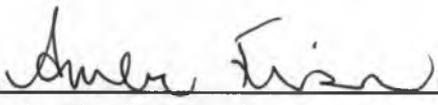
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PARENT/CAREGIVER EXPERIENCES OF RAISING A YOUNG CHILD WITH
MULTIPLE DISABILITIES

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The uniqueness of each family must be understood in order to learn from them and provide meaningful support options, which is especially important in understanding the experiences and perspectives of families who have a young child with multiple disabilities. This study sought to understand what it means to be a parent/caregiver raising a young child with multiple disabilities and the contexts that impact their experiences, including these families' transition from early intervention to preschool services. In this phenomenological inquiry, ten parents who had young children with multiple disabilities participated in a brief survey and in-depth interview that focused on understanding the participant's family and context. Findings exemplified the families' experiences in raising their young children with multiple disabilities across three categories: the impact of change, the power of individualization, and the importance of community. These findings emphasize the provision of services that are family-centered, the need for service providers to develop skills to support each family with individualized care, and the importance of establishing a form of community support that is available, accessible, and appropriate for all families raising children with multiple disabilities.

I certify that the Abstract is a correct representation of the content of this thesis



Chair, Thesis Committee

5/16/16
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For Connor

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Chapter 1: Introduction

Claire is a young child with special needs who has been identified with Down syndrome and a visual impairment. Claire is a happy and loving four year old girl who has challenges in all domains of development: motor/physical, cognitive, social/emotional, communication/language, and self-help/adaptive. She and her parents have recently immigrated to the United States from South Korea in order to better support Claire's needs. New to the country with only a basic understanding of English, Claire's family must learn how to navigate social systems relating to their daughter's and their family's needs.

In order for Claire and her family to receive adequate and appropriate support, their context must be acknowledged. When thinking about diversity amongst families, Hanson and Lynch (2013) emphasize, "just as the many variations among families must be appreciated, the very context in which families reside must be recognized" (p. 45). To be able to best support all families appropriately, the uniqueness of each family must be understood. It is especially important to understand the experiences and perspectives of families like Claire's who have a young child with multiple disabilities, in order to learn from them, provide meaningful support options, and empower them.

This chapter begins by exploring the meaning of *family* and the diversity that can be represented within different family units. Although each family is unique, a brief overview of family systems and functions will illustrate the interconnectedness of a family unit. The definition and prevalence of young children with multiple disabilities

will then be introduced along with the role of the family in raising young children with multiple disabilities. Lastly, with this basic understanding, the purpose of this study will be addressed.

Defining Family

Families are diverse in many ways, which can include a variety of people, living situations, and values, among other factors. In conceptualizing *family*, White and Klein (2008) define four features that distinguish families from other social networks: (a) families last for a longer period of time than other social groups; (b) families are intergenerational; (c) relationships between family members can be biological (i.e., siblings) and legal (i.e., marriage, adoption); (d) relationships among family members link them to a larger kinship network. While these four characteristics help us to capture the social essence and purpose of families, family membership can differ from family to family. Additionally, the definition or understanding of family can also differ depending on the culture (Friesen, Hanson, & Martin, 2015).

The composition and constellation of families continue to evolve. During the mid-twentieth century, the nuclear family was identified as traditional family form, with a husband, a wife, and two children (Holtzman, 2011). Furthermore, Christensen (1964) considered the criteria of family to consist primarily of married couples with children. Moving towards postmodern times, views of family continue to evolve in ways that are more inclusive and diverse, rather than following the homogenous “one-size-fits-all” model of a family. Holtzman (2011) has identified that heterosexual couples

postponing or forgoing marriage altogether, in addition to the progression of marriage and adoption rights for couples or partners who identify as LGBTQ has contributed to the evolution of the definition of family. Furthermore, Hanson and Lynch (2013) acknowledge divorced, blended, and foster families, as well as single-parent households and grandparents raising children as other diverse family compositions. As our individual and social conceptions of family are ever-changing, Holtzman suggests that, “these trends have ideological implications in that they contribute to changing individual- and societal-level conceptions of the family” (p. 619).

Regardless of its constellation, the complexity of the family unit can be viewed as interactive, reactive, and interdependent (Seligman & Darling, 2007). Turnbull, Summers, and Brotherson (1984) developed the Family Systems Theory to better understand the complexity of families. In considering this theory, it can be helpful to think of families as having a series of gears that are interconnected and best understood as a whole rather than separate parts. Family systems theory incorporates four main components, or gears: (a) *inputs* can consist of family characteristics, family size and constellation, family ideology, and cultural identification; (b) *process* can be characterized by family interactions, patterns and style of communication, cohesion, and adaptability; (c) *outputs* can consist of functions that families provide to their members, such as love, daily care, and socialization; (d) *change* can occur within and outside of the family unit throughout the life cycle. The gearbox as a whole depends on each individual subsystem to work together to maintain equilibrium.

The gearbox analogy of the family systems theory can be illustrated by considering Claire's family. In this family, inputs are characterized by the family structure containing a married mother and father with a child, as well as this family's strong identification with Korean culture and values. Claire's family's process is observed through their ability to work together and acceptance of their child's special needs. This family's outputs are characterized by their ability to provide love for each family member, as well as meet daily and routine health care needs. Lastly, change is illustrated by the family's move to a new country as a response to the identification of Claire's needs and challenges. Claire's family must work together to adjust to such change and maintain equilibrium.

To further understand the role of family, Hanson and Lynch (2013) provide a collective list of seven family functions that families may seek to fulfill. Families seek to provide (a) love and affection; (b) daily care and health maintenance; (c) economic support; (d) identity development; (e) socialization and guidance; (f) educational and vocational development; (g) recreation, rest, and recuperation (Hanson & Lynch, 2013). A family's ability to fulfill each function may be influenced by internal factors such as family structure (i.e., who is in the family), family interactions (i.e., their ability to communicate), or each family's place in the life cycle (Hanson & Lynch, 2013; Seligman & Darling, 2007). This is especially important in considering families raising young children with special needs. In Claire's family, her parents must have open

communication and the ability to work together in order to fulfill each family function and meet their family's needs.

Conversely, Hanson and Lynch (2013) identify external factors that may also influence families, such as changes in the economy, access to health care, and legislation. Taking a look at these functions within Claire's family, love and affection along with recreation and rest are functions that are easily met, however functions such as economic support and identity development are more challenging, given the family's recent experience of change. While there are many external and internal factors that can influence a family, each family has the ability to adjust and adapt to changes, although this may be challenging.

Young Children with Multiple Disabilities

More than 10% of people belong to families where at least one person has an identified disability (Hanson & Lynch, 2013). The World Health Organization (WHO) (2011) in conjunction with the World Bank estimated that about 5% of the world's children have a moderate to severe physical or intellectual disability. Bitsko and colleagues (2016) analyzed the most recent parent-reported data from 2011-2012 in the National Survey for Children's Health (NSCH) and found that one in seven children can be identified as having mental, behavioral, and developmental disabilities (MBDDs) in the United States. In addition, the following factors were identified to be associated with MBDDs in early childhood: (a) fair or poor parental mental health; (b) difficulty getting by on the family's income; (c) child care problems; (d) lacking a medical home (Bitsko,

et al., 2016). The prevalence of disabilities in combination with identified risk factors associated with disabilities in early childhood suggests that there are many families facing these challenges.

A family raising a young child with special needs may encounter a multiplicity of different and unique experiences when compared to a family raising a typically developing child. Hanson and Lynch (2013) describe the impact of disabilities on families presenting in a variety of ways. For example, families will plunge into new interactions with a range of professionals, parental employment and child care scenarios may depend on the support required by the child with special needs, employment status may affect a family's financial stability, and the level of need for the primary caregiver may become overwhelming. These experiences can be amplified for a family raising a young child with multiple disabilities.

For purposes of this study, the term *multiple disabilities* will be used as defined in the Individuals with Disabilities Education Improvement Act (IDEA) (2004):

Concomitant impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness.

Using this definition, children with two or more concurrent and distinct disabilities or diagnoses are identified as having *multiple disabilities*; furthermore noting that the needs

of these children are likely to be moderate to severe in nature. In regards to the nature of Claire's diagnoses, the simultaneous and unrelated occurrence of Down syndrome and a visual impairment qualifies her as a child with multiple disabilities.

For a detailed understanding of the prevalence of multiple disabilities in relation to all children with identified disabilities, the Office of Special Education Programs (OSEP) (2015) organized data reported for the 2013 Child Count for children with disabilities in each state in comparison to the United States as a whole. Throughout the nation, 1.09% of children with disabilities between the ages of three and five years were categorized under multiple disabilities. This percentage is derived from the number of children in the United States between three and five years of age who were categorized as having multiple disabilities, which was 8,135 children, compared to the total number of children with disabilities between three and five years of age, which was 745,336 children (OSEP, 2015). In comparison to the rest of the nation, California had 803 children who were identified with multiple disabilities between three and five years of age compared to a total of 76,345 children with disabilities between three and five years of age (OSEP, 2015). Thus, 1.05% of the total population of children with disabilities between three and five years of age in California has been identified with multiple disabilities.

There is an array of services and supports that children with multiple disabilities and their families may need to utilize. Appropriate services and supports may be necessary to support families and children at a very young age, during early intervention,

and as they transition to school environments, such as preschool. Special education legislation and types of supports that these families may use will be expanded on in Chapter 2.

Purpose of This Study

Although the prevalence of children with multiple disabilities is only small percentage of all children with disabilities, their needs are likely to be more intensive and require greater levels of support when compared to the rest of this population. Such unique and intensive needs can often present families with challenging situations both when the child is young and throughout the child's lifespan (Horn & Kang, 2012). Comprehending the reality of raising a young child with multiple disabilities can help in understanding how these children and their families can best be supported.

This study explores the experiences and perspectives of parents and caregivers raising young children with multiple disabilities during the transition to preschool. By sharing the stories of these parents and caregivers, the meaning and significance of the shared experience of raising a young child with multiple disabilities can begin to be understood. In addition, the meaning of these shared experiences will provide insight on how to best support the needs of these families. Using a qualitative, phenomenological research design, the shared meaning and experience of these parents and caregivers will become evident and can provide insight into the systems that empower and challenge families with children who have multiple disabilities during the transition to preschool. This study is guided by the following research questions:

1) What does it mean to be a parent/caregiver to a young child with multiple disabilities?

a) What are the experiences of a parent/caregiver raising a young child with multiple disabilities surrounding the transition from early intervention to preschool services?

b) How are the experiences of these parents/caregivers of young children with multiple disabilities shaped by their home, community, and societal context (Bronfenbrenner, 1979)?

Chapter 2: Literature Review

Families of young children with multiple disabilities often encounter unique experiences depending on the needs of their child and the types of supports and services required for their family to thrive. Further, due to the complexity of needs for children with multiple disabilities, it is likely that these challenges will extensively impact the child's development and impose long-lasting effects on the child and family throughout early childhood and beyond (Horn & Kang, 2012). Families may capably navigate having a young child with multiple disabilities, viewing it as a "shared challenge" and persevering as a more resilient family unit (Greeff & van der Walt, 2010; Hanson & Lynch, 2013). However, there may also be families who struggle obtaining information regarding their child's condition, are overwhelmed by emotional and financial stressors, face feelings of isolation, or experience difficulties obtaining services (Doubet & Ostrosky, 2015; Hanson & Lynch, 2013; Heiman & Berger, 2008; McIntyre & Phaneuf, 2007; Podvey, Hinojosa, & Koenig, 2013). The scope of these unique needs and challenges can expand beyond a child and family.

In efforts to understand the context of a young child with multiple disabilities, this chapter will begin by examining the ecological systems framework (Bronfenbrenner, 1979) and the bioecological systems framework (Bronfenbrenner & Ceci, 1994) as a basis for understanding the direct and indirect influences on a child and their family, and conversely how they influence their environment. Within these frameworks, the most direct level of influence within the ecological systems framework can be explored: the

individual, who in this case is a young child with multiple disabilities. As a young child exists not independently, but rather within a family context (Bailey, Raspa, & Fox, 2012), the importance of the family and the impact on the family in having a young child with multiple disabilities will be discussed. The role of children and families within special education service delivery will then be reviewed. Lastly, the disproportionality between the representation of and need for voices of families raising a young child with multiple disabilities in research will be examined. Gaps in research will be identified that establish a need for this study.

Ecological Systems Framework: Understanding Families in Context

Viewing the occurrence of raising a young child with multiple disabilities through the lens of the ecological systems framework (Bronfenbrenner, 1979), sociocultural systems that directly and indirectly influence and impact the development of an individual can be examined (microsystems, mesosystems, exosystems, macrosystems). Microsystems are the closest to the individual and are subject to function and interact daily, such as home and school. Mesosystems are the interactions and connections between microsystems, such as those between home and school. Exosystems are removed from, but directly influence the individual, such as the parent's workplace or the family's insurance provider. Macrosystems are the broader systems in place that influence an individual, such as special education policies and the educational system. Building on the ecological systems framework (Bronfenbrenner, 1979), the bioecological systems framework (Bronfenbrenner & Ceci, 1994) also takes

into consideration the influences that an individual's development across the lifespan and environments have on each other, this can be considered the chronosystem. The chronosystem can also include sociohistorical conditions that will influence each level of the ecological systems. Figure 1 illustrates the conceptual framework, providing examples within the different systems of influence on a family with a child who has multiple disabilities.

Discussing the appropriateness for applying the bioecological systems framework to families of children with special needs, Hanson & Lynch (2013) indicate that this framework "enables one to describe the range of influences on families and the interactions among systems over time" (p. 51). Referring back to Claire's family who was introduced in Chapter 1, the following provides an application of the bioecological systems framework: Claire is a four-year old girl with Down syndrome and a visual impairment whose family has recently migrated from South Korea to an urban city in the United States. Claire's primary microsystem is her family containing her mother and father; her characteristics (i.e., age, disability, personality) influence her family and her family members also provide their own personal characteristics (i.e., values, beliefs, abilities, knowledge) regarding Claire's disability. Other microsystems are Claire's inclusive preschool and the children's hospital that she frequents. As the child gets older, other relevant microsystems will become influential (i.e., elementary school, peer groups).

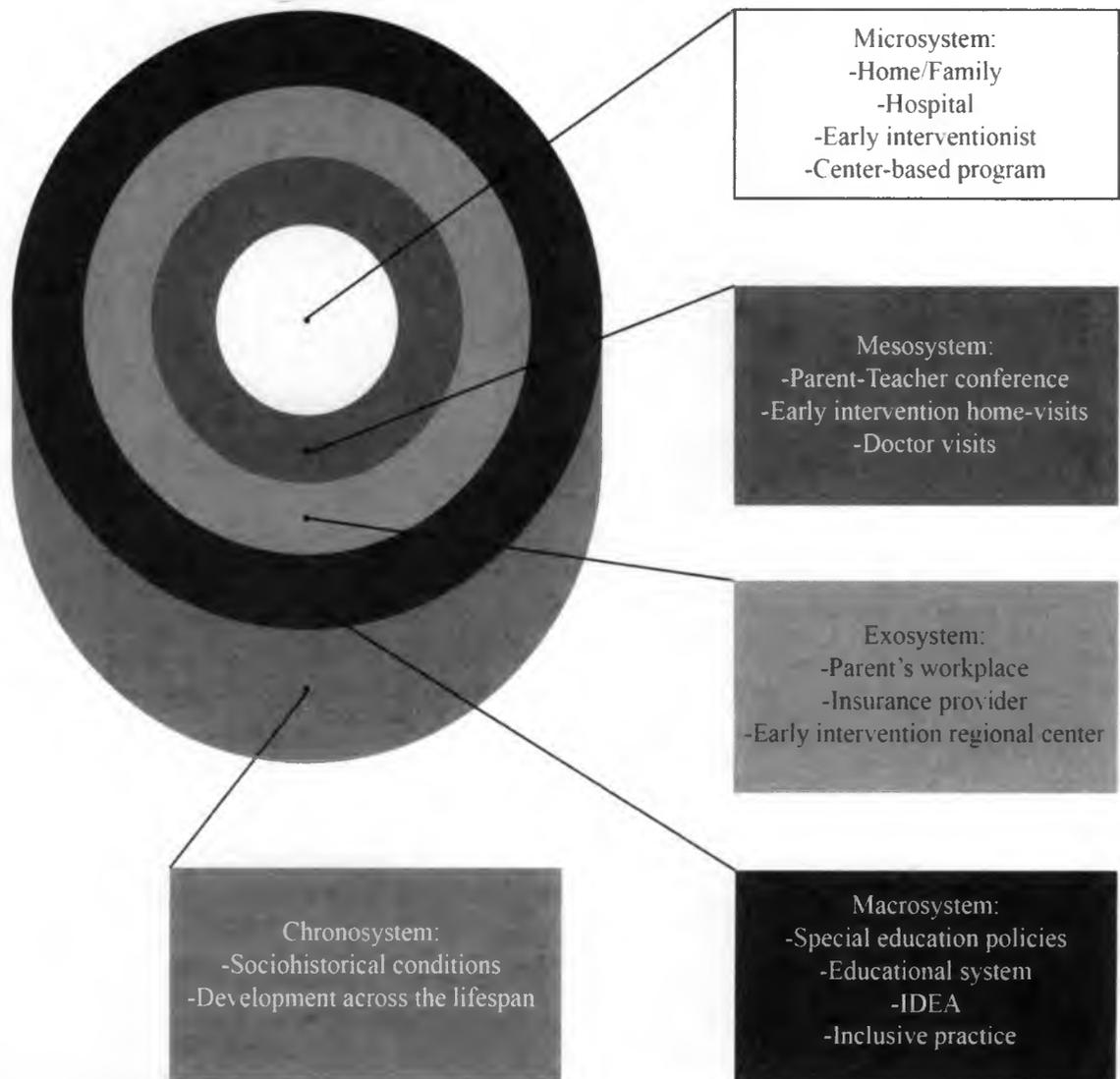


Figure 1. Examples of influences within the bioecological systems framework. This figure provides examples of various systems of influences that families may encounter when raising young children with multiple disabilities, applying each level of interaction to the bioecological systems framework (Bronfenbrenner, 1979; Bronfenbrenner & Ceci, 1994).

With Claire's microsystems in mind, the mesosystem level can be characterized by her parents' interactions between preschool, hospital, and their employers. The preschool's philosophy strongly encourages parent-teacher communication, even though a Korean translator is needed for a majority of the interactions. Claire has recently had problems with her heart that have warranted extended hospital stays. As a result, Claire's parents have had to alternate missing work in order to be with Claire and she has been missing school more frequently.

At the exosystem level, school and employment policies relating to Claire's hospitalization are applied. Claire's school attempts to correspond with her parents, but due to the language differences, this communication is fragmented and unclear. In addition, Claire's parents' employers have policies regarding inconsistent work attendance, which may impact their employment and their ability to provide for their family.

At the broader macrosystem level, Claire's family lives in a community that provides access to services low-income immigrant families and children with disabilities. The values and beliefs of these services support diversity and help to connect the family with other immediate supports within the community. Although there are broader systems in place to support Claire's family and other families facing similar issues, cultural values and beliefs differentiate depending on the population. Likewise, there are challenges and benefits at other system levels as well.

Lastly, at the level of the chronosystem, a combination of the current lack of services available for children with special needs in South Korea and the emphasis on early intervention in the United States has influenced the family's move to the United States. Claire's age during this time of transition also influences the availability and range of services provided to her, given her age and developmental challenges.

Further exploring the bioecological framework, White and Klein (2008) identify the main assumptions of the bioecological perspective as including: (a) individuals and groups are both biological and social in nature; (b) humans depend on their environment for survival; (c) humans are social in nature and depend on others; (d) human life is finite and time can be seen as a constraint and a resource; (e) interactions are spatially organized; (f) human interaction can be understood at different levels -- both at the population level and the level of the individual. These six main assumptions help to characterize and understand the types of interactions and influences occurring between each level of this framework.

With the example of Claire's bioecological system in mind, these main assumptions help to characterize the biological and social influences on the individual. Applying each component of the bioecological systems framework within the context of a young child with multiple disabilities helps to illustrate the potential impact that these systems may have on an individual and their family. With a fundamental understanding of the bioecological systems framework, an exploration of the importance

a young child's participation within the family microsystem will emphasize the importance of early learning and development.

Young Children with Multiple Disabilities and their Family Microsystem

Young children with multiple disabilities can be described as “a widely heterogeneous group in terms of their characteristics, capabilities, and learning needs” (Horn & Kang, 2012, p. 241; Jones, Jones, & Ewing, 2006), where such needs are present both in school and home environments. This influences the individual's microsystem which can directly or indirectly impact subsequent interactions between microsystems and the other systems involved: mesosystems, exosystems, and macrosystems. Khetani, Cohn, Orsmond, Law, and Coster (2013) discuss how a child's participation within their microsystem, specifically in home and community activities, provides “opportunities to acquire knowledge, skills, and relationships that are purposeful and culturally valued” (p. 234); it is through participation in these types of activities and routines that facilitates the full participation of a child with special needs within their family microsystem. For example, a responsive home environment for a child who is in the early stages of communicative development (pre-intentional) is essential in development of language and communication (Downing, 2011).

A central factor to promote inclusion in daily life has long been considered to be active family involvement (Xu & Filler, 2008). Taking a look at the physical home environment, Lewis (1987) reflects on the ability for families to reside in accessible homes, which allows for children to more wholly participate in family life and to gain

independence. As the primary context for most children is the home, families are a place where “young children learn and develop, adopting the cultural expectations of these contexts” (Friesen, Hanson, & Martin, 2015, p. 22; Hanson & Lynch, 2013). As the family microsystem directly influences the individual, the physical environment that houses the child and family can be a critical factor in determining the child’s capacity to develop and learn, maximizing the child’s ability.

Influenced by and influencing the physical home environment, the family atmosphere also plays a key role in a young child’s learning and development. In a world report on disability, WHO (2011) suggests, “the functioning of a child should be seen not in isolation but in the context of the family and the social environment (p. 36). Heiman and Berger (2008) identify family support and cohesion as central factors for positive parent–child relationships in families with a child with special needs. Relationships between caregivers and young children develop and grow through respectful, responsive, and reciprocal interactions (Gonzalez-Mena & Eyer, 2015). As humans are social creatures, infant-caregiver relationships are the first relationships a child will have; such relationships are fundamental in meeting a child’s needs and helping “the child develop new abilities that will become building blocks for the next stages of life” (Hanson & Lynch, 2013, p. 31).

Families raising a young child with special needs may vary in many ways, such as in their approach to seeking information relating to their child and their diagnosis or disability, collaborating with service providers and professionals, and supporting other

families (Bruns & Fowler, 1999). Depending on family values and ideals, other families may even remain passive throughout the process (Pang, 2008). Interestingly, Jones, Jones, and Ewing (2006) recognize when a child has a single disability or diagnosis, it is more difficult to diagnose second and third disabilities; moreover, it Jones and colleagues note that “parents and professionals often delay recognizing or accepting diagnoses of additional disabilities” (p. 128). The way families perceive relationships with professionals is often culturally defined and will influence their behaviors (Friesen, Hanson, & Martin, 2015). In raising a young child with special needs, it is important to note “each family may perceive their needs differently and thus may seek different resources” (Xu & Filler, 2008, p. 58). Just as each child is unique, each family is exceptional in their experiences and needs.

In addition, a family’s belief system may influence how families determine their priorities and use available resources (Noonan & McCormick, 2006). In referencing the experiences of families, Hanson and Lynch (2013) describe “the opportunities and options that are available to them in rearing and supporting a family member with developmental disabilities or risks is deeply embedded in the values and culture of the society within which the family resides” (p. 98). Regardless of a family’s approach or personal beliefs, however, families of children with multiple disabilities will likely be impacted by the intensity and severity of their child’s needs well beyond the early childhood years (Horn & Kang, 2008). One of the many important tasks families will face is working with the multiple service providers and obtaining services for their

child. The ability for a child to fully participate within their family and community microsystems has advanced and progressed over the past few decades, along with changes made through special education legislation.

Special Education Legislation: An Overview of Services in Early Childhood

Examining the historical evolution of the inclusion of individuals with special needs within society provides a greater understanding of the broader systems of influence a family with a young child with multiple disabilities may encounter. This may include the special education laws at the macrosystem level and special education services at the exosystem level. A growing acceptance for individuals with special needs has shaped their place and function within society.

As a result of the deinstitutionalization of individuals with special needs in the 1950s, 1960s, and 1970s (Stroman, 2003), changes in the social context in the way children with special needs are raised, socialized, and supported can be identified in the modern day role of the family and community in a young child's early learning and development. Legislation for school-aged children with disabilities to access and receive services was first passed in 1975 in the Education for All Handicapped Children Act, laying the groundwork of Individuals with Disabilities Education Act (IDEA). It was not until more than a decade later in 1986 that IDEA legislation included services for infants and toddlers with special needs, from birth to 36 months.

Six main tenets that work to support individuals with special needs and their ability to access their education are included in the IDEA legislation. These tenants

include: (a) an individual's entitlement to an individualized and appropriate education through an individualized education program (IEP); (b) free appropriate public education (FAPE); (c) least restrictive environment (LRE); (d) appropriate evaluation; (e) parent-teacher participation; (f) procedural safeguards and parent rights (IDEA, 2004). These six core ideas transcend through all parts serving individuals with special needs. This includes the legislation referred to as Part C of IDEA providing services and support for young children and their families.

There are two ways a child can qualify for early intervention services through Part C legislation. First, a child will qualify to receive services if they have a developmental delay that “demonstrates a significant difference between their current developmental abilities and the expected developmental milestones for their chronological age” (Friesen & Hsia, in press, p. 7) in one or more of the following developmental domains: cognitive, physical, communication, social-emotional, and adaptive development. The second way a child can qualify to receive early intervention services is if they are diagnosed with a physical or mental condition that can likely result in a developmental delay (IDEA, 2004); these would include conditions such as genetic disorders, hearing and/or vision impairment, severe attachment disorders, and disorders related to substance exposure, among others. With these physical or mental conditions, children become eligible for services based on the diagnosis rather than a measurable developmental delay. In some states, although it is not required, children may qualify for services if they are at-risk to

developing a temporary or permanent disability (Friesen & Hsia, in press); this may include biological or medical conditions, such as failure to thrive and low birth weight.

An importance on the early years of a child's life can be illustrated by the abundance of opportunities for growth and learning. Howard and colleagues (2013) highlight the importance of the early years of development as a pivotal time for learning and the ability to stimulate brain growth and development by nutrition, nurturance, and secure relationships with adults. Further recognizing the importance of providing early intervention services, Bitsko and colleagues (2016) suggest, "children are more likely to outgrow speech or language problems or certain developmental delays than other mental, behavioral, and developmental disabilities, particularly if they receive early intervention" (p. 223). Together, the National Research Council (NRC) and the Institute of Medicine (IOM) (2009) suggest that the identification and treatment of mental, behavioral, and developmental disabilities (MBDDs) through early childhood intervention might improve the long-term well-being for individuals with these identified disabilities, along with providing potential overall cost savings and health improvements.

For those who qualify for early intervention services, a multidisciplinary team of service providers, which can include speech therapists, occupational therapists, physical therapists, and deaf and hard of hearing specialists, will collaborate with the child's family to develop functional and meaningful goals for the child and family through an individualized family service plan (IFSP). An IFSP is a document created by the child's team that prescribes the specific development and learning supports required by the child

and family through infant and toddler early intervention services (Friesen & Hsia, in press). Provided in the IFSP, services for the child and family can occur in many places: the child's home, community, infant/toddler center, group or clinical setting. In discussing the focus on the family in early intervention services, Jung (2010) emphasizes "*how* supports are provided is just as important as *what* supports are provided" (p. 10)

Six months before a child's third birthday, a transition meeting is held to ensure that early childhood special education services and provisions that align with the child's needs are in place (Friesen & Hsia, in press; Podvey et al., 2013). On a child's third birthday, the child officially transitions out of early intervention services under Part C. They will then transition into services for school-aged children with special needs outlined in IDEA under Part B services, where services are provided for children with special needs between the ages of three- and twenty one-years old. During this transition, the IFSP designated in Part C changes into an individualized education plan (IEP) to support school-aged children, as described in Part B (IDEA, 2004).

Philosophies and service delivery models guiding Part C and Part B service systems differ greatly (Branson & Bingham, 2009; Podvey et al., 2013). While the transition to Part B services still requires some form of parental involvement, participation is focused primarily in the assessment and decision-making process of the IEP (Bailey, Raspa, & Fox, 2012). Whereas a family who has received continuous early intervention services beginning shortly after their child's birth may feel well-equipped to transition to Part B and preschool services, this may not always be the case. In some

cases, this transition process can occur shortly after families learn of their child's disability or at a time when parents/caregivers have just begun to grasp the lifelong implications of their child's diagnosis (Branson & Bingham, 2009). In the case of transitioning to Part B services, each child and family will have a unique experience due to their own exceptional developmental and ecological system contexts; each family will be coming from a different experience within the Part C atmosphere and timeframe.

It is through collaborative family and team partnerships (i.e., a child's mesosystem) that meaningful outcomes can be achieved (Horn & Kang, 2012). This is especially important to create positive and strong relationships when transitioning from early intervention services in Part C to services for school-aged children defined in Part B (Podvey et al., 2013). To support the concept of a "smooth transition," Malone and Gallagher (2008) state, "it is important for systems to consider the importance of levels of coordination and true collaboration between Part C and Part B" (p. 353). Supporting transitions means supporting the collaboration between a child's family, school, and service providers (i.e., a child's mesosystem), this can occur by focusing on and supporting the relationship between home and school. Attributes of a well-planned transition can include service continuity, reduced disruptions for the child and family, assuring child preparedness, and maintaining legal requirements throughout the transition process (Branson & Bingham, 2009).

Taking a closer look at the drastic difference between number of children receiving services under Part C and Part B, the settings that services are provided can be

unique to each child and family. OSEP (2015) provides the most recent data overview based on data reported for the IDEA 2013 Part B Child Count and Educational Environments and Part C Child Count and Settings. Interestingly, the Part C (birth through three) and Part B 619 (three through five) Data Display for California indicated that 34,759 infants and toddlers with disabilities were receiving Part C services while 76,345 children with disabilities were receiving Part B 619 services (OSEP, 2015). The number of children receiving Part B 619 services was more than twice that of the number of children receiving Part C services. With that said, more than half of the children and families receiving services under Part B 619 did not participate in Part C services that supported the child and family through family-centered practices. Rather, these children entered into the system at a point where services focus primarily on and emphasize a child's educational and academic achievements.

In discussing the central role of the family for a young child, Bailey and colleagues (2012) explain, "the essential assumption of a family-centered approach is that young children cannot be viewed apart from their families, nor can services be provided without a consideration of the family context" (p. 217). The Division of Early Childhood (DEC, 2014), a nonprofit organization that advocates on the behalf of children with special needs between birth through eight years old and their families, defines 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 choices to strengthen child, parent, and family functioning. (p. 9)

Due to the wide scope of abilities and challenges demonstrated by children with multiple disabilities, truly individualized programs require educational teams to work together to develop a meaningful curriculum for each child and their family (Horn, Lieber, Li, Sandall, & Schwartz, 2000; Jones, Jones, & Ewing, 2006). For it to be considered meaningful instruction, content must be identified as relevant to the child and family in terms of interests, goals, and limitations (Horn & Kang, 2012).

Taking into consideration the significance of family context, a family-centered approach has emerged as a recommended practice within the field of early childhood special education (DEC, 2014) and across a variety of other professional groups and associations (Bailey et al., 2012). The DEC (2014) further emphasizes family participation and involvement in the following topic areas: assessment, environment, instruction, teaming and collaboration, and transition. The presence and involvement of family facilitates the connectedness of the child to his or her ecological system, which further supports the young child's learning and development.

While IDEA (2004) procedures strive to assure a smooth transition, this time is often experienced to be difficult for children, families, and providers (Connelly, 2007). Although a family-centered approach is widely recognized as a universally recommended practice (DEC, 2014), "implementation has been a challenge due to factors

such as leadership, training, attitudes, and lack of resources” (Bailey et al., 2012, p. 217). Challenges during this time can be reflected in the experiences of families going through the transition process from Part C to Part B services.

Family Perspectives: Important and Necessary

There is an importance of understanding families’ experiences in raising a young child with multiple disabilities in order to understand their challenges and identify potential ways to support these children and families. This is especially important regarding critical transitions these families face, including the transition from Part C to Part B services. Viewing transition process from Part C to Part B services as a critical time, Podvey and colleagues (2013) identify that this process “provides the bridge between two settings in which children must function and is an important construct to study in early childhood” (p. 211). A review of three existing studies seeking the experiences and perspectives of parents of children with special needs will be examined. These following studies were selected to review because they provide insight to a variety of experiences and perspectives for parents raising children with special needs.

Podvey, Hinojosa, and Koenig (2013) explored the experiences of six families over three months during the transition from early intervention to preschool special education services, specifically focusing on services and therapists. All families in this study were middle-class, English-proficient, Caucasian individuals between the ages of 30 and 45 who were married to their child’s other natural parent and were residing in a

metropolitan area of a major northeastern city. The child of each participant either had speech and/or motor delays or was on the autism spectrum. Each participant completed seven semi-structured interviews over the course of the three-month transition period. Three themes and one overarching theme emerged from the data analysis: transition is scary, therapy is central to progress but not transition, and communication is key to comfort. The identified overarching theme was *The Outsiders*, where further elaboration provides that parents felt like outsiders in their new role after their child's transition to early childhood special education preschool services. The authors suggest that the experiences of these families during the transition process emphasized the current state of confusion surrounding the preschool transition process.

Mulla, Harrigan, Gregory, and Archbold (2013) sought parent perspectives and experiences of the process of cochlear implantation for their child with complex needs. Ten parents of children between two and eleven years of age with varying additional diagnoses and disabilities participated in semi-structured one-on-one interviews. The same general topic was covered in all interviews, but the semi-structured design allowed for freedom of interviewer and interviewee to discuss issues of interest in more detail. Four themes emerged from data analysis: assessment process, reported benefits of cochlear implantation, wearing the processor, and educational issues. Findings indicate that outcomes and benefits of cochlear implants for this group of children were able to be explored due to the facilitated discussion of the perspectives and experiences with this group of parents.

Tadema and Vlaskamp (2010) examined the time and effort in taking care of children with profound intellectual and multiple disabilities (PIMD) by distributing a questionnaire to 133 Dutch families of children with PIMD. The questionnaire collected information pertaining to caring tasks, the level of parent burden in caring for their child, and the level of support parents received. Findings concluded that meeting the basic needs of a child with PIMD is highly intensive and support helps to alleviate burdens and stresses of caring for a child with PIMD. Gaining the perspective of the parents helped to identify that support services available need to be optimized and improved in order to fully support this population of children and families.

These three studies provide important insights to parent perspectives and experiences; however, two of these studies (Mulla et al., 2013; Tadema & Vlaskamp, 2010) focus on issues that do not relate to the transition between Part C and Part B services. The third study (Podvey et al., 2013) captures the experiences of a homogenous group of parents, specifically revolving around experiences in the shift of their roles from family-centered to child-centered programs and services. Emphasizing the importance of the preschool transition process as a whole, researchers have identified that there has been little research on this topic (Connelly, 2007; Malone & Gallagher, 2008).

In addition to acknowledging the lack of research on this topic, voices of parents/caregivers of children with severe disabilities have not been well-represented in early intervention literature (Salisbury & Copeland, 2013). It is imperative to understand the ways these parents, families, and children can experience this transition to preschool

services in order to assess the cohesion of these two parts under the same law. This understanding will assist in identifying what is working within the system and what could be improved upon to maximize this experience for everyone involved.

Summary

In summary, this review of research examines ways that a young child with multiple disabilities and their family influence and are influenced by their environment and their context. An understanding of special education laws and service systems relating to young children with special needs identifies the complexities and potential challenges of navigating these systems and services. Further examination identifies attributes of these families and challenges that they may encounter throughout their journey of raising a young child with multiple disabilities. Existing research illustrates the experiences and perspectives of parents raising children with special needs, however the voices of parents and caregivers raising young children with severe disabilities must be acknowledged and better represented.

The importance of understanding the meaning of the experiences of parents and caregivers of young children with multiple disabilities is fundamental to informing practice that supports every child and family appropriately and sufficiently. The emphasis on parent perspectives and experiences surrounding the preschool transition process in this study will allow for a unique understanding of the strengths and challenges of these families while navigating the transition process. This study will provide insight to the shared meaning of parent and caregiver experiences in raising a young child with

multiple disabilities and ways that these families could be better supported will be identified.

Chapter 3: Methodology

Methodological Approach

The purpose of this study was to take a closer look at what it means to be a parent/caregiver raising a young child with multiple disabilities. This study considers parent/caregiver experiences surrounding their child's transition from early intervention to preschool services. In addition, how the experiences of these parents/caregivers are shaped by their home, community, and society is examined. Through a qualitative, phenomenological inquiry, the shared meaning of these parents/caregivers is explored.

Phenomenological inquiry seeks to describe “the common meaning for several individuals of their lived experiences” (Creswell, 2012, p. 76). In describing the shared meaning surrounding a phenomenon, what participants experienced and how they experienced it are explored (Moustakas, 1994). Although each individual has a unique experience, phenomenology seeks to identify a common meaning that is shared among individuals (Plano Clark & Creswell, 2010).

Due to the heterogeneous nature of individuals with multiple disabilities and their families, experiences “may share some attributes, but they possess their own uniqueness as well” (Horn & Kang, 2012, p. 243). The purpose of this phenomenological inquiry is to find common ground among individuality and exceptionality amongst the parents/caregivers in this sample. Upon collecting data from each individual in regards to their unique experience, significant statements surrounding the phenomenon can be identified through data analysis (Plano Clark & Creswell, 2010); this analysis will yield

emerging themes and a description of the essence of the phenomenon. Using this type of narrative process, further exploration of these shared experiences will help in beginning to grasp the nature of the phenomenon occurring (van Manen, 1997).

Participants

For this study, I sought participants who were parents or caregivers of a child between the ages of three- to five-years old who was diagnosed with multiple disabilities. As described in Chapter 1, the term *multiple disabilities* was defined as:

Concomitant impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.), the combination of which causes such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness. (IDEA, 2004)

Snowball sampling was initially used to locate family members or caregivers for this study (Plano Clark & Creswell, 2010). With each participant, guidance was requested as to who they knew that fit the inclusion criteria that may want to take part in the study and they were given a recruitment letter to share. However, participants repeatedly disclosed that they did not know any other individuals willing to participate who fit the criteria.

As a result, the recruitment strategy was adapted in order to find families who met the inclusion criteria. Using convenience sampling, family members and caregivers were recruited through faculty, colleagues, and community members and selected because they

were available, convenient, and met inclusion criteria (Gay, Mills, & Airasian, 2012). Specifically, two participants were recruited through a university faculty member, two participants were recruited through a community support organization, and the remaining six participants were recruited through colleagues.

In total, ten different family members/caregivers participated in this study. All of the participants were women between the ages of 25 and 45 and were biological mothers of a child with multiple disabilities between the ages of three to five. The family members resided in urban, suburban, and rural regions in the northern part of a state, and were diverse in the level of education they had attained (high school graduates to doctoral candidates). A variety of family constellations were represented among participants: seven mothers were married to or in a domestic partnership with the child's biological father, one mother was remarried, and there were two single mothers. Some of the families also had older or younger children as well as the child with multiple disabilities. Four participants indicated that languages other than English were used regularly in the home (Tagalog, Hungarian, Chinese, American Sign Language, and Korean). Participant demographic information has been organized in Table 1.

Participant	Age Range	Ethnicity	Location	Education	Marital Status	Occupation
Sierra	25-35	Korean	Urban	Graduate	Married	Student
Sloan	25-35	Caucasian	Urban	Doctoral	Married	Student
Tessa	25-35	Caucasian	Suburban	Some college	Married	Stay-at-home mom
Ramona	35-45	Hispanic/ Native American	Urban	Some college	Single	Student
Eloise	35-45	Hungarian	Rural	Masters	Married	Stay-at-home mom
Kat	25-35	Filipino	Suburban	Bachelors	Married	Student
Kelly	35-45	Caucasian	Rural	Bachelors	Married	Self-employed
Fiona	35-45	Caucasian	Suburban	Some college	Remarried	Student
Camille	35-45	Chinese	Suburban	Masters	Domestic Partnership	Property manager/ Broker
Iris	35-45	African-American	Urban	High school diploma	Single	Security officer

Table 1. Participant demographic information.

A variety of diversity was represented within the parents'/caregivers' children who were diagnosed with multiple disabilities. The children had challenges across different developmental domains (sensory/motor, cognitive, communication/language, social-emotional, and self-help/adaptive). Specifically, three children had challenges in three domains, three children had challenges in four domains, and four children had challenges in all five domains. Children received a range of services to support their development, including speech therapy, occupational therapy (OT), physical therapy (PT), applied behavior analysis (ABA), adaptive physical education (APE), deaf and hard of hearing services (DHH), visual impairment services (VI), feeding therapy, counseling services, and social skill groups. These services were administered through a variety of agencies and funding sources: local school districts, local children's hospitals, regional centers, California Children's Services (CCS), In-Home Supportive Services (IHSS), and private insurance. One child attended a private for-profit preschool, while the remaining nine children attended public preschools. Table 2 provides an overview of developmental domains affected by the challenges of each participant's child.

Participant	Sensory Motor	Cognitive	Communication Language	Social Emotional	Self-help Adaptive
Sierra	✓	✓	✓		✓
Sloan	✓	✓	✓		✓
Tessa	✓		✓		✓
Ramona	✓	✓	✓	✓	✓
Eloise	✓		✓	✓	✓
Kat	✓		✓	✓	
Kelly	✓	✓	✓	✓	✓
Fiona		✓	✓	✓	
Camille	✓	✓	✓	✓	✓
Iris	✓	✓	✓	✓	✓

Table 2. Developmental domains affected by child's multiple disabilities.

Researcher's Perspective

After graduating with a Bachelor of Arts in Human Development from Sonoma State University and a minor in early childhood education, I began a master's program in marriage and family counseling at California State University of Long Beach; I completed the first year of this program before having a change of heart and deciding to pursue a career in special education. I am currently in my final semester of the Master of Arts of Special Education program with an emphasis in early childhood at San Francisco State University.

My past experiences working with individuals with disabilities, include one year as a teaching assistant/intern at an elementary school, one year and a half as a special

education paraeducator for a child with multiple disabilities in an elementary school, two years working as a behavior therapist for children with autism spectrum disorders (ASD) and other behavior-related challenges who are between the ages of two- to eight-years old, and one year working as a co-teacher in an inclusive toddler classroom.

The primary research question proposed in this thesis relates specifically to my experiences as a special education paraeducator in working with a child with multiple disabilities. When I started working with this child, he had limited means of communication and extreme behaviors. With persistence and perseverance, I worked tirelessly with this child as he established effective communication skills, friendships, and a newfound confidence. Through it all, this child taught me far more than I could have ever taught him. While unfortunately this case took a turn for the worst and abuse had to be reported in the home, this experience ignited my passion for working with this population.

In contemplating what could have been done differently for this family and the countless other families raising a young child with special needs, it became clear that the voices of parents/caregivers for children with severe disabilities have not been well represented (Salisbury & Copeland, 2013), especially during times of transition (Connelly, 2007; Malone & Gallagher, 2008). The current study provided an opportunity to begin to understand the perspectives and experiences of parents/caregivers raising a young child with multiple disabilities by hearing their stories.

Instruments

In undertaking this phenomenological inquiry, two data collection instruments were used: a brief survey and a semi-structured interview. These instruments focused on personal and family experiences, in addition to a variety of social factors that may influence the child and family.

The first tool was a brief survey that allowed parents/caregivers to provide demographic and family information. A two-page survey consisted of questions relating to parent/caregiver and family demographics (sex, age, ethnicity, language, level of education, marital status, and occupation), family constellation. Further information relating to the child's diagnoses and services (diagnoses and age at the time of each diagnosis, developmental domains affected by diagnoses), in addition to services received by child and family was also gathered on this survey. A copy of the survey is provided in Appendix A.

The second tool was a semi-structured interview that allowed for an exploration of the parent/caregiver experiences in raising a young child with multiple disabilities, focusing on the transition between early intervention and preschool services. The purpose of the interview component was to allow parents/caregivers to express their experiences in raising a young child with multiple disabilities, especially surrounding the time of transition from early intervention to preschool services. The first section of the interview contained questions relating to learning about the parent/caregiver, child, and family in terms of family dynamics, relationships, and attitudes. The second section of

the interview explores social influences and can be dissected into three subsections: IFSP services, IEP services, and supports. The final question asks participants to reflect on their own experiences of raising a young child with multiple disabilities in defining what it means to them to be a parent/caregiver to a young child with multiple disabilities. A sample of open-ended interview questions used to guide each interview is provided in Appendix B.

Pilot

Piloting was used to test and refine these data collection instruments (Yin, 2015). Maxwell (2013) suggests that the importance of piloting a study is to “develop an understanding of the concepts and theories held” by the participants (p. 67). The brief survey and interview were piloted in the beginning of December 2015 with a parent who had a young child with multiple disabilities and who was also a student in an early childhood special education master’s and credential program. This parent and colleague was able to provide thoughtful and critical feedback on both instruments used, and revisions were made based on this participant’s feedback and suggestions (Yin, 2015). Specifically, a clear focus to the interview was created by focusing on the the transition between early intervention and school-aged services.

Procedures

Interviews with the family members occurred between the beginning of February and the beginning of April. I worked with each participant to determine a time and place

of their choosing to meet, taking up to five minutes for coordination. Meetings took place either at a coffee shop convenient to the participant or in the participant's home.

Upon meeting, we went through the informed consent and I answered any questions that arose, this took up to five minutes to complete. Next, I distributed the brief survey to the participant, which took no longer than five minutes to complete. After completion of the brief survey, I began the semi-structured interview starting with open-ended questions and collecting data accordingly. Each interview was tape recorded and spanned between forty to one hundred ten minutes in length.

Concluding our meeting, each participant was offered a selection of two children's board books as a small token of appreciation for sharing their experiences. Each participant was open to sharing their experiences and was assured anonymity in responses. Upon completion of the interview, participants were asked to share the parent/caregiver recruitment letter with other individuals who could qualify as potential participants.

After each meeting was completed, I transcribed each interview verbatim. In addition to transcribing interviews after each meeting, I took notes on my observations and experiences during each interview and during the transcribing process after each interview. Within one to five days of the interview, I emailed each participant the transcribed interview through a shared document, giving them the opportunity to add, change, or delete any responses they had shared. Although given the opportunity, none of the participants opted to make revisions to their transcribed interview. The process of

member checking the data with each family member/caregiver was important in ensuring that the experiences and perspectives they wanted to share were accurately collected (Gay, Mills, & Airasian, 2012; Yin, 2015). Although given the opportunity to make revisions, all participants left the transcribed interview as is.

Data Analysis

In conducting phenomenological research, Creswell (2012, p. 61) identifies data analysis as a five step process: (a) significant statements are highlighted that provide understanding for how the phenomenon was experienced, this is called *horizontalization*; (b) *clusters of meaning* are themes developed from the highlighted significant statements; (c) the *textural description* is then developed from the significant statements and themes to describe what the participants experienced; (d) the *structural description* also uses the significant statements and themes to describe the context in which the participants experienced the phenomenon; and (e) the structural and textural descriptions are then used to describe the *essence* of the phenomenon. Creswell's (2012) data analysis procedures were used in this phenomenological research.

To begin data analysis, horizontalization was used once the individual interviews were transcribed and member checked by the family member/caregiver. Using both a Word document and then NVivo, a qualitative data analysis application, significant statements within the interviews were highlighted that provide understanding for how the phenomenon was experienced for each participant. This process is iterative, in that it was repetitive or recursive, looping back and forth (Marshall & Rossman, 2016; Rossman &

Rallis, 2012). Specifically looking to explore the experience of raising a young child with multiple disabilities during the preschool transition, this ongoing, recursive process helped to understand the shared meaning of these parents/caregivers. Throughout this process, I reflected on my observations, notes, and began to develop clusters of meaning from the significant statements into themes.

Using the significant statements, clusters of meaning were formed and then developed into themes. At this point, two individuals with expertise in early childhood special education reviewed 30% of the data and noted the themes that they individually identified. I met with both of these individuals to discuss their findings and used their input to strengthen and revise themes, further contributing to the iterative process within this research (Rossman & Rallis, 2012). An example of a theme that was strengthened through these meetings was the Power of Individualization and the identification of positives and challenges associated with this theme. Resulting themes are organized in Table 3 and will be expanded on in Chapter 4.

Continuing to Creswell's (2012) third data analysis procedure, conceptualized themes identified from the clusters of meaning were then connected with the data from other participants to provide a textural description of what the participants experienced. The structural description was also developed from the significant statements and themes to describe the home, community, and societal contexts in which the participants experienced the phenomenon. The textural and structural descriptions

provided meaning to support the initial research questions and describe the essence of the phenomenon experienced by the participants.

Throughout this qualitative study, trustworthiness was established “by addressing the credibility, transferability, dependability, and confirmability of the data and findings” (Gay, Mills, & Airasian, 2012, p. 375). The following approaches were taken in order to establish trustworthiness: member checking, ongoing analysis, multiple forms of analysis, and outside review of the data (Yin, 2015). This included ensuring a diverse sample of participants were included to share their experiences and perspectives. Each interview spanned a substantial amount of time (averaging 75 minutes) to provide the space for in-depth information to be shared. Member checking was conducted to ensure the participants felt their experiences and perspectives were accurately portrayed. Multiple forms of ongoing analysis were used to identify significant statements and develop them into themes. As an outside review of data, input from two other early childhood special education professionals strengthened and refined the emerging themes. Each of these approaches contributed to the trustworthiness of this study.

		Participants									
		Sierra	Sloan	Tessa	Ramona	Eloise	Kat	Kelly	Fiona	Camille	Iris
Themes	1. Impact of Change										
	(a) The impact of having a child with multiple disabilities	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(b) The impact of relocation for services and supports	✓	✓		✓	✓	✓	✓	✓		
	(c) The impact of a change in services and supports	✓	✓	✓	✓	✓			✓	✓	✓
	2. Power of Individualization										
	(a) Positive experiences of individualization	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(b) Feeling lost in the system	✓	✓		✓	✓	✓	✓	✓	✓	✓
	3. Importance of Community										
	(a) Immediate support system	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	(b) Desire for community with shared experiences and knowledge	✓	✓	✓		✓	✓	✓	✓	✓	

Table 3. Themes.

Chapter 4: Results

This study sought to explore what it means to be a parent raising a young child with multiple disabilities during the transition from early intervention to preschool-based services. By interviewing parents, insights into how home, community, and societal contexts shaped the experiences of these families were also examined. Through the lens of the bioecological systems framework (Bronfenbrenner, 1979; Bronfenbrenner & Ceci, 1994), these contexts were considered in terms of the child and family's interactions with their home and school environments (microsystems), between home and school (mesosystem), service agencies and organizations (exosystem), special education policies and cultural values (macrosystem), and development across the lifespan and sociohistorical contexts (chronosystem).

Three overarching categories emerged through the data analysis that relate to the research questions guiding this study, which include: the impact of change, the power of individualization, and the importance of community. Within each category, important themes emerged that are represented across the interviews (see Table 3). These findings, detailed below, provide insight into the experiences and context of parents/caregivers raising young children with multiple disabilities as they enter preschool settings.

Impact of Change

Change within a family is inevitable. For families with children who have multiple disabilities, dealing with changes can be more complex given the supports and services needed for their child. Family members discussed three key times of change that

had a major impact on their family units. These include: (a) the impact of having a young child with multiple disabilities; (b) the impact of relocation for services and supports, and; (c) the impact of a change in services and supports.

The impact of having a young child with multiple disabilities. While having a child will likely influence all family units and the interactions within it (microsystem), the impact of such a change when the child has multiple disabilities is unique. Family members detailed both positive experiences that occurred within this change as well as some of the challenges unique to these participants in raising a young child with multiple disabilities.

Five participants identified the presence of having a young child with multiple disabilities as a change within their family unit that strengthened relationships and interactions. For example, in reflecting about her daughter Bea, Sloan stated that she is “a go-go-go person and my husband is a laidback person. Bea has really slowed me down and that has helped my relationship with my husband.” She also shared that the presence of her daughter had increased communication with Sloan’s extended family as they will call to check in to see how Bea and the rest of the family is doing. Kat stated that welcoming her daughter Leona into her family had brought her and her husband closer, stating, “It’s teamwork for us.” Ramona identified that having Benji in her family has “definitely kept us together.” Although she initially thought that Benji would cause division within her family, she recognized that Benji “ends up being more like a magnet because all of a sudden the kids have this connection with him, they want to be with me

because of Benji.” Lastly, Eloise was able to distinguish that the presence of Maximus made them “complete as a family.”

The interviews also gave voice to the challenges that eight of the family members had experienced within their families in having their child with multiple disabilities. For example, Fiona and her family strongly identified with their faith and found community within their church family (mesosystem). However, the family was no longer welcome at their local church due to her son’s behavioral challenges. As a result, the rest of the family was unable to attend church services given that they could no longer bring him and could not find another option for childcare for Theo. Iris shared how after learning of her son’s diagnoses during her pregnancy and the challenges Jonas would face, Jonas’ father no longer wanted to be present in his life. Iris recalled, “I had no one. His dad isn’t in his life because he felt like he didn’t want a child with disabilities or anything like that. So in the beginning I was really going through it.”

The impact of relocation for services and supports. Seven of the families in this study were significantly impacted by the change of moving, including both international relocation or moving to a different community within the same state. In addition to the stress that comes with moving for many people, there was the complexity of building supports and services for their child with multiple disabilities within their new community. While the impact of change experienced by moving was primarily associated with positive factors for the families, it also created a unique challenge for one family in particular.

In the case of two families, moving internationally required the families to adjust and learn how to navigate a different set of cultural values and beliefs. For example, Sierra and her husband moved to the United States from South Korea and subsequently started their family. Their second child, Jasper, received multiple diagnoses within his first year. Reflecting on their choice to stay in the United States, Sierra detailed the drastic differences between the availability of services (mesosystem and exosystem) and emphasis on child early development (macrosystem and chronosystem) in the United States, when compared to the lack of services and underemphasis of early development in South Korea. Commenting on the importance of early intervention and special education services for her family, Sierra expressed that, “I didn’t want to lose the services [for Jasper]. The services are supporting him and without it I don’t want to imagine what is going to happen to him.” Similarly, Kat and her family moved internationally, in this case coming to the United States from the Philippines. For this family, a primary decision in making the move and leaving family was in order to access services for their daughter, Leona. Kat elaborated on her and her husband’s decision:

I went to the Philippines in 2012 to study nursing and brought [Leona] with me because she was going to have a nanny there and my mom was there and there would be more support. When we got her diagnosis a year later when we left, we decided that we wouldn’t go back to the Philippines anymore, so nursing school had to be stopped. I had to redo all of the prerequisites and all of that. But it was

a better decision for Leona because she has a lot more support here [in the United States] in terms of school, ABA, speech, and all of that.

Just as these two families found hope in relocating to a different country, moving locally can also reflect a positive change for a family. For example, Kelly's family was initially located in a large city during the first few years of Darwin's life and Kelly found that it was "harder to find a community of special needs folks." After Kelly and her husband moved to a rural town for a lifestyle change, she identified that they now "have a community that is more understanding and accepting. The community is smaller and welcoming."

Not all relocation experiences have been easy on these families. For example, Eloise and her family were originally from a European country and relocated to the United States for her husband's employment. It was not until they moved across the state for another employment opportunity that they experienced difficulties with their son's services and individualized educational program (IEP). Reflecting on her challenges, Eloise explained her frustrations with reestablishing services after moving (mesosystem) and working with her local school district's department of special education (exosystem):

[Before we moved], the services went so smoothly. When we moved here, I thought I would just hand in our IEP and everything would be the same as where we left it. No way. The transition from IFSP to IEP was so smooth [in our old school district], that I would never imagine there would be such a fuss with moving within [the same state], it's not even another state and its so different.

The impact of a change in services and supports. The third area detailed by the families that reflected a significant time of change related to times where services or supports for this child with multiple disabilities changed. Primarily, this related to the transition from early intervention (Part C) to school-based services (Part B). As this transition brings many changes to children and their families (i.e., different diagnostic criteria, different service providers, different type of setting for services), a range of experiences were described by the participants. Families experienced a drastic difference after transitioning from early intervention to preschool services, such as not feeling prepared, having to seek services outside of the school district, and having challenges working with their school districts.

Eight out of the ten participants had experienced the transition process that occurs when a child turns three in which they leave early intervention services legislated under Part C of IDEA (2004) and begin services within a preschool setting as dictated by Part B of the same law. The two participants whose children did not experience this transition were Kelly and Kat. Kelly's son Darwin was medically fragile during his first three years, so he was not able to participate in early intervention services. Kat and her family were living in the Philippines during Leona's first three years, and there was no early intervention service system available to Leona in the Philippines at this time.

The preparation for this transition of services and supports was often stressful. Coming from effective early intervention services, Eloise felt unprepared and

uneasy during the time leading up to and after Maximus' transition to preschool services. She reflected:

I'm not sure I had enough information about how it's going to look like after he turns three. I always knew that early intervention is up to three years, they are letting our hands go after that and there is a transition and they really liked to prepare us for this time. I couldn't really see further than saying goodbye at three years old and there's going to be something else. We just went through this whole procedure. I don't know if I had enough information.

Citing an abrupt transition process similar to Eloise's experience, Tessa recalls, "[The transition] was pretty smooth, but it is kind of a shock because when he turns three and then there is no grace period, that's it."

During the transition process to preschool services, Camille and her family experienced challenges learning how to navigate and receive services (mesosystem) through the school district (exosystem). Much of her family's challenges were experienced in attempting to obtain services that she felt were appropriate for supporting Aurora in accessing her education. Camille described her challenges:

We had a dispute with the school district. What they offered to us, I didn't really like the program for kids like her, they did not offer basically anything. I did not end up getting any services, we had to fight for everything, she didn't get anything, she didn't get a para, she didn't get a bus, she didn't get anything. She

cannot move. I understand they will not give you anything to begin with, but not nothing for kids like her. That was not a fun process.

Adjusting to the different ways that services and supports are delivered with many preschool settings was also a change for some families. For example, after transitioning to preschool services, Ramona felt lost and frustrated that she was not in direct contact with Benji's preschool teachers and service providers as she had been during the home visits the family had received previously. Ramona expressed her frustrations:

He gets three hours [of services] a day and that's it. Before, he was in school for three or four hours and having two different therapists coming to the house one hour each two days out of the week. And they were also teaching me, they would be giving me little lessons on top of that. And now everything is done at school, so I miss the lesson. I would say that would be the biggest downfall.

For Sloan and her family, they realized that the primary goal of Bea's services in preschool was to facilitate her participation in this setting. In turn, Sloan decided to look elsewhere for more therapies that will help Bea outside of school. She explained:

To get those services in school, we're doing them in school because we want her to be able to sit and participate in school. Before, it was about Bea just developing and now it's developing for the classroom. It's not as great, which is why we're going to be doing physical therapy outside of school, we already do swim, we already do horseback riding, and we do those types of things, but we haven't pushed for a lot of other physical therapy because we've had it in early

intervention and we've had it in school, but it's so only focused on direct school that we have to do more outside. We didn't have to do outside before [during early intervention], we were doing it on our own with them and we were doing swim and all of these things, but now we really have to do a lot more focused therapies outside.

Power of Individualization

In exploring the experiences of parents during their child's transition to preschool services and the contexts that shaped this, it became clear that their experiences were influenced by interactions with teachers, service providers, and administrators (mesosystem and exosystem). Each participant identified at least one teacher or service provider during the preschool transition process who maximized or made a difference in their overall experience by providing individualized support in their interactions with these children and their families. However, eight parents also identified times when they did not experience individualized support, instead they identified feeling lost in the system. Some of these experiences occurred during early intervention services, while other experiences occurred later on during preschool years. Both of these types of experiences are detailed below.

Positive experiences of individualization. Each family member identified specific individuals who took an individualized approach to working with their family and child, either through early intervention, preschool services, supervisors, or community support groups (mesosystem and exosystem). In the case of Iris, she even

detailed feeling supported in her prenatal care, she recalled, “The doctors and social workers were really good and really nice, helping me out with paperwork and directing me in the right directions to show me what I should be doing to get what he needs.”

Within early intervention services (birth to age 3), six participants identified ways that individual service providers individualized their practice to include and support the parent. For example, Tessa remembered the importance of her son’s early interventionist and how influential she was to Tessa’s understanding of early intervention services:

She explained to us that they are professionals, but they are only here an hour or two a week, so as parents we have to realize that it’s up to us and they are here to help our child, but they are also here to teach us to do what they are doing. She made it clear and explained that to us. Whereas the speech therapist never said anything like that, the occupational therapist never said anything like that, you kind of catch on eventually, but that’s a lot of wasted time before you realize it.

Further emphasizing the support that she received from this particular early interventionist, Tessa remembered, “She was good at incorporating things that I have here so I can try using things in a different way than I would think, so that was helpful.”

For Eloise and her family, after they relocated to the United States, she had few connections with people near her. Eloise’s interaction with Maximus’ early interventionist during the weekly home visits was one of the few regular interactions she had with an adult at that time. Emphasizing the significant role that Maximus’ early interventionist played in Eloise’s experience, she remembered:

When she came once a week, it was a festive time for me. I really liked her, we could even chat about other stuff. It was a really good relationship between us and for quite a while I really didn't have too many relationships here. So it was there for me to have connection with the world.

Ramona shared a similar experience of a service provider giving individualized attention to her family during a challenging time as they relocated to a homeless shelter due to a domestic violence situation. For Ramona, it was important during this time for her to have an individual who could provide not only speech therapy for her son, but could also show support for Ramona and her family during this difficult time:

One woman particularly, she stayed with us for about eight months before we went to the homeless shelter and I was so sad. We left and she was still calling me saying that she could still see us there in [the homeless shelter]. She followed us to the homeless shelter and came every week. She would come see us while we were living in the shelter, we would go to the park and do our little things there. It made me feel so good because it was like I had left everybody and everything behind so she was sacred, she's the little angel who stayed with us and followed us.

When it was time to transition out of early intervention services, Ramona and Kat used technology to stay in touch with influential early interventionists and service providers. The speech therapist who supported Ramona before, during, and after her time in the homeless shelter became connected through Facebook to stay in touch. Ramona

shared how they are “friends on Facebook. Every once in awhile I’ll say hi, poke her, or something.” Kat also continued to keep in touch with some of her daughter Leona’s service providers; they “keep in touch through the phone or email.”

In transitioning from early intervention to preschool services, eight participants shared positive experiences through individualization within preschool settings. For example, Eloise shared that two days into his preschool career, her son Maximus became ill and required emergency brain surgery. Maximus’ preschool teacher worked to provide individualized support during this challenging time for Eloise and her family, helping Eloise feel positive about Maximus’ experience and potential for achievement in this new setting:

When he was still recovering, the other kids drew him and signed special notes saying “I miss you” and “get well.” On the second week, we had a home visit from the teacher who brought all of the children’s notes....So I think we will have a good relationship with the school and the school itself is a family-oriented school. I can see that they are really proud of this; everybody knows your name. It’s a community school, so it’s much better to have him enrolled there, I hope he can stay there and will achieve a lot.

For Kelly, it was important for a teacher to be creative and try new methods in the classroom to help Darwin be successful. Kelly shared that not all of his teachers have been this successful or demonstrated the same amount of effort as a select few of Darwin’s previous teachers have. In reflecting about their family’s experiences, Kelly

identified the presence of certain teachers individualizing their approach to teaching

Darwin:

I think some teachers have been really great, in being supportive, understanding, and helpful. I think the teachers who worked most successfully were teachers that could think outside of the box and be able to look at different tactics they can use that aren't necessarily out of the book. [His old preschool teacher] was one of the first people who worked successfully with Darwin because she worked on figuring out what his triggers were and ways to stop him or redirect him.

Beyond the Darwin's school (microsystem) and interactions between school and family (mesosystem), Kelly also identified the director of special education (exosystem) as an influential member of Darwin's team. She shared:

Thankfully for us, we ran into a situation where we were out of options and [Darwin's old preschool] wasn't able to accommodate him anymore and so we had to go into the district. At that point, the Director of Special Education took one look at his medical records and one look at what was going to be his IEP and said it was unacceptable. We got lucky that she started working in [our district] and was good. This is unacceptable, he should be getting speech, he should have gotten early intervention, OT, he needs to have a neuro-psych analysis done, he needs all of these things, thankfully for us, she got our IEP on track.

With the individualization provided by this director of special education, Darwin was able to receive the services he was entitled to, which may have been different if this specific individual was not involved with Darwin's case.

Feeling lost in the system. While many positive experiences were experienced, nine family members identified instances of feeling lost in the system. Most commonly these related to supports and services received in preschool settings and in interactions with school district administration (exosystem).

In the case of Romana and her family, a primary challenge was arranging a way for her son Benji to get to preschool. As a single mother, Ramona has to drive her older children to school in a neighboring town. In order to have her older children arrive on time, they need to leave the house before a bus is able to arrive for Benji. If Ramona takes Benji to preschool after dropping off the other children, he has already missed between forty-five minutes to one hour of his three-hour school day. Unfamiliar with who to contact at the school district to solve this conflict, Ramona continued to bring her older children to school first, which left Benji missing up to one third of his school day and service for at least three quarters of his school year at the time of her interview.

Some families detailed feeling lost and frustrated by the interactions they had with particular teachers. For example, although Kelly identified some teachers who have provided individualized attention for making Darwin successful in school, she also worked with other teachers who have not provided the same type of individualized support:

I think other [teachers] have been a little more challenged by Darwin and are not sure how to handle him. I think a lot of times people would try to use techniques that work with autistic kids on Darwin and it never worked well at all. Darwin is by far not autistic. He is so far from autistic, considering he wants to be super social and in your face, chatty, all of these things that autistic kids are not.

Families also detailed feeling lost in regards to the school selection process that is necessary in some districts (mesosystem). For example, Fiona detailed the challenging process of selecting a school for her son, Theo:

I'm not really happy with this school district. It was a hard transition because all of the schools [in this district] are so segregated. You go to Chinatown, all Chinese, you go to [another neighborhood], all Spanish. We have a brand new apartment, we have a beautiful view, yet the schools are all African-American. I actually spent months looking at all of the programs, and all of the schools, I picked ten schools and they put him in the one closest to us that I didn't even list as an option. So then I had to go back and fight to get him in another school, so now he's in [his current school] and it's difficult.

Having a school placement that is not convenient, familiar, or a good fit for the family can be challenging. Describing a similar experience to Fiona's, Kat shared her challenges and frustrations with Leona's school placement:

I didn't like the lottery system in [this city]. I cried about her going to this school. This was not one of our choices; we didn't even know it existed. We

went through all of the rounds, we were still hoping we would get into any of the schools [in our neighborhood]. I would think if you had an IEP you would have a leg up...I thought there were going to be more concessions for kids on the spectrum, apparently not. The school district is saying that each school should be able to provide and cater to all kids, but kids are different. This school location is very inconvenient for us, it's tough.....My husband went to the special education offices everyday for one week trying to get somebody to read our letter and consider our plea and there wasn't anybody there, it was very very stressful. I became very upset, crying because I didn't know, Leona doesn't know this place.

Feeling lost in the system can also extend to schools districts (exosystem) and special education policies (macrosystem). For example, Camille identified challenges with legal procedures as identified in special education policies, and the incongruities between the written law and the way the law is put into practice at her daughter's school district:

To me I feel [the law] is there, they just have to say, "It's a law, it's there." But to really implement it to everybody's need, I'm not too convinced. I think it's kind of stressful for the teachers to service all of these kids, too many kids, too much on their workload, they don't get proper training, they want to do a good a good job but they don't have the time and they don't have the tools. I'm not really convinced that they can teach my kid. They need to pay the teacher better.

Feeling frustration between her interactions with her local school district, Camille and her partner decided to enroll their daughter into a private school that was not required to follow the special education laws and policies that dictate services in a public school.

All other families in this study received services through the public school system, though Sloan, Tessa, Kat, and Kelly are able to afford supplementary services to support their child's preschool services. In working with her local public school district, Eloise recalled challenges in understanding special education laws and policies:

I was given some information about the IEP before, but it's written information and if you give out written materials, it has to be formal and usually bureaucratic. It has to tell you everything, which I was lucky to keep those procedural guidelines from the last IEP because I could find things I needed now. That time it was not needed, I read through it and thought, "Who would not agree on an IEP?" I could never imagine. Now I know what the situation would be to use this line or that. It was telling me about my rights, why are there so many rights I have, when would I feel I would have to use it?...Now I know that it's not that easy to get all of the services he needs. They don't deny it that he needs the services; they just say they cannot provide them. What can you do?

Importance of Community

A family's values, culture, and characteristics will influence their need for and how they seek support. In the interviews, all ten of the families acknowledged the importance of their immediate support system, which included their partners, extended

family, and close friends (microsystem and mesosystem). However, the unique experience of raising a young child with multiple disabilities made it difficult for members of some immediate support systems to relate to and fully understand the experiences of these parents. In turn, seven families described the importance of a community where their experiences could be understood by others with similar experiences (exosystem) and in which knowledge and information could hopefully be shared. The importance of community within immediate support systems and in a larger community are detailed below.

Immediate support system. Each family member identified members in their immediate support system as being key (microsystem). For four of these family members, their husbands are their main support. Classifying her support system, Sierra recalls, “My greatest support system is my husband. He is supporting me to do all of these different roles.” Sierra’s husband works with her to help take care of their three children when Sierra is working on her graduate studies. Tessa recognized similar characteristics of her husband’s support:

My husband is there for me daily, if anything is going on or if I’m having trouble with this or that, I can talk to him and get encouragement and he supports our family financially, if he wasn’t able to do that I don’t know what we would do.

In the case of five of the interviews, family members described their extended family as being important supports, which included their parents, siblings, cousins, close friends, or in-laws as part of their immediate support systems. For example, Sloan’s

mother-in-law had moved from another state in order to better support Sloan and her family. Sierra has an aunt and uncle who live in a neighboring town, so they are able to visit with them once a week or every other week. Speaking of her support system, Tessa shared that “a lot of my parenting and emotional help, it’s from my cousin and sister.” Iris’ support system involved primarily friends. As she is not emotionally or geographically close to her parents or siblings, and being a single parent, Iris relies on lifelong friends for emotional support and occasional caretaking help with her son Jonas.

For six of the families, the immediate support systems were not geographically close, resulting in the family using technology as means of connection and communication. Tessa talked with her cousin and sister on the phone and Kelly’s family uses videochat technology to connect with her family support system. Kelly described her family’s use of technology, “We do a lot of FaceTime, and then Darwin has always loved FaceTime on the phone, so he picks up the phone and calls my mom and sister.”

While all the families had an immediate support system, some of these relationships did not fully understand the experiences of raising a young child with multiple disabilities. For example, Kelly described some of the challenges she experiences with her family:

I think one thing on the family side, it’s been interesting because our family is really tight. I think they try really really hard to understand all of the challenges that Darwin has, but I also think that they’re not involved in the day-to-day and sometimes they will come and they’re great, they’re an awesome support and

they're wonderful. Sometimes they come and it's challenging because they're trying to give direction or guidance on how to discipline him or handle him better, tell us we're not being consistent. It's challenging trying to make them understand the day in and day out, they sometimes lose sight of how much the behaviors are affected by the fact that he has half of a brain and is wired differently than other kids.

Challenges to being fully understood were also felt with close friends. As Kelly further detailed:

[For friendships], the preschool years have been hard, trying to figure out where Darwin's challenges and differences are. My best friend has three kids, they're older. I think that she has always tried to be supportive, but she doesn't totally get it. She doesn't get the challenges and the day-to-day stuff that we go through with Darwin, even though she tries.

Camille also identified challenges with having friends in their immediate support system that may not understand the reality of raising a young child with multiple disabilities. She shared:

It's different. I think it's hard for a friend just to talk about [having a child with special needs]. I don't want it to be sympathetic conversation. They invite us to the normal birthdays and stuff, we can't do all of the jumping and stuff, it's too much for Aurora, but we still go. They all know, they care, but they don't really know how to respond. After a while you just get used to it, but we don't want the

conversation to be around this topic because they don't relate to this whole situation. They all care, but you go with them to have fun, not to talk about all of these issues, there should be some other venue to address all of these issues, not at a friend's gathering.

Desire for community with shared experiences and knowledge. In the case of seven of the families, there was a desire to belong to a community who shared experiences of raising a child with special needs (mesosystem). Specifically, these families expressed a desire to belong to a community that is understanding, aware, and supportive of raising a young child with special needs.

Some families had yet to find this community. For example, Sierra wanted to find others that understood the reality of raising a child with similar challenges faced by her son. However, she has yet to locate or join this type of community with shared experiences. Sierra explained:

We still need those [community] supports, and getting those right supports and being able to connect with people, that's another thing. Our part would be because we don't have a parents group yet, I just have my friends group, but it's just parents with typical children. I mean, I have a friend who has a special needs child, but it's not like the same type of deafness, I want that kind of group.

On the other side of this paradigm, Camille was an example of someone who had already established a community with other parents who have children with special needs that attended school with her daughter Aurora. Camille discussed the importance of this

type of community and the influence it has on raising a young child with multiple disabilities:

There are parents who don't want to talk about it, but there are parents who are more positive than others and those are the ones who are pretty active and reach out. We'll do playdates or moms hanging out, moms night. Certainly talking about special needs, they make it feel like it's not just you, everybody has a challenge, we share the challenges. I think it makes it easier to face it.

Having an established community proved to be an important source of strength and identity for some families. For example, Sloan suggested that the best part of having a young child with multiple disabilities was in "finding a new community. We have so many people that we would have never connected with before, that now we connect with so many more people in charities and groups, we're sort of finding that extra community." Likewise, Fiona has established a connection with her community support organization. This sense of empowerment from belonging to a community with shared experiences and understanding was evident. Fiona elaborates on her sense of community with shared experiences:

There's a lot of support. I love [our local community support organization]. I feel like you connect with a unique community where there's benefits, nothing but benefits. There's people there to support you, there's extra classes, there's another community that you get to bond to. It actually has its benefits.

The presence of social media functioned as a means of community for these families. This type of technology provided many of these families with the ability to connect with individuals with shared experiences even if they never met in person. For example, discussing challenges of her daughter Bea's rare genetic condition, Sloan shared her excitement with finding a support group through social media:

In the beginning we were too focused because in the beginning we were dealing with all this stuff with the new baby and I guess we just had blinders of where we were looking specifically. It was difficult to find something because we were looking for something way too specific. I know it also didn't exist in the city at the time, Bea is the second kid in the area to be diagnosed with her condition.... We have a Facebook group and its part of the foundation for [the specific genetic mutation] research and its international, but we pretty much just work with the people nationally. We met all these other families, who some I've never actually met, but some of them I have. I know that I could text fifty different people if a question came up. We have a really great outside community of people with that condition.

Also using the social media platform of Facebook, Eloise was able to stay in touch with mothers who had children with special needs in her home country in Europe, who she met before her family relocated to the United States. Eloise elaborated by sharing, "Through Facebook, I follow them and sometimes I share some news with them. We don't call each other on the phone, but we know all about each other." Iris also identified

the use of technology in helping her locate another local community support. After using the Google search engine to help her locate a disability center near her, she was able to establish in-home nursing services for her son Jonas.

For eight parents, the importance of community was associated with a quest for further knowledge and information regarding their child with multiple disabilities. This type of community could take the form of support groups, local community organizations, social media groups, or other forms of support.

For example, Sloan provided two examples of ways her community helped her access information and knowledge relating to her daughter's needs. Leading up to her daughter's first IEP, Sloan and her family attended a Father's Day event for families who have children with visual impairments. Through this event, Sloan and her husband met parents who had just gone through the IEP process. These parents sent Sloan copies of their children's IEPs so that Sloan and her husband would have knowledge and information to help them prepare for their daughter's IEP. Sloan recognized her appreciation for these parents, "Although our kids were very different, we could see what the language and the process was, what to expect, who to take if you want to, knowing what your rights are." Sloan identified that a second source for knowledge and information was through the Facebook group dedicated to the rare genetic condition that her daughter was diagnosed with. Through this community support, Sloan and her husband were able to gather further information relating to their daughter's condition and learn about ways to best support Bea.

Fiona's community support organization has a parent education component that had provided support in parenting and managing her child's needs. Fiona also showed the importance of her local community support organization by describing the knowledge and information available through parent education classes:

My son likes to go there because I think it makes him feel good that his mom is getting some help. It gives me tools so that I can be more calm and respond in a different way versus reacting. So by going there, it makes Theo happy because he gets to play and I'm also learning. I've learned so much.

Camille reflected on her ability to access knowledge and information through her community. Working with her community support organization, Camille was able to navigate her daughter's services, but she identifies that it may not be as easy for other parents who may not have the time to go out of their way to search for these services and knowledge. Camille recalled:

Just establishing services, I think it was not easy. It's not straightforward: you have to learn it the hard way. For me, maybe it was a little bit easier because I got some help from somebody at [our community support organization]. I don't think everybody else got the same kind of experience. You have to have the time to go out there and search for that answer. You have to meet the right person sometimes, not everybody has time. Not everybody has knowledge or the right information for you because everybody has different issues to deal with.

Chapter 5: Discussion

This study sought to understand the experiences of families raising a young child with multiple disabilities, including the transition from early intervention services to preschool. Further, this study examined how home, community, and societal contexts influenced the experiences of these families' experiences. Findings exemplified the families' experiences in raising their young children with multiple disabilities across three categories: the impact of change, the power of individualization, and the importance of community.

The first research question sought to understand what it meant to be a parent/caregiver of a young child with multiple disabilities. What became evident from these families, especially within the Impact to Change theme, was that these families exemplified cohesion and resilience as a result of their experiences. In facing challenges or change, the families were able to work together, either as a family unit or with service providers, in order to achieve an equilibrium that allowed them to function successfully as a family (Turnbull et al., 1984). For example, most of the families faced relocation in some manner (detailed in the impact of relocation on services and supports subtheme), and despite the stress and challenges that come with this, especially in building supports and services for their child with multiple disabilities, most of the families who relocated were able to be successful. As this may not always be the case for families going through these types of change, continued work to support families who are not able to achieve equilibrium is needed.

A strong message that resonated from these families was the power of individualization (second theme). While many of the families detailed experiences where they had a certain professional really seek to understand their child and family, there were also stories of feeling lost and unheard. These findings are a reminder of the difference that meaningful family-centered services can make for families. Families should be able to access services and supports guided by the individual family's needs and strengths, in order for the family to strengthen their ability to fully meet the family's needs (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). More than two decades ago, McBride and colleagues (1993) identified that there is a "substantial discrepancy between what service providers report as typical practices with families and what they perceive to be ideal levels of family support" (p. 416). This may also still be valid today, as the needs of families who participated in this study often were not understood or acknowledged by service providers, especially when transitioning from early intervention into preschool services. These families still need the tools to continue to maintain equilibrium, in addition to perpetuate cohesion and resilience, as raising a child with multiple disabilities is a lifelong process. Service providers should strive to implement services that are family-centered, putting the family's needs and strengths first and foremost.

An important aspect of this study was to better understand the experiences of these families during their child's transition from early intervention services to preschool-based services. In early intervention, many of the families in this study felt comfortable

with their child's services and service providers. Parents were able to learn from the professionals, often within their own homes and community. Regardless of the cohesion and resilience demonstrated by many of families leading up to the child's third birthday, the shift from early intervention to preschool services was experienced as a challenging time for a lot of the parents in this study. This transition was eased in the case of each family through an encounter with at least one service provider in early intervention or preschool services who provided individualized support to the child and family. Having an individual who cared to learn about their child, provide information, and guide the family through this change was key. However, this was not experienced through interactions with all teachers, service providers, or supervisors.

When families are able to collaborate with professionals who take the time to show compassion, their overall experience is positive. The experiences of these families emphasized the need for professionals who are willing and able to take a closer look at each child and family, identify specific supports that the child and family need, and ultimately have the ability to provide what is needed, all while taking diversity and culture into consideration. These positive experiences lift the morale of the families and generate more positivity and greater outcomes than if their needs are not recognized, supported, or met.

Of course, it is essential that professionals are highly qualified. However, along with the required degrees, credentials, and field experiences, successful service providers and teachers are those individuals that can translate this knowledge and seek to learn and

empower each individual family and their child with special needs. In turn, educational degrees and credentialing programs need to focus on partnerships with families. Students who have the ability to learn about, and from, families or even who are able to have hands-on experiences developing a relationship with a family, may be better equipped and prioritize this within their future employment. It is also important to note that these professionals are needed at all levels of the special education system, from teachers and therapists to supervisors and administrators. Having the passion to provide appropriate and necessary supports and services to these children and their families goes hand-in-hand with professional knowledge, experience, and understanding.

The second research question guiding this study sought to explore how the home, community, and societal contexts shaped these families' experiences. Community was a strong aspect that positively influenced the experiences of these parents (detailed in the Importance of Community theme). For the parents in this study, their needs were not fully met by their immediate support system as this was composed of individuals without experience of raising a young child with multiple disabilities themselves. These families sought to be understood by a community of shared, similar experiences. In this community, they had or hoped to have the ability to access knowledge and information that will help them in their lifelong journey of supporting their child. The families who had established a community of support felt more prepared to handle difficult situations and were able to more successfully navigate through other types of services and supports.

Five of the families participated in a parent-run, community support organization focused on supporting families who have children with special needs. This was a powerful source of support in giving these parents the support that they needed. This concept of assembling a community of families with shared experiences that is available, accessible, and appropriate seems key in supporting families with children who have special needs. Ideally, this type of community should be available to all families regardless of their geographical location, easy to access for all families, commonly known throughout the broader community, and be able to provide appropriate support to each family, taking diversity into consideration. While for some families, a physical location was important to be able to go to, others shared how social media platforms could provide this support. Establishing this type of community with shared experiences seeks to enrich the well-being of each family raising a young child with multiple disabilities and works to support these families through all of their transitions, expected and unexpected, that they will encounter.

Limitations

An open and honest discussion of limitations helps demonstrate to what extent the findings can be generalized, in addition to identifying challenges for potential researchers seeking to create a similar study or replicate a study (Plano Clark & Creswell, 2010). Three limitations of this study include the homogenous nature of the participants, the reliance on an interview as the primary data source, and the lack of family involvement in data analysis.

While a variety of diverse characteristics were represented in the family participants within this study (i.e., ethnicity, geographic location, education level), there was homogeneity in terms of their sex and family constellations. All of the participants in this study were female. Ideally, there would be an equal or more representative participant group that also included males/fathers in order to understand these experiences in raising a young child with multiple disabilities. Further, there is a need for representation of different family constellations. In this study, there were seven families who had opposite-sex parents who were married, two single mothers, and one opposite-sex blended family. Ideally, the sample population would be representative and inclusive of other diverse family constellations, such as adoptive families, foster families, LGBTQ families, and/or grandparents raising children.

A second possible limitation relates to the data collection tools. Two data collection measures were used in this study: a brief survey and an in-depth interview. Considering and incorporating other data tools, such as observations and interviews with other family members or service providers, would contribute to understanding the experiences and contexts of these families. Further, a longer timeframe paired with these types of data tools would allow for a more in-depth work with each family, such as being able to follow the parents and families for an extended time through observations or a series of interviews (i.e., conducting interviews with each family before, during, and after the preschool transition process).

A final limitation of this study is the limited input the participants had during the data analysis process. While all participants were given the opportunity to member check the interview transcripts, no participants provided any additional information. Ideally, it would be beneficial to have the families involved in reading and providing input on emerging themes. However, it is recognized that these families have limited time and that providing time for the interviews was challenging in itself. Further consideration into involving families with young children with multiple disabilities within studies may be needed.

Future Directions

Future directions for research are suggestions that highlight further areas of inquiry (Plano Clark & Creswell, 2010). Future directions that could extend research focusing on families raising young children with multiple disabilities include: an exploration of these families and their ability to navigate times of change; how to help teachers and other professionals effectively provide individualized care to these families, and; an inquiry of what constitutes a positive community of support for these families. Lastly, a wider focus of disabilities is also suggested.

The impact of change, one of the three categories in the findings, identified three significant times of change for these families: having a child with multiple disabilities, relocation for services and supports, and change in services and supports, including transitioning to preschool-based services. An exploration of why some families are able to handle these times of immense change better than others when they have a child with

multiple disabilities will provide further understanding of the types of supports and services that different families may need.

The power of individualization in creating a positive experience in the lives of families with young children with multiple disabilities was evident across many experiences, including the transition to preschool. Research expanding on ways to effectively support teachers and service providers in becoming agents of positive change by providing individualized care is essential to best supporting these children and their families.

The importance of community for families raising young children with multiple disabilities was clear within these data, whether it was used to find information, seek people who understood similar experiences, or even just connect with online. This suggests that there is a need to fully understand what constitutes a positive community for these families. An inquiry that seeks to identify the characteristics of community systems that are important to families with young children with multiple disabilities, and when these are most important to have access to (i.e., when their child is first diagnosed or born, the transition to preschool, etc.) is important.

A final suggestion for future research is to apply this study to other disability categories. For example, focusing a future study on parents raising children with autism spectrum disorders or parents raising children who are deaf or hard of hearing. This would provide insight to the commonalities, strengths, and challenges among the experiences of parents raising children representing a variety of needs.

Conclusion

This study sought to understand the experiences of a parent/caregiver raising a young child with multiple disabilities, including the experience of transitioning from early intervention services to preschool-based services. Further, this study examined how home, community, and societal contexts influenced the experiences of these parents raising young children with multiple disabilities. It is essential for family voices to be heard. In learning about the perspectives and experiences of these families, there is an opportunity to better empower and support these children and their families.

Giving these families an opportunity for their voices to be heard provides an opportunity for professionals to gain insight to how these families can be best supported. The experiences and perspectives of Camille's family characterize the significance of supporting these families from early on in their experience. Although Camille and her partner were able to afford a private education for their daughter, Aurora, and support their daughter in the near future, they were not able to anticipate the next step in raising their daughter with multiple disabilities. This understanding emphasizes the importance of providing family-centered services that seek to support the identified needs of each individual family and empowering them to be advocates for their child and family throughout this lifelong process. Camille reflected on her experiences of raising her daughter, Aurora:

To me, it's like any kid, I mean a kid is never easy. You might see a difference [between Aurora and a typically developing child] when they're older. A normal

kid might leave you one day. But for me, this might be a lifelong challenge...I only know to the point of her age, I don't know what the next step is. When we reach the next step, then I'll do it, but right now I go day by day...Being a parent is challenging, it's just a different challenge [raising a child with multiple disabilities]. Right now I think it's challenging [for all parents with a young child], but ours will never go away. It's just a lifelong process; we have to plan it out.

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Appendix A: Brief Survey



Getting to Know You and Your Family

Parent/Caregiver Information

1. What is your sex?

Male Female Other: _____

2. What is your age?

18-25 25-35 35-45 45-55 55+

3. What is your ethnicity? List any and all that apply.

4. What language(s) is/are spoken in your home?

5. What is your highest level of education?

6. What is your marital status?

7. What is your occupation?

8. If you have a spouse/partner, what is their occupation?

Family Information

9. Does your family have any pets?

10. Who is in your family?

<u>Name</u>	<u>Age</u>	<u>Relationship to you</u>

Child Information

11. How old was your child when they were diagnosed?

12. What diagnoses has your child received?

13. What areas does your child have challenges with?

Sensory or motor	Cognitive	Language or communication
Social or emotional	Self-help or adaptive	

14. What services, if any, are your child and/or family receiving as a result of your child's diagnosis?

Please use the space below if there is anything else you would like to share about you, your family, and/or your child.

Appendix B: Interview Questions

Learning about the family, including the child with special needs

What is something special that your family does together?

Tell me about part of your family's daily routine that has been going well.

Is there a part of the routine that has been more challenging?

How do you balance parenting responsibilities with your hobbies/free time?

What has been the best part of parenting a child with special needs?

What has been the most challenging part of parenting a child with special needs?

How has ____ influenced your relationship between spouse/significant other/immediate family?

Having a child with special needs, how has this affected your employment or career? How about your significant other's/child's second caregiver?

How has your or your significant other's job/career influenced your family?

Has having a child with special needs influenced your relationships with extended family? Friendships?

Can you tell me about ____'s peer group or children who ____ interacts with regularly?

How do you think your family's culture has influenced your approach to ____'s care and education?

Learning about the parent's experiences of the child's services

Services: IFSP

Describe your overall experience with early intervention services (birth to 3).

Can you tell me about your relationships with _____'s infant/toddler teachers/service providers? EI administrators?

How do you think these services influenced you? Your child? Your Family?

Services: IEP

Describe your overall experience of transitioning from IFSP to IEP.

How have services changed since transitioning from an IFSP to an IEP?

Tell me about your relationships with _____'s teachers/service providers in preschool? Administrators?

Have you noticed any difference between IFSP and IEP? If so, what/how is it different?

Is there anything you wish could have been done differently during the transition?

How has the educational/medical system influenced _____, you, and your family?

Throughout this transition process, how has your knowledge of the educational/medical system grown?

In what ways, do you feel you could be more supported through this process?

From your experience, how have the special education policies/system and/or medical system influenced ____ and your family?

Learning about the family's support system

Support

Describe your support system. What does your support system do for you?

Outside of your family, what other supports have helped you? (neighborhood, community programs, childcare, extended family).

How do you think any of these supports have influenced ____?

What type of support has been challenging to secure or find?

Describe your interactions with other parents who have children with special needs?

Final Question

Speaking from your experience, what does it mean to you to be parent of a preschooler with multiple disabilities?