EARLY INTERVENTION AND EARLY CHILDHOOD SPECIAL EDUCATION SERVICES: AN EXAMINATION OF ACCESS PATTERNS, BARRIERS, AND SUPPORTS

by

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(Under the Direction of Ashley J. Harrison)

ABSTRACT

It is important for children with developmental delays and disabilities to receive intervention services before kindergarten entry either in the form of early intervention (EI) [birth to the third birthday] or early childhood special education (ECSE) [three years old to kindergarten entry] (Bailey, 2005; Moeller, 2000; Rickards et al., 2009; Zwaigenbaum et al., 2015). However, many children who have needs and would likely qualify for services do not receive them (e.g., Paff, 2017; Rosenberg et al., 2008). Lack of services is coupled with differential rates of service access for some sociodemographic groups of children (e.g., Feinberg et al., 2011; Rosenberg et al., 2008).

The first study in this dissertation examines the overall rates of children accessing services within the EI and ECSE age ranges in a local county by comparing the number of children accessing these services locally to the number of children accessing these services at state and national levels. Additionally, this study examines how the local access numbers compare to the number of children who might be eligible for services based on prevalence estimates as a whole and by the child's race. Finally, children from different sociodemographic groups are compared to one another to determine if any disproportionalities exist. This local county’s EI and ECSE service providers perform well when compared to state and national averages, but still, fewer than half of children who likely qualify for services are not receiving them. Differences in rates of access emerge across socioeconomic groups, but importantly most groups appear to be significantly underutilizing services.

To identify factors contributing to success accessing services, the second study in this dissertation explores the barriers and supports impacting service access. Interviews were conducted with caregivers of children who were six years or younger with a developmental delay or disability. A socioecological model was used as a framework to organize the themes and both novel and replicated themes emerged at the Individual, Interpersonal, Organizational, and Community levels. Suggested future directions in research and practice to increase service access informed by the themes are discussed.

INDEX WORDS: early intervention, early childhood special education, barriers, developmental delays

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DEDICATION

To Seth

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INTRODUCTION AND LITERATURE REVIEW

Early Intervention and Early Childhood Special Education

Children between the ages of birth and 21 years identified as having a developmental delay or disability are guaranteed a free and appropriate education by the Individuals with Disabilities Education Improvement Act (IDEA; 2004). Infants and toddlers (birth until the third birthday) can receive early intervention (EI) services through Part C of IDEA. Preschool children (three to five years old) have a similar but distinct set of guidelines affording them access to early childhood special education (ECSE) services under Part B of IDEA (IDEA, 2004). EI and ECSE have distinct sets of eligibility requirements that enable children to receive services (Danaher et al., 2004). Thus, although the services are interrelated, researchers should study and examine them separately based on their differences.

Benefits of Intervention Services for Children with Developmental Delays or Disabilities Before Kindergarten Entry

It is imperative that service providers identify all children eligible for EI and ECSE services as early as possible and that those children receive services prior to kindergarten entry, in light of the research indicating the importance of young children receiving services and intervention (e.g., Bailey, 2005; Moeller, 2000; Rickards et al., 2009; Zwaigenbaum et al., 2015). For example, one randomized control trial study, with participants with autism or a developmental delay between the ages of three years and five years, demonstrated cognitive improvements for the group receiving in-home intervention for up to a year after the intervention ended compared to a control group (Rickards et al., 2009). Another study analyzed the relationship between how early children who were deaf or hard-of-hearing were enrolled in early intervention and children's growth in vocabulary development by the age of five years. Researchers found children in this study who entered early intervention earlier developed higher language skills at five years of age (Moeller, 2000). Based on studies examining interventions implemented for children with autism spectrum disorder (ASD), one review determined that interventions should be implemented as early as possible and should address behavioral, social, cognitive, language, adaptive, and emotional domains (Zwaigenbaum et al., 2015). This review indicated that early intervention leads to better results developmentally for those children receiving services (Zwaigenbaum et al., 2015). Moreover, parents also reported positive family outcomes (e.g., reporting high levels of skill to take care of their child, reporting having the ability to obtain supports) after receiving early intervention services (Bailey et al., 2005). One meta-analysis, reviewing the existing literature on early interventions, determined that these interventions led to better cognitive, social, and academic outcomes for the children receiving them (Camilli et al., 2010). Additionally, the child who receives evidence-based services will likely have better social skills and improved classroom participation in second grade (Bierman et al., 2017). Each of these studies suggests the importance of providing services for children with delays or disabilities between birth and five years as well as the significance of enrolling children in these services as early as possible.

Although early intervention leads to beneficial outcomes for many children, children who have experienced adverse life events might be in even greater need of EI and ECSE services because of data suggesting they start school with a disadvantage. Researchers predict that children from low income backgrounds had heard 30 million fewer words by three years of age than their peers from families that had greater advantages (Hart & Risley, 2002). More specifically, research has revealed that adverse events in a child's life such as living in poverty or being abused are associated with poorer outcomes (e.g., higher rates of mortality, obesity, behavior and learning problems, poorer academic outcomes and adult health concerns; Berry et al., 2010; Brooks-Gunn & Duncan, 1997; Burke et al., 2011; Chartier et al., 2010; Fiscella & Kitzman, 2009; Goldfeld & Hayes, 2012; Starfield, 2005). Additionally, studies indicate children who do not have access to a quality preschool program might have a higher likelihood of requiring later special education services (Albritton et al., 2016). Early intervention services might be particularly helpful in aiding children who come from disadvantaged backgrounds to close the gap with peers. Although these will not be discussed in detail here, in addition to services available for children with developmental delays and disabilities implemented before kindergarten entry, services available for children coming from families classified as having a low socioeconomic status (SES) also provide benefits to children and their families (e.g., Albritton et al., 2016; Bierman et al., 2017; Camilli et al., 2010; Campbell et al., 2001; Campbell et al., 2002; García et al., 2016; Nelson et al., 2003).

Framework for Conducting Disparities Research

Although there is evidence to suggest EI and ECSE services help children with developmental delays and disabilities to narrow the gap between themselves and their peers, there is also preliminary evidence to suggest that families from disadvantaged backgrounds and traditionally underserved families are less likely to access these services (e.g., Albritton et al., 2016; Feinberg et al., 2011; Rosenberg et al., 2008). Without access to these services, these children will likely begin school with less smooth transitions and less preparation than their peers. Research has examined these trends at the state and national levels, but additional research should examine inequities in child health access and outcomes at a local level to ensure those preventable disparities in health access and outcomes are avoided. Research conducted at a local level also allows for more targeted intervention development based on the variability in districts and states.

Existing frameworks or models can be helpful in systematically assessing the causes of disparities. The vast majority of research examining disparities in service use focuses primarily on access to healthcare; however, many of the models in this literature can apply to service use disparities in education as well. Health and education are interconnected, as health affects children's readiness for school (Currie, 2005) and education affects one's health outcomes (Cohen & Syme, 2013). Additionally, the goals of education and health are interrelated, and some researchers argue that by eliminating the achievement gap, the health disparities for those individuals would, in turn, be reduced (Fiscella & Kitzman, 2009). As EI and ECSE services both involve a child's health, examining disparities in accessing these services warrants investigation; however, it is important to adapt existing models to take into account education-specific factors.

One model for conducting health disparities research includes three general steps: 1) identifying and defining the nature of existing disparities, 2) determining mechanisms that contribute to disparities, and 3) creating interventions to reduce the identified disparities (Kilbourne et al., 2006). As a result of the interrelated nature of health and education and early intervention, this framework can be used to comprehensively identify hypothesized disparities in accessing EI and ECSE services and to work toward ameliorating unequal access. Although this overall model of examining disparities (Kilbourne et al., 2006) will inform the following studies, the specific factors examined potentially leading to disparities will be adapted from several different models to more comprehensively examine educational factors.

Disparities Research Step 1: Identify the Disparities

The first step in conducting this line of research includes defining the concept of disparities. A difference exists between a health inequality and a health inequity. A health inequality can be defined as a difference in health outcomes, but a health inequity indicates there is some difference in health outcomes that is avoidable (Carter-Pokras & Baquet, 2002). Although disparity is not synonymous with inequity, recently, in the public health field, disparity has become associated with the term injustice (Carter-Pokras & Baquet, 2002), indicating more individuals in the field are using the term to indicate differences that are avoidable and unfair. When defining disparity for the purposes of one's study, one should operationally define disparity by indicating the health aspect being compared (e.g., services accessed), as well as the population groups being compared (e.g., by race). Additionally, the implications for policy should be considered based on one's definition of disparity (Carter-Pokras & Baquet, 2002). Next, the way in which these disparities are measured must be determined. One model follows five steps in determining how to measure disparities: (a) outline which health domain to measure, (b) decide which population groups across which to compare the health domain, (c) pick a reference group among the population groups previously determined (e.g., the reference group could be a majority group such as White children), (d) determine if the groups will be compared relatively or absolutely, and (e) decide if any aspect of the measurement will be weighted more heavily than other elements (Evans et al., 2001). After finalizing the definition for disparity and determining the way it will be measured, identifying of disparities can be addressed.

Second, there are multiple methods one can use for detecting disparities so the specific approach for identifying disparities needs to be carefully selected. Prior studies have used nationally representative datasets to identify rates of accessing EI or ECSE services (e.g., Feinberg et al., 2011; Rosenberg et al., 2008). By using datasets that are nationally representative, researchers can discuss whether specific and local groups of children are accessing services at lower or higher rates than other children at the national level. One downside to this approach is that using national data might wash out any differences seen regionally or by state (Morrier & Gallagher, 2012), so using local population data to identify disparities can be a helpful alternative to parse out specific disparities in regions with distinct sociodemographic characteristics. Patterns can vary at the local level due to different sizes of special education programs and representation of groups in the community, and it is important to understand these differences that might be missed when examining national trends (Artiles et al., 2005). This understanding can be especially helpful when designing a new intervention to initially be implemented and tested in one discrete location.

Other studies have examined state-wide data that is representative of one state (Barfield et al., 2008; Clements et al., 2008). Using such an approach, researchers can make the claim that there are state-wide disparities among some groups because their initial sample was representative of the region under study. Often, looking at differences across states leads to variability in results (e.g., Morrier & Gallagher, 2012), suggesting differences exist in terms of eligibility and processes between states. Districts might also differ in the way they are funded and the way their processes function, so more research is needed on district- or county-wide data before planning interventions. A sample coming from one district would also be appropriate if the research question is examining the potential disparities of a school district and as long as the researcher has data from the entire district. It is more difficult to determine rates of disparities when analyzing a convenience sample or volunteer sample because these sampling methods are likely not representative of the population being studied.

Disparities Research Step 2: Determine Mechanisms that Contribute to Disparities

Many models have been developed to help comprehensively measure the different mechanisms contributing to health disparities. Horn & Beal (2004) propose a model that is designed to elucidate all the domains that could be contributing to disparities, which may help researchers develop comprehensive assessment approaches and has the following levels: Individual, Health Systems, Community, and Societal. Under each of these levels, the researchers propose different factors contributing to disparities. For example, variables related to disparities at the Individual level include parent education or socioeconomic status (SES), at the Health Systems level include insurance systems, at the Community level include violence and education, and at the Societal level include racism (Horn & Beal, 2004). One of the strengths of this model is that it comprehensively provides level-specific examples and emphasizes the importance of considering factors at each of the included levels.

A similar model to the one presented by Horn & Beal (2004) is the ecological model of health which includes Intrapersonal, Interpersonal, Institutional, Community, and Policy Levels (McLeroy et al., 1988). Under this model, the Intrapersonal level includes individual factors that contribute to health behavior. One strength of this model is how it breaks the Individual level from the Horn & Beal (2004) model into two dimensions, the Intrapersonal and Interpersonal levels, allowing researchers to hone in on each area in more detail. Examples of factors that fall under each level include knowledge (Intrapersonal) and social network (Interpersonal; McLeroy et al., 1988). Another group of researchers added additional factors to the ecological model, and the factors provided are helpful in understanding the different levels ("Office of Health Access," n.d.). Although the Policy level in the model includes several helpful examples, one weakness of this model is that the Policy level is the highest level, and therefore, the model does not include more systemic factors such as culture and racism.

An adaptation of the model created by Arcia et al. (1993) takes the approach that places the origin of the disparities on a spectrum ranging from mainly family-influenced factors to mainly program-influenced factors (Birkin et al., 2008). An example of a mostly family-influenced factor preventing service usage in this model is acculturation, and an example of a mostly program-influenced factor is cost (Birkin et al., 2008). This model has a strength in that it presents the factors affecting disparities on a spectrum with some factors falling somewhere between the mainly family-influenced and mainly-program influenced ends of the spectrum. One negative of this model is that it does not account for even broader factors such as policies.

Another model conceptualizes the factors as falling under a broader health system factor which encompasses patient factors and provider factors (Kilbourne et al., 2006). The patient factors and provider factors then overlap to produce the clinical encounter factors. An example of a health system factor would be the culture of the healthcare organization, an example of a patient factor might be individual beliefs, an example of a provider factor would be bias, and an example of a clinical encounter factor would be cultural competence (Kilbourne et al., 2006). This model specifically takes a health services perspective as opposed to a public health-based perspective (Kilbourne et al., 2006). A positive of this model is the way it presents the relationships between the factors with the health systems factor encompassing the patient factors and provider factors, which overlap at the clinical encounter level. Again, a negative aspect of this model is the lack of a broader view of disparities potentially resulting from factors outside of the health system, such as at the government or cultural level.

A final study approached the identification of the mechanisms of disparities by conducting a literature review which classified the areas that can result in disparities into three domains: (a) organizational, (b) structural, and (c) clinical (Betancourt et al., 2003; Brach, 2000). This framework used cultural competence as the basis for determining the mechanisms that result in disparities. Although factors other than cultural competence might result in disparities in service usage, this model considers cultural competence to be an underlying theme that cuts across several levels of mechanisms of disparities.

By using a combination of all of the previously developed models and by using qualitative and quantitative approaches, researchers can ensure they are evaluating all aspects potentially leading to disparities. Before determining the causes of disparities, the different models and the various levels of factors should be considered by research teams to inform the development and use of survey tools and interviews. This consideration of factors allows for a thorough examination of all aspects that could be leading to disparities in accessing services. None of the models for studying health disparities include sufficient information for the purposes of studying educational disparities in isolation; therefore, this study provides a new model that combines factors from a range of different fields to guide the current educational research.

The goal of the current study will be to use findings to help identify additional factors through qualitative research methods that should be considered for inclusion into this education-specific disparity model and confirm the inclusion of factors from the health disparities literature and to provide qualitative support for the previously theorized barriers/supports or those identified in different sectors than education (i.e., mental or physical health). The models for general health disparities are also taken into consideration because this domain is more highly studied, and it is predicted that some of the same factors will also lead to educational disparities. This study will help inform the development of a comprehensive disparities model specific to the educational domain. Using the ecological model (McLeroy et al., 1988) as a foundation, researchers can add the societal level (Horn & Beal, 2004) to this model, making it even broader, as well as taking into consideration the cultural competence emphasized by Betancourt et al. (2003). Essentially, this new model combines or considers all the strengths of the other models in addition to providing a structure to include additional factors discovered using qualitative research methods. More specifically, the developed educational disparities model organization accounts for the structures of the models created by Birkin et al. (2008) as well as by Kilbourne et al. (2006). This new model is more comprehensive than previously developed models and has been created with access to educational services in mind. See Figure 1.1 for a graphical display of the newly developed model.

However, this model has been adapted from health disparities research, and it is unclear if the same mechanisms contribute to disparities in accessing educational services. As such, qualitative research is an important step for examining if similar barriers exist in this distinct system. Qualitative research use theory as the basis of creating an outline for examining a concept (Sandelowski, 1993 as cited in Wu et al., 2016), but qualitative research is based on exploration (potentially based on a theory) as opposed to being driven by a hypothesis (Creswell, 1994 as cited in Wu et al., 2016).

Disparities Research Step 3: Create Interventions to Reduce Disparities

The final step in conducting disparities research according to the model presented by Kilbourne et al. (2006) is to create interventions to reduce disparities. The components of this research step require a careful review of the existing literature to examine if current interventions designed to increase engagement in EI or ECSE are tailored specifically to groups experiencing disparities. This allows for a determination as to whether new interventions are required or if existing interventions can be adapted appropriately. Data collected in step 2 can inform the development or adaptation of interventions that specifically target groups under accessing services. Representatives from these groups should be consulted in development and adaption phases to ensure maximum success (Kilbourne et al., 2006). The most effective interventions are both adapted to the population of focus and are implemented among the population of focus using advanced approaches to implementation (Kilbourne et al., 2006). Information gathered as part of Step1 helps to document which specific groups should be targeted with these interventions, which as previously mentioned, shapes the nature of the intervention approach. While the current studies propose to collect data only to connected to questions related to Steps 1 and 2, the hope is this information will inform future research targeting this final step.

Purpose and Aims

The current project includes two studies designed to align with Steps 1 and 2 of the disparities reduction framework to help inform an intervention to reduce disparities in families accessing EI and ECSE services. The first study examined if disparities in accessing early intervention and early childhood special education services exist in one local county in Georgia. This study also compared the rates of accessing EI and ECSE services among children in this county to national reported rates and expected rates of utilization derived from two prevalence estimate studies (Paff, 2017; Rosenberg et al., 2008). To determine if different usage patterns align with specific demographic groups, the sample was stratified across race and ethnicity when making comparisons. This step aligns with Step 1 in the model of conducting disparities research

(Kilbourne et al., 2006) in that it helps to identify disparate use of services among for particular demographic groups. This approach is similar to using statewide data, but on a smaller, county-based scale, which as mentioned before is helpful because it will likely contribute to more tailored and more effective local interventions.

Based on the lack of research on the identification of why disparities exist in accessing EI and ECSE services, the second study is an exploratory study. Using qualitative methods this study examined barriers and supports that local families experienced accessing EI and ECSE services. This study aligned with the second step presented in the Kilbourne et al. (2006) model of health disparities research by beginning to determine the causes of disproportionate access of these services. The information obtained from these interviews will inform the finalization of the newly adapted educational disparities model presented earlier (see Figure 1.1). Through qualitative interviewing, factors were examined at each of the levels included in the model, paying particular attention to those levels that may be easier to intervene upon (i.e., individual, interpersonal, organizational, and community).

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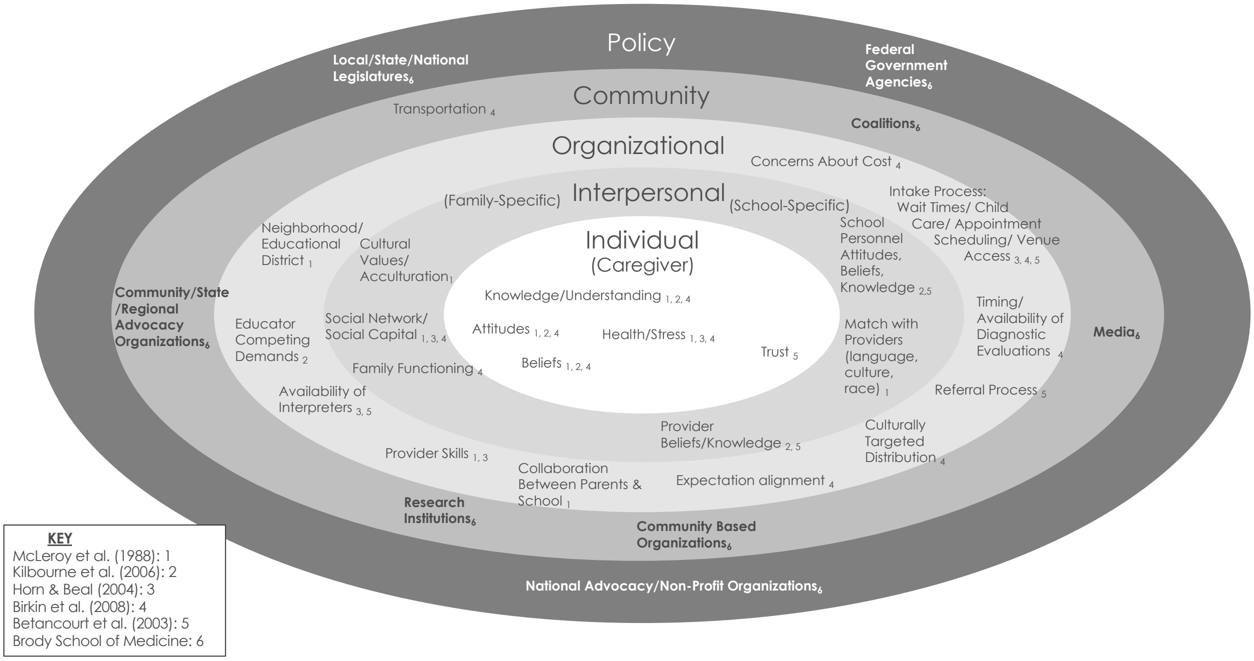
Figure 1.1

Model of mechanisms that may contribute to educational disparities



CHAPTER 2

EXAMINING LOCAL RATES AND DISPARITIES IN ACCESSING EI AND ECSE SERVICES

Children with developmental delays and their families benefit from accessing intervention services as early as possible (Bailey et al., 2005; Moeller, 2000; Nelson et al., 2003; Rickards et al., 2009; Zwaigenbaum et al., 2015). Sociodemographic differences in rates of accessing special education have been studied in school-age populations, but preschool disparities have not been examined as extensively. Additionally, the school-age disparities results are mixed, with some research suggesting higher referral rates for Black or African American and Hispanic students compared to White students for special education (Hosp & Reschly, 2003) and other research indicating an underrepresentation of students whose primary language is not English in special education at some grade levels (Samson & Lesaux, 2009). There are many potential explanations for variability in service access, including the proposal that differences might be the result of funding practices for the eligibility categories for special education (Parrish, 2002 as cited in Morrier & Gallagher, 2012) or broad sampling regions. Even more unclear is whether disparities exist in EI and ECSE and what this pattern looks like with the relatively minimal research in the younger age ranges. Given the importance of early services, additional research should analyze the rates of participation in early childhood services as well as document usage patterns and potential mechanisms for under- or overrepresentation of sociodemographic groups of children at the preschool age range.

Available Services

The Individuals with Disabilities Education Improvement Act guarantees children with disabilities between the ages of birth and 21 years a free and appropriate education (Individuals With Disabilities Education Act, 2004), but the nature of the services and eligibility requirements differ for services offered to children between birth and their third birthday and between children three to five years old (Danaher et al., 2004). More specifically, many states have distinct sets of eligibility guidelines for each of these types of services which make it unlikely that a child receiving EI services would automatically continue to receive ECSE services when he or she turns three years old (Danaher et al., 2004). As a result of the documented differences in eligibility criteria for these two programs, eligibility rates and rates of accessing services for the EI and ECSE age ranges should be examined separately (Danaher et al., 2004). Much more research has been conducted at the EI and school-age levels than the ECSE level (National Research Council, 2002 as cited in Morgan, Farkas, Hillemeier, & Maczuga, 2012). This relatively unexamined age range warrants additional study.

Under Access of EI and ECSE Services

Research is mounting to document that EI and ECSE services are widely being underutilized. According to previous research using a nationally representative dataset, 12% of 9-month old infants and 13.8% of 24-month old infants qualify to access EI services based on direct child assessment data (Rosenberg et al., 2008). Although these children should theoretically be receiving services as a result of having developmental delays or disabilities, only 10.1% of those eligible children received services (Rosenberg et al., 2008). Another study, which used stricter criteria and the same nationally representative dataset, estimated that at 9 months

9.3% of infants met eligibility criteria for EI services and at 24 months 10.1% met criteria (Feinberg et al., 2011). Only 9% of these eligible infants at 9 months and only 12% of eligible children at 24 months received the necessary services (Feinberg et al., 2011). Both studies estimating eligibility rates and reported service usage rates for children eligible to receive EI services indicate an overall underutilization of these services.

Limited research has been conducted on the preschool age range (3 years to approximately 5 years) regarding access and uptake of services. One study that combined the EI and ECSE age ranges reported that 4.7% of children up to the age of five years would meet the researchers' criteria for developmental delay nationally and that 21.6% of the children included in data collection had unmet therapy needs, either recognized or unrecognized by the parent (Magnusson et al., 2016). The criteria for this study depended on parent report data collected as part of the National Surveys of Children with Special Health Care Needs and the researchers reported that their method for determining developmental delay might have excluded children whose parents did not recognize a delay in their child (Magnusson et al., 2016). Although this study likely underestimates the extent of the number of children with a developmental delay, it still documents an underutilization of services both from families in which the parent recognizes the therapy need and from families who do not recognize the therapy need. Additionally, the Magnusson et al. (2016) study examines all children under the age of five years and does not separate the two age ranges (EI versus ECSE), which have previously noted distinct criteria for eligibility to receive free services. Another study that examined the preschool age range independently estimated that 13.22% of children in the preschool age range should be accessing services (Paff, 2017). This study used data from the Early Childhood Longitudinal Study- Birth Cohort, which includes direct child assessment data of several domains, and reported an underutilization of services with only 20.26% of families deemed eligible for ECSE services accessing either EI or ECSE services (Paff, 2017). The results from this study align with results from the Rosenberg et al. (2008) study and most likely represent a more accurate estimate of percentage of children eligible for ECSE services. Nevertheless, both studies documenting ECSE eligibility rates and reported service usage rates show an underutilization of services for this age range as well. Therefore, many children between birth and kindergarten entry qualify for services but are not receiving these beneficial services.

Preliminary EI Research on Disproportionality

Research designed to understand why these dramatic patterns of underutilization are occurring are an important first step in ensuring more eligible children receive the services they need. Disparities in accessing these services for both age ranges might be one important contribution to the underutilization; however, more research is needed to bolster this preliminary research body. In alignment with Step 1 of the disparities reduction framework (Kilbourne et al., 2006), research has begun to document disparities in accessing EI services for certain groups of children. One study using a nationally representative dataset found that Black or African American children were less likely to receive EI services than children of other races and ethnicities (Rosenberg et al., 2008). Another study found no significant differences among racial groups accessing services at 9 months, but at 24 months, White children were five times more likely to access services than Black children (Feinberg et al., 2011). An additional study, using the National Early Intervention Longitudinal Study data found that single parent households waited longer for access to services than dual parent families and that non-White families indicated more difficulty in finding services compared to White families (Litt & Perrin, 2014).

Other studies have specifically examined states or certain areas of the country. According to a dataset collected in Massachusetts, the Pregnancy to Early Life Longitudinal (PELL), EI referral and enrollment in Massachusetts was positively associated with low level of maternal education, having government insurance, and Hispanic ethnicity, but maternal birthplace being outside the U.S., maternal first language being a language other than English, and maternal race being Asian were negatively associated with EI referral and enrollment (Clements et al., 2008). This negative association was also observed between children from regions with greater than 15% poverty and EI enrollment (Clements et al., 2008). Another study examining EI referral rates using the same PELL dataset, but only including children who weighed less than 1200 grams, found that children of Black mothers were less likely to be referred for EI services and were referred later for EI services than children of White mothers (Barfield et al., 2008). In this same study, children of mothers with government or no insurance were referred later than children of those with private insurance and children of mothers living in areas with higher rates of poverty were referred later than children of mothers not living in impoverished areas (Barfield et al., 2008). These studies provide valuable regional analyses of disparities, but other regions and districts have different systems, funding, and demographic information, which will likely lead to different results.

A study conducted in Hawaii found that uninsured children and children with parents in the military were underrepresented in the enrollment in EI services (Shapiro & Derrington, 2004). Finally, a team of researchers collecting data from a hospital associated with the University of Chicago determined that, as income decreased, the likelihood of receiving EI services also decreased (Fefferman et al., 2017). Only one study examining sociodemographic patterns of EI usage suggested equal rates of age at developmental delay diagnosis. More specifically, a study conducted in South Carolina, revealed no difference in terms of timing of receiving a developmental delay diagnosis between White children and Black children but found that both groups of children received the diagnosis late (after 3 years of age for three-quarters of individuals and after 5 years of age for one-quarter of individuals; Mann et al., 2008). This variability observed across states further confirms the claim by Morrier & Gallagher (2012) that regional differences may be meaningful. Although research demonstrating disparities in EI services is mounting, future research should extend this work to the ECSE age range, examine the causes of these disparities, and study ways to reduce them. Furthermore, these studies show mixed findings, so additional research in more local areas is needed. To plan an intervention, local data from the area in which one plans to conduct the intervention needs to be analyzed for this purpose.

Preliminary ECSE Research on Disproportionality

Although fewer studies have been conducted analyzing the disparities in accessing ECSE services compared to accessing EI services, preliminary research has documented disparities in accessing ECSE services as well. For example, one study indicated that children whose primary language is not English, children from low socioeconomic backgrounds, Black or African American children, and Asian children were less likely to receive EI or ECSE services for this age range than children from other groups (Morgan et al., 2012). This study used national data from the Early Childhood Longitudinal Study- Birth dataset to determine rates of disparities among sociodemographic groups in accessing either EI or ECSE services.

Additional research found differences across five states in terms of equal representation across race/ethnicity in early childhood special education (Morrier & Gallagher, 2012). This study revealed underrepresentation among Hispanic children in four states, underrepresentation among Asian children in two states, overrepresentation among Black children in one state, overrepresentation of American Indian children in one state, and underrepresentation of American Indian children in one state (Morrier & Gallagher, 2012). These preliminary studies indicate disproportionality in accessing services for the ECSE age range, but as the Morrier & Gallagher (2012) article suggests, these disproportionalities vary greatly across regions. This variability makes it difficult to plan interventions that aim to increase more equitable service access. Additionally, both under- and overrepresentation of groups of children can be problematic. Based on the variability in policies for states and districts, studies should also examine rates of accessing these services on smaller scales to plan more effective interventions to reduce these disparities and increase equitable access for all children. Some studies have examined EI and ECSE rates at the state level (e.g., Barfield et al., 2008; Clements et al., 2008; Morrier & Gallagher, 2012), but even smaller-scale studies are necessary to determine the nuances of the rates of disparities within counties and districts. More locally oriented studies may help to determine the specific populations to address when trying to examine barriers to accessing these services as opposed to trying to identify barriers in wider and thus more complex and diverse systems, such as the entire EI and ECSE population in the United States.

Current Study

The current study sampled a county classified as a small metro (Ingram & Franco, 2013) in the northeastern part of Georgia. Approximately 35.2% of people in this county live below the federal poverty line, and the industry with the highest percentage of employed civilians in this county are in the “Educational services, and health care and social assistance” industry (32.8%). The next highest percentage of employed civilians in this county are in the “Arts, entertainment, and recreation, and accommodation and food services" industry (16.5%; U.S. Census Bureau, 2016). This county will be referred to as a "local county."

Aims of Current Study

Underutilization of services and disparities in accessing both EI and ECSE services have been documented at the national level and in some instances at the state level. However, to help inform the identification of specific barriers impacting service use, the current study aimed to identify if underutilization of services or disparities in accessing services exist at the local level for both the EI and ECSE age ranges. This study had the following goals:

1) Compare local rates of EI and ECSE service access to estimated rates of eligibility for the EI age range (13.8%; Rosenberg et al., 2008) and for the ECSE age range (13.22%; Paff, 2017). Based on previous results from the studies conducted at the national level documenting wide underutilization (e.g., Rosenberg et al., 2008; Paff, 2017), it is hypothesized that an underutilization of both EI and ECSE services will exist.
2) Compare local rates of EI and ECSE service access to national U.S. Department of Education rates of EI (3.1%) and ECSE (6.4%) to contextualize how one local county is performing. It is hypothesized that local rates of accessing EI services will be lower than national rates because of the low documented rate of EI enrollment in Georgia compared to other states (Rosenberg et al., 2013). It is also hypothesized that local rates of accessing ECSE services will be lower than national rates because Georgia had a lower percentage of children enrolled in ECSE services in 2014 than all states except for Alabama and Texas, and was tied with Hawaii (tied), and Montana for third lowest (U.S. Department of Education, 2016).

3) Compare local rates of EI and ECSE service access to U.S. Department of Education state rates of EI (2.1%) and ECSE (4.6%) to determine how one local county is performing compared to other Georgia districts. It is hypothesized that local rates of EI and ECSE service access will be similar to or higher than state rates based on the presence of a university and specific programs aimed at increasing service usage in this area.
4) Identify whether certain sociodemographic groups have a lower likelihood of accessing EI and ECSE services. Specifically, the service use patterns will be examined among the following sociodemographic groups at the EI age range: race/ethnicity, insurance status, and primary language. Based on results from previous research (Barfield et al., 2008; Peterson et al., 2004; Rosenberg et al., 2008), it is hypothesized that White children have a higher likelihood of receiving services than other underserved racial/ethnic groups of children. Further, we hypothesized children with insurance will have a higher likelihood of receiving services than children without insurance and children from homes where English is the primary language will have a higher likelihood of receiving services than children from homes where English is not the primary language.
5) To further contextualize sociodemographic patterns of usage, this study also compared actual usage rates among different groups to expected prevalence estimates of 13.8% for groups in the EI age range and 13.22% for groups in the ECSE age range. Even if differences in rates of access exist among groups of children, it is still hypothesized that all groups of children within each sociodemographic group will be under accessing services based on the percentage of the population that may be eligible to receive services.

Method

Sample

Data for the EI age range (birth to 3 years old) were obtained from a local Babies Can't Wait (BCW) center that provides services for multiple districts in Northeast Georgia. Babies Can't Wait is the Part C provider in Georgia. The secure BCW database was reviewed at the local center and de-identified data for one local county were manually recorded into a separate table. Any children who received early intervention services during the 2015-2016 school year were included. Data for the preschool age range (3 to 5 years) were also obtained from a local school district. Individuals who received early childhood special education services at any point during the 2015-2016 school year were included in a de-identified spreadsheet to align with the Babies Can't Wait data.

Local population data were obtained from American Community Survey (ACS; United States Census Bureau, 2016) for individuals in this local county between birth and the age of five years from the years 2012 through 2016. The American Community Survey is distributed to a sample of the population each month of each year, and this survey includes questions about additional information (e.g., education, transportation) that is not included in the census that only occurs every ten years (United States Census Bureau, 2020). Data are provided for the racial/ethnic percentage of individuals in this county as well as the percentage of individuals under the age of five years to allow for stratification of the data set.

Sociodemographic Variables

By nature of the EI data set, all children included in the database were eligible for EI services. The following factors were also recorded for each participant in the EI de-identified sample: gender, race, ethnicity, date of first Individualized Family Service Plan (IFSP), language, interpreter needed, referral source, number of family members, number of siblings, primary caregivers, current insurance, income, primary diagnosis, and secondary diagnosis. For the ECSE age range, the data set included children who had been evaluated for ECSE services, but only those who had been found eligible (i.e., had a primary disability listed) were included in the analysis for this study. In addition to including for each child their eligibility status and reason for eligibility, sociodemographic data were also compiled in an Excel spreadsheet for each child including child's age, gender, race, eligibility category, and date of entry into services. The demographic categories selected for each range were based on what was available in the preexisting databases and align with previously explored sociodemographic categories. Demographic variable information for a local county in Georgia is included in Table 2.1.

For the purposes of this study, race/ethnicity groups were chosen to align with the census data and the data provided by the Babies Can't Wait center and local school district; thus, Hispanic or Latino was listed as a race/ethnicity. More specifically, if a child had Latino or Hispanic listed as their race or ethnicity, then this child was considered to be Hispanic or Latino regardless of other race or ethnicity listed. For insurance status groups, children were placed into one of the following three groups: private insurance, public insurance (e.g., Medicaid), and no insurance.

Within the EI each data set, odds of children accessing services based on the following sociodemographic groups with which they identify were examined: a) racial/ethnic groups (e.g., Feinberg et al., 2011; McManus, Carle, & Rapport, 2014; McManus, Magnusson, & Rosenberg, 2014; Paff, 2017; Rosenberg et al., 2008; Scarborough et al., 2004; Sullivan & Sullivan, 2013), b) primary language groups (e.g., Barfield et al., 2008; New et al., 2002; Paff, 2017; Peterson et al., 2004), and c) insurance status groups (e.g., Barfield et al., 2008; Magnusson et al., 2016;

Paff, 2017; Rosenberg et al., 2008; Scarborough et al., 2004). Only race/ethnicity was examined at the ECSE age range because of lack of availability of data for the other factors for this group.

Data Analysis

For the EI age range, none of the sample had missing data for race/ethnicity or for primary language. Two participants did not have insurance data and were excluded for the insurance analyses, and two participants had insurance listed as Medi-Share and were included in the "no insurance" category. For the ECSE range, the entire sample had race/ethnicity data.

Aim 1: Comparing Local Rates of Service Usage to Expected Rates of Service Usage

Analyses were conducted to examine how one local county's EI and ECSE service access rates compare to the number of children who may be eligible for these services. These rates were determined through previous studies (i.e., Rosenberg et al., 2008 and Paff, 2017) that estimated the number of children who may qualify for EI services and ECSE services based on direct child assessment data.

Early Intervention. To determine how local rates of EI service access compare to estimated rates of service access, the local percentages were compared to the estimated percentage of EI eligibility obtained by Rosenberg et al. (2008; 13.8% of the total population). A chi-square goodness of fit test was used to determine if actual local rates differed significantly from the expected rates of participation based on the literature.

Early Childhood Special Education. For ECSE services, the local rates of actual ECSE service access were compared to the estimated rates of service access (13.22% of the total population) obtained from Paff (2017) and local census data by running a chi-square goodness of fit test. This analysis helped to determine if a local underutilization of services exists for ECSE services.

Aim 2: Comparing Local Rates of Service Usage to National Rates of Service Usage

Statistical analyses were conducted to examine how local rates of EI/ECSE service usage compared to national rates of service usage. By examining local rates of EI/ECSE service access with national rates, one local county's performance regarding serving children under the age of five can be compared to how the nation provides these services as a whole.

Early Intervention. Next, another chi-square goodness of fit test was used to compare local rates of EI service access to national rates of EI service access in 2016 described by the U.S. Department of Education (2018; 3.1% accessing services nationally) to determine if these differ significantly.

Early Childhood Special Education. Then a separate chi-square test comparing local rates of ECSE service access to the national rate of children accessing ECSE services in 2016 also described by the U.S. Department of Education (2018; 6.4% accessing services nationally) was conducted.

Aim 3: Comparing Local Rates of Service Usage to State Rates of Service Usage

These analyses examined how local rates of EI and ECSE service usage compare to rates throughout the state of Georgia. According to the U.S. Department of Education, Georgia has a lower percentage of children accessing these services than national averages, so it was important to illustrate comparisons from this local county with the states averages as well.

Early Intervention. An analysis was conducted to assess how local rates of EI service usage compare to state rates of EI service usage. A chi-square goodness of fit test was used to compare local rates of EI service access to state rates of EI service access in 2016 (2.1% accessing services in Georgia) obtained from the U.S. Department of Education (2018).

Early Childhood Special Education. The final analysis of this type helped to determine if local rates of ECSE service usage significantly differ from state rates of ECSE service usage. Using a chi-square test, local rates of ECSE service access were compared to state rates of ECSE service access in 2016 (4.6% accessing services in Georgia) obtained from the U.S. Department of Education (2018).

Aim 4: Identify Disparities in Service Usage at the EI and ECSE Age Ranges

To help determine if rates of accessing services differ by sociodemographic group (i.e., race/ethnicity, insurance status, primary language status), risk ratios were calculated for each sociodemographic group. Calculating risk ratios is the preferred method for determining disproportionate representation of various sociodemographic groups of children because it gives the opportunity to compare each group of children to all other groups of children (Westat, 2004 in Morrier et al., 2012). In addition to demonstrating how this local county as a whole compared to expected, national, and state averages, risk ratios reveal additional sociodemographic patterns of service access in this local county.

Early Intervention. A risk ratio (RR; Bollmer et al., 2007) was calculated to measure disproportionality among the following factors in terms of accessing local EI service usage: racial/ethnic groups, primary language groups, and insurance status groups. To calculate a risk ratio, Figure 2.1 illustrates the equation that was used for each of the sociodemographic groups within the previously mentioned sociodemographic factors compared to the majority group (Bollmer et al., 2007).

This process was repeated for the other sociodemographic factors to determine risk ratios for each of the sociodemographic groups (i.e., race/ethnicity and insurance status) in the EI age range. Based on the lack of research documenting differences in service usage, a RR of 0.50 or less to be the cutoff for underrepresentation of a group was used, and a RR of 1.50 or more was the cutoff for overrepresentation of a group, as in previous research (e.g., Morrier & Gallagher, 2012). For the EI age range, the Native Hawaiian or Other Pacific Islander group was removed from the analyses because no one from this group received services in the local area. See Table 2.2 for additional demographic information for the sample. Although income data were included in the EI data set, this variable was excluded from analyses due the difficulty in comparing the information obtained from the EI data set to the available information provided by the ACS.

Early Childhood Special Education. Similar procedures were conducted with regards to calculating a risk ratio for each of the race/ethnicity groups for the ECSE age range. Only risk ratios for race/ethnicity were calculated for the ECSE age range due to the original data set not including sufficient information for the categories of insurance status and primary language groups. Additionally, for the ECSE age range as well, the Native Hawaiian or Other Pacific Islander group was removed from analyses because no one from this group received local services.

Aim 5: Comparing Local Group Rates to Expected Group Rates Based on Population Estimates

After the risk ratios were calculated for the various sociodemographic groups and patterns had emerged in terms of which groups were more or less likely to access services than other groups, additional analyses were conducted to continue to help further contextualize these patterns in the local context. These analyses were conducted to help compare how the rates of children within sociodemographic groups in this local county compared to how many children may be eligible from each of these groups in this local county. These efforts allowed for not only a comparison of usage pattern between sociodemographic groups to examine if disparities exist but also provided a comparison of usage relative to expected numbers of utilization for each sociodemographic group to examine if specific groups are underutilizing services compared to predicted eligibility.

Early Intervention. The number of children from each sociodemographic group accessing EI services was compared to the number of children from each sociodemographic group estimated to access EI services using the same 13.8% (Rosenberg et al., 2008) estimate across all groups. To understand the patterns of access better, a chi-square goodness of fit test was also calculated for each group of children within each sociodemographic factor (i.e., race/ethnicity, insurance status, primary language). For example, within the race/ethnicity factor, a chi-square goodness of fit test was calculated for White children, Black or African American children, American Indian/Alaskan Native, Asian, multi-racial, Hispanic, other comparing their actual rates of accessing services to their expected rates of accessing services.

Early Childhood Special Education. Finally, the number of children from each sociodemographic group accessing ECSE services was compared to the number of children from each sociodemographic group estimated to access ECSE services using the same 13.22% (Paff, 2017) estimate across all groups. Again, to better understand the patterns of access, a chi-square goodness of fit test was calculated for each racial/ethnic group of children.

Results

Demographic Data

According to ACS data, in the small metro in northeast Georgia, this survey reported that 5.6% of this local county population was under the age of 5 years. This information was used to calculate the approximate number of children between birth and three years and between three and five years in this county by splitting the data into the younger three-fifths representing 0-, 1-, and 2-year-olds, and the older two-fifths representing 3- or 4-year-olds in alignment with the EI/ECSE age split. Thus, about 4,100 children under the age of 3 years old lived in this local county at the time these estimates were published. Table 2.1 displays the demographic data for children between birth and three years in this local county as of 2016.

To estimate the number of children in the ECSE age range, this same population estimate from the ACS from the years 2012 through 2016 was used. The ECSE age range begins when a child turns three years old, and, for the purposes of this study, ends when a child turns 5 years old. Because children enter kindergarten at different ages, 5 years was chosen as the cutoff age to use for the purposes of these estimates. This information was used to calculate the approximate number of children between three years and five years in this county by using the older two-fifths representing 3- or 4-year-olds. Thus, about 2,734 children in the ECSE age range lived in this local county at the time these estimates were published. Table 2.1 displays the demographic data for children in the ECSE age range in this local county as of 2016. From the collected data from this local county only the race/ethnicity variable was available, so this variable was the only one included for analyses.

Then to determine the estimated number of birth up to three years of age and three up to five years of age in each sociodemographic category, the total number of children in each of these age categories (determined from the calculations discussed above) was multiplied by each of the sociodemographic category percentages (also obtained from the ACS). This calculation resulted in the total number of children in each sociodemographic category for birth through the end of the second year and the total number of children in each racial/ethnic category for three years through the end of the fourth year.

Data Analysis

Aim 1: Comparing Local Rates of Service Usage to Expected Rates of Service Usage

Early Intervention. Results revealed that significantly fewer children are receiving EI services in this local county than would potentially qualify based on these previous prevalence calculations, $\chi^2(1, N = 4100) = 191.68, p < .001$. Whereas about 570 children would be expected to be enrolled in services based on research calculations using a rate of 13.8% (Rosenberg et al., 2008), only 204 children were enrolled in local EI services. These analyses indicate a significant local underutilization of EI services exists.

Early Childhood Special Education. Results indicated significantly fewer children are receiving services in this local county than would potentially qualify based on previous estimates of children who might be at risk for having a developmental delay or disability who may qualify them for services, $\chi^2(1, N = 2733) = 106.55, p < .001$. Specifically, about 364 children might qualify for services using an eligibility rate of 13.22% (Paff, 2017), and only 143 children were accessing services, which indicates a local underutilization of ECSE services.

Aim 2: Comparing Local Rates of Service Usage to National Rates of Service Usage

Early Intervention. Children in this local county were significantly more likely to access EI services than children nationally, $\chi^2(1, N = 4100) = 17.99, p < .001$. If 3.1% of children accessed services locally (U.S. Department of Education, 2018), then about 128 children would be accessing services, but the 204 children accessing services locally is significantly more than would be expected. This result indicates a higher rate of accessing EI services locally than nationally.

Early Childhood Special Education. When comparing the number of children accessing ECSE services in this local county to the national percentage (6.4%) of children accessing ECSE services (U.S. Department of Education, 2018), no statistically significant difference emerged, χ^2 (1, *N* = 2733) = 3.73, *p* = .053. Using the national percentage to predict local service usage, about 176 children would be accessing services locally. Although lower than the national usage rate, the local number children (143) is similar not significantly different from what would be expected based on national percentages.

Aim 3: Comparing Local Rates of Service Usage to State Rates of Service Usage

Early Intervention. Children in this local county examined were significantly more likely to access EI services than children in Georgia generally, χ^2 (1, *N* = 4100) = 48.88, *p* < .001. Whereas it would be expected that about 86 children accessed EI services compared to the overall state percentage, 204 children were enrolled in services. These analyses indicate a higher access rate locally than at the state level.

Early Childhood Special Education. No statistically significant difference was found between children accessing ECSE services in a local county compared to the rest of Georgia, χ^2 (1, *N* = 2733) = 1.01, *p* = .314). More specifically, using the percentage of children accessing services statewide, it would be predicted that approximately 126 children would access services locally, and 143 children accessed services locally. This result indicates that children locally access services at a similar rate to what has been observed across Georgia overall.

Aim 4: Identify Disparities in Service Usage at the EI and ECSE Age Ranges

Early Intervention. To examine the likelihood of a child from one specific sociodemographic group receiving services compared to children from other groups, risk ratio analyses were conducted. As used in previous research, a risk ratio of 0.50 or less was used as the cutoff to show underrepresentation of a group, and a risk ratio of 1.50 or more was used to be the cutoff for overrepresentation of a group (e.g., Morrier & Gallagher, 2012). A risk ratio between .50 and 1.50 indicated equitable access for that group compared to other groups. Results are presented in Table 2.3. When examining the race/ethnicity variable, American Indian and Alaska Native, Asian, White, and Other children were underrepresented, and Black or African American and Hispanic or Latino were overrepresented. Results related to insurance status revealed children with private insurance are underrepresented, and children with public health insurance or no insurance are overrepresented. Finally, with regard to primary language, children whose primary language is English are underrepresented, and children whose primary language is a language other than English are overrepresented.

Early Childhood Special Education. To compare the likelihood of a child from a specific group receiving services to children from other groups receiving services, risk ratio analyses were conducted comparing each group of children to children in all the other groups. Results are presented in Table 2.3. For the ECSE age range, the data revealed American Indian and Alaska Native, Asian, White, and Other children were underrepresented. Black or African American children, Hispanic or Latino children, and children whose parents identified as having more than one race/ethnicity were overrepresented.

Aim 5: Comparing Local Group Rates to Expected Group Rates Based on Expected Estimates

Early Intervention. Finally, to aid in interpreting the results indicating group differences in terms of rates of accessing services, follow-up analyses were conducted to compare sociodemographic groups not only to the reference group but also to compare the total number of children accessing services within each sociodemographic group to the expected number of children within that sociodemographic group based on predicted eligibility percentages determined by previous research (i.e., 13.8% from Rosenberg et al., 2008). These analyses examined how the total number of children accessing services in each sociodemographic group compared to the number of children in that sociodemographic group who might be eligible for services. A series of bar graphs (Figure 2.2, Figure 2.3, and Figure 2.4) were created to visually compare the actual rates of usage for each sociodemographic group to expected rates of usage for each sociodemographic group.

White children, $\chi^2 (1, N = 4100) = 222.38, p < .001$, Black or African American children, $\chi^2 (1, N = 4100) = 20.20, p < .001$, and Asian children, $\chi^2 (1, N = 4100) = 21.77, p < .001$, were accessing services at a lower rate than would be expected for the EI age range. No significant difference between expected and actual usage rates was found for children in the other racial/ethnic groups (i.e., American Indian/Alaskan Native children, χ^2 $(1, N = 4100) = 1.14, p = .285$; multi-racial children, χ^2 $(1, N = 4100) = 3.54, p = .060$; Hispanic children, χ^2 $(1, N = 4100) = 1.30, p = .254$; and children identified as Other, χ^2 $(1, N = 4100) = 1.14, p = .285$). For children whose primary language is English, they are accessing services at a significantly lower rate than anticipated, $\chi^2 (1, N = 4100) = 210.72, p < .001$. For children whose primary language is not English, fewer children are accessing services than would be anticipated (i.e., 64 children accessing compared to the expected number of 84), but this difference is not statistically significant, $\chi^2 (1, N = 4100) = 2.88, p = .090$. Finally, within the insurance status groups, children with private insurance. $\chi^2 (1, N = 4100) = 165.51, p < .001$, children with no insurance (including those children with Medi-Share), χ^2 $(1, N = 4100) = 5.47, p < .001$, and children with public insurance, χ^2 (1, N = 4100) = 50.72, $p < .001$, are all accessing services at a lower rate than would be expected.

Early Childhood Special Education. Finally, to determine if groups of children were over or under accessing services as a group (rather than comparing them to other groups of children), the total number of children in each group accessing services were compared to the total number of children expected to access services based on previous research (13.22%; Paff, 2017). White children, χ^2 (1, N = 2733) = 132.82, $p < .001$, Black or African American children, χ^2 (1, N = 2733) = 4.23, $p < .05$, and Asian children, χ^2 (1, N = 2733) = 15.86, $p < .001$, are accessing services at a lower rate than would be expected for the ECSE age range. Children in the other racial/ethnic groups are accessing services at a similar rate to what would be expected for each of these groups in the ECSE age range (i.e., American Indian/Alaskan Native children, χ^2 (1, N = 2733) = 0.73, $p = .393$; multi-racial children, χ^2 (1, N = 2733) = 0.52, $p = .472$; Hispanic children, χ^2 (1, N = 2733) = 1.02, $p = .313$; and children identified as Other, χ^2 (1, N = 2733) = 0.74, $p = .391$). A bar graph with these comparisons is included as Figure 2.5.

Discussion

This study examined several questions related to patterns of EI and ECSE service access in a local county. Specifically, results of this study revealed an overall under access of services for both the EI and ECSE age ranges when compared to the number of children who might be eligible for services based on previous research using direct assessment data (e.g., Paff, 2017; Rosenberg et al., 2008). Whereas predicted rates are 13.8% for the EI age range (Rosenberg et al., 2008) and 13.22% for the ECSE age range (Paff, 2017), in this local district usage of EI and ECSE is 4.9% and 5.2%, respectively. Although results indicate an under access for both age ranges compared to expected rates, rates of service access for the EI age range indicate this local county has a higher percentage of children accessing services than at the national and state levels. For the ECSE age range, it was found that a similar percentage of children are accessing services when compared to both national and state percentages. The higher or similar rate of access to services compared to the national rates was unexpected in this county due to the expectation that the rates in this county would more closely align with Georgia, which has a lower documented percentage of children accessing services as a state than nationally (2.1% of children accessing EI services in Georgia compared to 3.1% nationally, 4.6% of children accessing ECSE services in Georgia compared to 6.4% nationally; U.S. Department of Education, 2016) and has been documented as a state with lower utilization compared to other states (e.g., Rosenberg et al., 2013; U.S. Department of Education, 2016). This indicates that as a whole the currently examined county is comparable or even a model for other districts at the national and state levels.

The success of this county compared to other counties in the state, and even the national averages, warrants further research examining specific patterns of sociodemographic group access. This research would help to elucidate groups of children that may be doing particularly well or particularly poorly. It is important not to assume because overall numbers for a district look good in comparison to national and state rates that access rates are equitable across socioeconomic groups. More specifically, the disparities or disproportionate access of certain groups might not be as apparent in a district performing well as they may be in a district performing more poorly, thereby warranting a more fine-grained examination.

One explanation for this local county performing better than the state and national averages may be due to some of the unique collaborations in place. Specifically, the school district has an Early Head Start and Head Start programs which are required to engage with the EI and ECSE providers, and these different entities refer children to each other readily, thus increasing the number of children participating in EI and ECSE services. This system of collaboration is not always the case across other districts and states as the two services are often conceptualized and organized as distinct. Additionally, in the current district, the ECSE and its leadership are located in the same place as the early learning leadership which provides opportunities for communication. Furthermore, in this local county the Office of Early Learning conducts Child Find, and the personnel from the Office of Early Learning serve on community collaboratives with EI personnel. With these collaborations in place, these programs are likely to follow up with referrals to ensure children get the services they need, and these data seem to reflect the school-age population (Hosp & Reschly, 2003). Previous literature has documented the importance of effective communication, common goals for interventions, and a shared desire to improve health as methods of addressing health disparities (Dankwa-Mullan & Pérez-Stable, 2016). These collaborations in this local county suggest communication, having common goals, and a shared desire to improve access to services.

Due to this county having these collaborations and this communication among its service providers, it was a good candidate for which to examine patterns of access as well as taking a closer look for disparities. Examining patterns of service access differences in sociodemographic groups' rates of service access give a better idea of ways to continue increasing equitable access to services even in a region that is already performing above average. In line with a disparities reduction framework (Kilbourne et al., 2006), to support equitable service use a more thoroughly understanding of disparities is needed through an examination of the patterns in a range of counties. Different recommendations might be needed for counties performing well and counties performing poorly.

Although this local county is performing well compared to national rates and state rates, this study aligns with previous research showing a continual under access of EI and ECSE services compared to the number of children who may be eligible based on studies providing prevalence estimates (e.g., Rosenberg et al., 2008; Paff, 2017). This result is particularly important when taking into consideration that this local county is performing similar to or better than the national rates and state rates. When comparing this county to other counties (especially across the state of Georgia), it is likely that many other districts are under accessing services at an even greater rate. Although there are improvements that could be made in this local county in terms of potentially increasing the number of children accessing services, other counties might need even more support to reach the number of children who likely have delays or disabilities that would qualify them for services. It will be helpful for future research to track patterns across the state of Georgia to determine where interventions are needed to increase service access. Additionally, it will be important to determine reasons for this under access to help plan specific interventions. For example, previous research has indicated factors ranging from the individual level to the policy or societal level. If families with lower health literacy face more barriers to accessing services (Jimenez et al., 2013), then interventions to increase health literacy might be warranted. If services are not available within the community (Little et al., 2015), then interventions to increase training programs for providers or to start new programs in areas lacking them may be the direction to head with interventions. Understanding if particular groups are experiencing disparities helps inform the development of more specifically tailored interventions; thus, the results might inform taking an approach of aiming to help specific sociodemographic groups more readily access services as opposed to an approach of widely trying to increase access for all groups.

Race/Ethnicity Patterns of EI Service Access

After establishing how this district compares to state and federal EI usage rates, the current study also sought to examine usage pattern across different sociodemographic groups to assess for disparities or differences in rates of access of EI services. This analysis was conducted in two different ways. First, simple risk ratios were calculated to examine how utilization in specific sociodemographic groups compared to other reference groups. Second, to further contextualize these findings additional analyses were conducted exploring how the total number of children in each sociodemographic group actually accessing services in this local county compared to the number of children presumed eligible for services based on eligibility estimates (Rosenberg et al., 2008; Paff, 2017).

The first examination of service access across sociodemographic groups revealed some predicted findings, as well as some unanticipated findings. One confirmed hypothesis was that for the EI age range, Asian children, American Indian and Alaskan Native children, and children with race classified as Other were found to be less likely to access services than White children. This finding aligns with a study conducted in Massachusetts also found that Asian mothers were less likely to obtain EI referrals for their children and subsequent EI enrollment (Clements et al., 2008). However, contrary to the hypothesis that all underrepresented groups would be less likely to access services, results from the current study revealed that Black or African American children and Hispanic children accessed EI services at higher rates than children of other races/ethnicities and were disproportionately represented. When exploring the previously published literature the current findings were not completely unprecedented. Although research for the younger age range has typically revealed an under access of services for underrepresented groups (e.g., Black or African American; Rosenberg et al., 2008; Feinberg et al., 2011; Fefferman et al., 2017; Clements et al., 2008; Barfield et al., 2008), one study for the EI age range indicated children with Hispanic mothers were overrepresented in EI service access (Clements et al., 2008). Similarly, this study also indicated a slight overrepresentation of children whose mothers are Black or African American accessing EI services (Clements et al., 2008). One hypothesis for the mixed findings is that although this research is trying to isolate the variable of race, this is extremely challenging to do. For example, Clements et al. (2008) also attribute some of their findings to the association of low SES with Black or African American maternal race. Thus, children whose mothers are Black or African American are more likely to have a lower SES, which likely increases their environmental risk. In this local county about 12.3% of families with a White householder fell below the poverty level while about 36.6% of families with a Black or African American householder fell below the poverty level (United States Census Bureau, 2016). Similar to the study conducted in Massachusetts, Black or African American children are more likely to live in poverty in this local county, which may increase their environmental risk impacting potential delays. Whether a group of children is under- or overrepresented, factors such as test bias, socioeconomic status, and services meeting the needs of families are likely playing a role, and either direction of representation can be problematic (e.g., Bailey et al., 2005; Rosenberg et al., 2008; Skiba et al., 2008).

To help contextualize these between race comparisons, the data were also examined by comparing actual rates of service utilization within each sociodemographic group to the number of children within each sociodemographic group who may be eligible for services. These analyses help to further elucidate trends in service access among different groups of children by documenting not only how groups compare to one another but how these groups are generally accessing based on prevalence estimates of eligibility. When compared to the number of children who might be eligible for services, White children, Black or African American children, and Asian children were significantly under accessing services; American Indian/Alaskan Native children, multi-racial children, Hispanic or Latino children, and children with race/ethnicity classified as Other were accessing services at a similar rate to what would be expected. These findings are important because they reveal that even though Black or African American children are accessing EI services at a higher rate than some other races/ethnicities and do not exhibit a clear disparity in this sense, within this group there are still significant differences between how many children are accessing services and how many children may be eligible. This study indicates that only the Hispanic group locally is performing at equitable rates and rates compared to those expected. Generally, after identifying and understanding these differences in access rates, interventions can be developed informed by this understanding (Kilbourne et al., 2006). By recognizing and studying the patterns in a high performing district, these results can begin to advise educators on how to tailor Child Find efforts and other interventions specifically to these groups that continue to under access service in the local area.

Race/Ethnicity Group Patterns of ECSE Service Access

Within the ECSE age range, the first examination of service access across sociodemographic group showed that children identified as American Indian and Alaska Native, Asian, White, and Other were accessing services at a significantly lower rate when compared to the other races/ethnicities. On the other hand, children identified as Black or African American, Hispanic or Latino, and Multi-Racial were accessing services at a significantly higher rate when compared to the other races/ethnicities. These ECSE results closely align with the EI results showing a similar pattern of sociodemographic group access. Some of these similarities may be due to the overlap in children served by EI and ECSE. Specifically, EI providers help with the transition to ECSE services, so it would be expected that EI and ECSE service providers will be interacting with a similar population. Additionally, families are required to seek out these services as opposed to the school-aged population who may be more easily identified once already enrolled in school. Although Black or African American children, Hispanic or Latino children, and multi-racial children were not predicted to access services at higher rates than other races/ethnicities in the current study, the patterns of access to services appears to mirror some of the literature found for school-age children (e.g., Hosp & Reschly, 2003). More specifically, the Hosp & Reschly (2003) study found that children who were Black or African American or Hispanic got referred to special education at higher rates than children who were White. This study demonstrated a similar trend in a local county for a younger population. This study indicates the importance of studying each age range that receives a distinct set of services separately. Based on differences in EI and ECSE service structure (e.g., EI service providers going to children's homes and ECSE service providers being at a school or other center), it is not surprising that some of the ECSE patterns align with other public school trends for the older age groups.

These initial ECSE results were also more closely examined by conducting additional analyses exploring how the actual number of children within each sociodemographic group accessing services compared to the number of children within that sociodemographic group who might be eligible for services. Although Black or African American children and Hispanic or Latino children received ECSE services at a higher rate than children of other races and ethnicities, when compared to the number of children who may be eligible, White children, Black or African American children, and Asian children were all significantly under accessing services. Only the Hispanic/Latino group was accessing services at comparable rates and more readily than peers from other racial groups. With less research for the ECSE age range, it was more difficult to predict results for a local county, and this study contributes to the literature by identifying patterns of ECSE service access in a local county. Similar to how more Black or African American children live below the poverty threshold compared to White children in this local county, 39.2% of Hispanic or Latino families also live below the poverty line compared to the 12.3% of White children (U.S. Census Bureau, 2016). Again, with poverty impacting environmental risk, Hispanic or Latino children may be exposed to higher environmental risk increasing the need for EI and ECSE services.

Additional EI Sociodemographic Comparisons: Primary Language and Insurance Status

For insurance status and primary language groups, analyses were only conducted for the EI age range because of the limited information from the ECSE age range in the original data set. Regarding the primary language spoken by the family, children from families whose primary language is not English were significantly more likely to access services than children from families whose primary language is English. Furthermore, when comparing these rates to the rates of children who may be eligible for services in each of these groups, children whose primary language is English are accessing services at lower rates than would be expected while children whose primary language is not English are accessing services at a similar rate as what would be expected. Although these results were not anticipated, another study found that children whose primary language was a language other than English were underrepresented in special education in kindergarten, but overrepresented in special education by third grade (Samson & Lesaux, 2009). The results from the current study align with this study but for a younger age range. Previous research has attributed some of the disproportionality in representation of English language learners in special education to bias in referral source (Harry & Klingner, 2014 as cited in López & Linn, 2018) and biased assessment instruments (Skiba et al., 2002).

When examining the insurance status, children from families who had private insurance were less likely to access services than children who had public insurance or no insurance. This finding might be somewhat biased because children who have a disability may qualify for public insurance based on their disability. With this being the case, these children would likely need to access services at higher rates than those children who do not qualify for public insurance based on a disability. This result should be interpreted with caution due to this fact, and this result should not be interpreted as children with public insurance or no insurance being overserved. Furthermore, it is possible that children with private insurance have a higher likelihood of accessing private services, which could possibly decrease their use of publicly funded EI services. Finally, children from families with a lower income are more likely to qualify for public health insurance. Thus, some of these differences may be accounted for by a higher percentage of children from families with lower income qualifying for services due to the multiple risk factors associated with living in poverty (Coutinho & Oswald, 2000; Coutinho et al., 2002; National Research Council, 2002). With more children from families with a lower income potentially being eligible for services due to facing multiple risk factors (Coutinho & Oswald, 2000; Coutinho et al., 2002; National Research Council, 2002), children living in poverty may qualify for services at a higher rate than children who are not living in poverty. Compared to the number of children who may be eligible for services in the no insurance, public insurance, or private insurance groups, children in all these groups were significantly under accessing services. Thus, children with any insurance status would benefit from an increase in access to services.

Differences Between the EI and ECSE Age Ranges

Furthermore, differences were observed between the EI and ECSE age ranges. Specifically, children in the EI age range accessed services at higher rates than the national and state averages while children in the ECSE age range accessed services at similar rates to the national and state averages. The requirements and qualifications for accessing EI services differs from the requirements and qualifications for accessing ECSE services (Danaher et al., 2004), and it was found that in a county in Georgia, these differences led to variances in rates of accessing services. More specifically, EI services are typically based in the home and are family-centered while ECSE services are typically based in a school or early learning center and are individual-centered. Furthermore, different criteria exist for EI and ECSE services that may result in children no longer qualifying for services once they age up into the ECSE age range (Danaher et al., 2004). These differences in location of services and focus of services may contribute to some of the differences observed in this study. It is important to consider these differences when trying to increase access to services across all age ranges. For example, families may find it helpful if ECSE service providers came to their homes or if transportation was available and advertised for the ECSE age range.

Limitations and Future Directions

This study also had some limitations. The first major limitation was that confounding factors were not controlled for in either age range. Prior research has argued that calculating disproportionate access of services based on race and ethnicity requires the control of confounding factors such as primary language and SES (e.g., Morgan et al., 2012). Morgan et al.

(2012) argue that including only race and ethnicity will overestimate the variance assigned to this one factor, because previous research has revealed children from some race and ethnicity groups are more likely to experience other factors (e.g., environmental, economic) that are related to higher rates of delays (e.g., National Research Council, 2002). Although factors such as family income and insurance status were examined for the EI age range, these factors were not put into one regression model to control for the overlapping variance of these factors due to the inability to conduct a regression with the data available. More specifically, the EI data set only included those children who qualified for services, and the ECSE data set only included those children who were evaluated for services. For neither age range was there a comparison group of children who did not receive services but lived in the county. Thus, based on not having access to the entire population, insufficient data were available to have a dependent variable that allowed comprehensive coverage of children accessing and not accessing in the county. Furthermore, these other factors (e.g., insurance status, primary language) were unavailable for the ECSE group, and the researcher aimed to have parallel analyses across both age ranges. Additionally, some of the examined factors were missing for the ECSE data set and neither included additional relevant factors, such as parental level of education and family monthly expenses. In addition to sociodemographic factors being missing, other data were not included such as if any children received private services. A final limitation of this study is the use of only one rate each for state rates, national rates, and children who may be eligible rates. Instead of adjusting for certain groups potentially showing a higher need for services, this study used one rate at each level of analysis across all groups and potential levels of need. Because of the lack of availability group specific eligibility, it would not have been possible to calculate unique rates for each group of children, so a common rate across all groups of children was chosen.

Future research should continue to examine patterns of service access across other counties in Georgia. As this study helped show, rates of service access for EI and ECSE services appears to vary by geographical area, so it will be important to identify other counties that may contribute additional information to the identifying of these patterns (e.g., more rural counties, more urban counties, counties with a lower median family income). Additionally, future research should begin to examine why some families are accessing services when others are not accessing services to help plan how to increase service access.

Study Summary

This local county analysis demonstrated rates of children accessing services at the EI and ECSE age ranges that were similar to or higher than national and state rates to help determine the performance of this local county with regard to serving children under the age of five through EI and ECSE services. That said, overall, the results of this study reveal an under access of services across almost all groups of children. With the knowledge that some children who may qualify for services are not accessing them, the next step would be to identify patterns in who is under accessing and barriers to accessing services (Kilbourne et al., 2006).

The examination of disparities revealed that some groups (i.e., Asian, American Indian and Alaskan Native children, and Other) were disproportionately underrepresented in EI and ECSE service access. However, in alignment with research conducted within the school age population (e.g., Hosp & Reschly, 2003), this study found that Black or African American and Hispanic or Latino children were disproportionately overrepresented in EI and ECSE service access. The additional steps to contextualize the group findings revealed that despite this overrepresentation Black or African American families were still under accessing compared to predicted eligibility rates. This is an important step toward demonstrating which particular groups should be targeted in interventions designed to increase use generally but also more equitable use.

To help gain more information about what barriers or supports exist for families, it will be important to learn more about the experiences families face when trying to get services for their children. This study elucidates that is important to gather information from a range of sociodemographic groups given the different patterns observed. Once more information has been obtained regarding both the rates and patterns of service access and the experience families have had in obtaining services, then specific interventions can be planned to address these concerns. With the results from the current study as well as future studies, interventions can be put into place to increase availability of services as well as access to services.

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Table 2.1

Percentage of Total Population and Number of Children in a Local County in Georgia Between Birth and Three Years Based on Data from ACS

Demographic Variable	Number of EI-Aged Children (Percentage of Population)	Number of ECSE-Aged Children (Percentage of Population)
Race/Ethnicity		
American Indian and Alaska Native	8 (0.2)	5 (0.2)
Asian	177 (4.3)	118 (4.3)
Black or African American	1121 (27.1)	747 (27.1)
Hispanic or Latino	434 (10.5)	289 (10.5)
Native Hawaiian and Other Pacific Islander	0 (0.0)	0 (0.0)
White	2312 (55.9)	1541 (55.9)
Two or more	70 (1.7)	46 (1.7)
Other	8 (0.2)	5 (0.2)
Insurance Status		
No insurance	273 (6.6)	182 (6.6)
Private health insurance	1667 (40.3)	1111 (40.3)
Public health insurance	2196 (53.1)	1465 (53.1)
Primary Language		
English only	3524 (85.2)	2350 (85.2)
Language other than English	612 (14.8)	408 (14.8)

Note. In the cases of EI data that do not add up to 4137 children, it is due to differences associated with rounding. In the case of the ECSE data, the number of children does not add up to 2758 due to differences associated with rounding.

Table 2.2

Number of Children Accessing EI and ECSE Services in a Local County in Georgia from the 2015-2016 School Year

Demographic Variable	Number of Children Accessing EI Services	Number of Children Accessing ECSE Services
Race/Ethnicity		
American Indian and Alaska Native	0	0
Asian	1	0
Black or African American	85	73
Hispanic or Latino	73	30
Native Hawaiian and Other Pacific Islander	0	0
White	42	32
Two or more	3	9
Other	0	0
Insurance Status		
No insurance	20	-
Private health insurance	27	-
Public health insurance	155	-
Primary Language		
English only	140	-
Language other than English	64	-

Note: Data related to level of income, insurance status, and primary language are not included for children accessing ECSE services due to these data not being included in the service provider data set.

Figure 2.1

Example of How the Risk Ratio for Primary Risk for "Primary Language Other than English" Group Compared to "Primary Language English" Group was Calculated

$$\text{Risk ratio} = \frac{\text{Risk for those with a primary language other than English}}{\text{Risk forthose with English as primary language}}$$

$$\text{Risk for those with a primary language other than English} = \frac{\text{Students accessing EI services who have a primary language other than English}}{\text{Total number of students who have a primary language other than English}}$$

$$\text{Risk for those with English as primary language} = \frac{\text{Students accessing EI services who have a primary language that is English}}{\text{Total number of students who have a primary language that is English}}$$

Table 2.3

Risk Ratios for Participation in EI and ECSE Services

Demographic Variable	Risk Ratio (EI)	Risk Ratio (ECSE)
Race/Ethnicity		
American Indian and Alaska Native	0.00^{*}	0.00^{*}
Asian	0.11^{*}	0.00^{*}
Black or African American	1.81^{+}	2.76^{+}
Hispanic or Latino	4.71^{+}	2.24^{+}
White	0.20^{*}	0.22^{*}
Two or more	0.86	3.85^{+}
Other	0.00^{*}	0.00^{*}
Insurance Status~		
No insurance	1.55^{+}	-
Private health insurance	0.23^{*}	-
Public health insurance	3.04^{+}	-
Primary Language~		
English only	0.38^{*}	-
Language other than English	2.63^{+}	-

*Group significantly underrepresented (i.e., RR < 0.50)

$^{+}$Group significantly overrepresented (i.e., RR > 1.50)

~Additionally, it should be noted that the insurance status and primary language groups were not examined for the ECSE age range due to data not being included in original data set.

Figure 2.2

Expected Versus Observed Numbers of Children Participating in EI Services by Racial/Ethnic Group

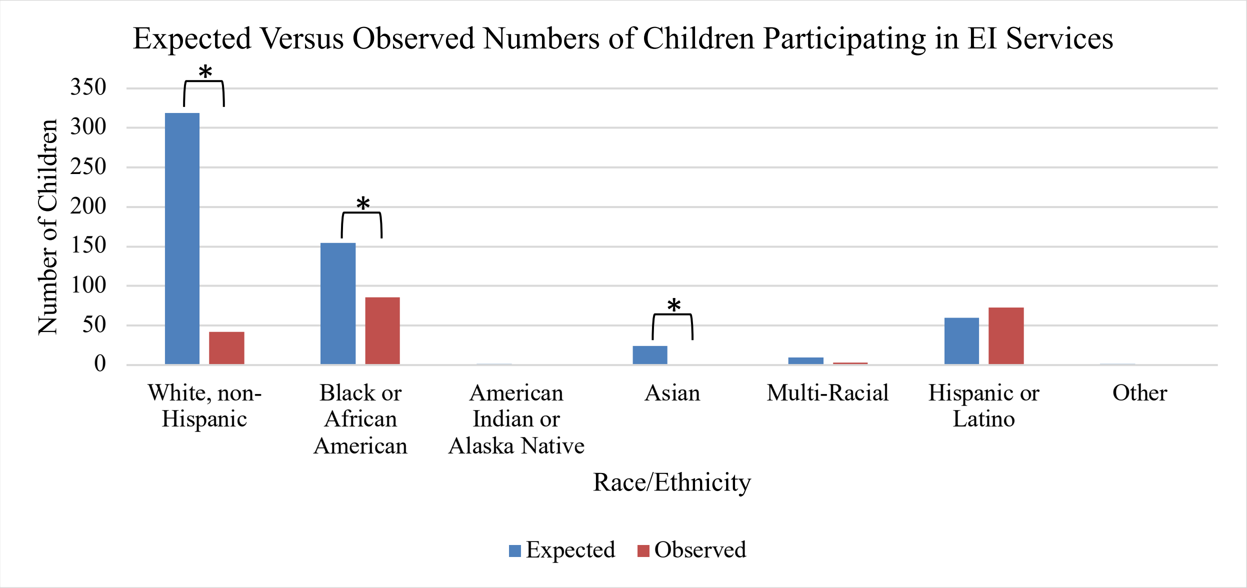


Figure 2.3

Expected Versus Observed numbers of Children Participating in EI Services by Primary Language Group

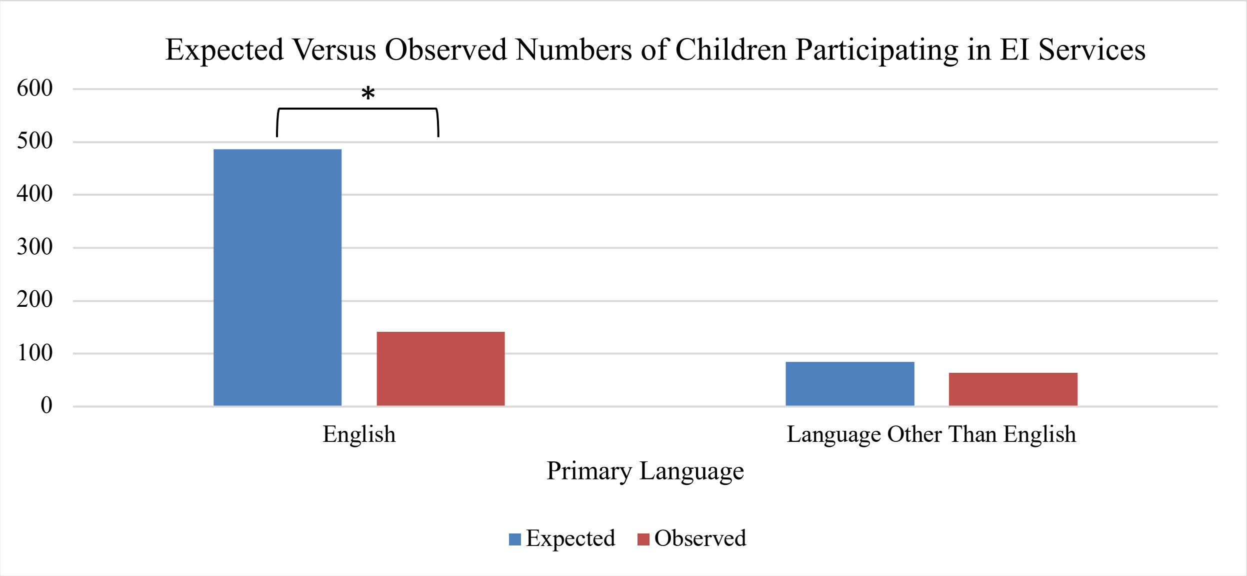


Figure 2.4

Expected Versus Observed Numbers of Children Participating in EI Services by Insurance Status Group

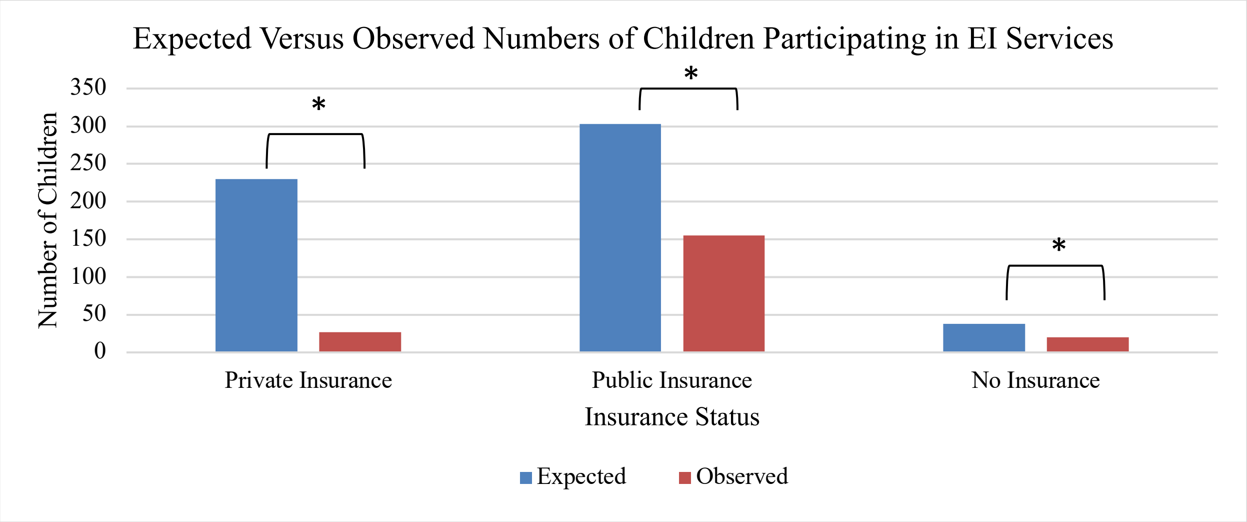
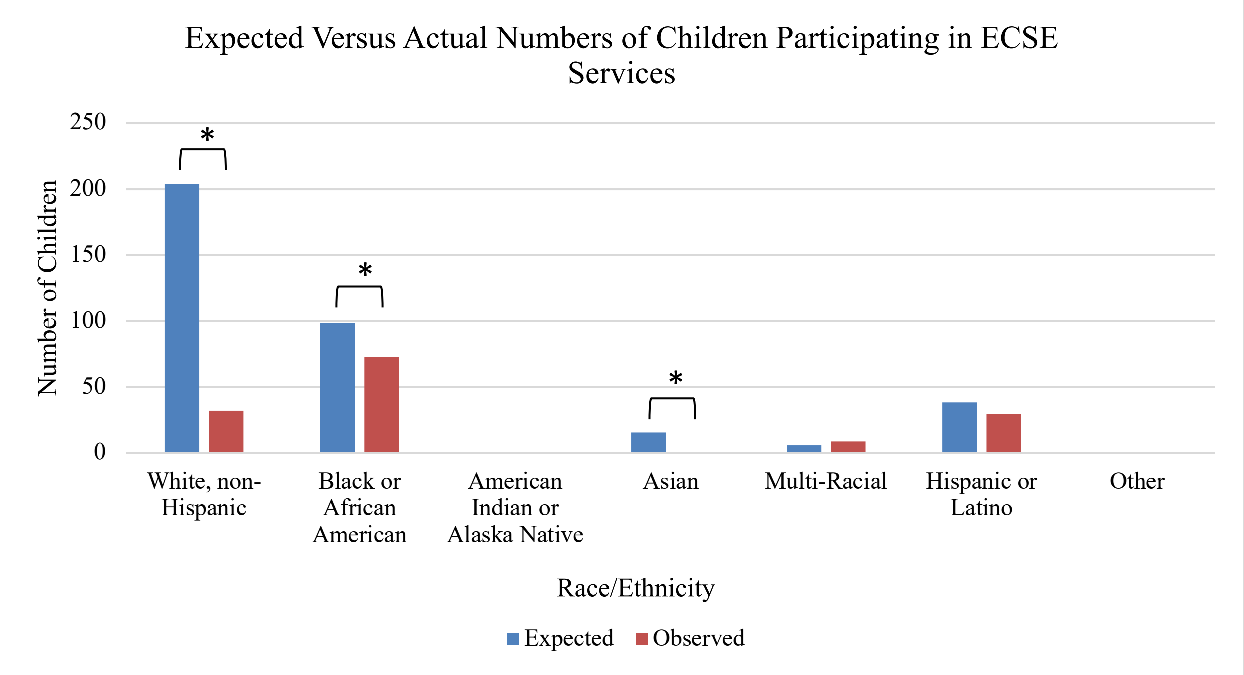


Figure 2.5

Expected Versus Observed Numbers of Children Participating in ECSE Services by Racial/Ethnic Group



CHAPTER 3

IDENTIFYING BARRIERS IN ACCESSING EI AND ECSE SERVICES

After identifying whether or not disparities exist in service use, the next step in a disparities reduction framework is to determine potential reasons for the disparities by examining barriers and supports impacting usage (Kilbourne et al., 2006). Although research has documented underutilization and disparities in accessing early intervention (EI) and early childhood special education (ECSE) services, limited research has examined barriers and supportive factors that impact accessing these services. This important step needs to be completed to plan how to increase service usage among all groups, but especially among those with lower rates of accessing services. With research suggesting a great deal of variability in service use patterns across states (e.g., Barfield et al., 2008; Clements et al., 2008; Fefferman et al., 2017; Feinberg et al., 2011; Hosp & Reschly, 2003), these barriers should be examined at the local level to identify factors distinct to each geographical area. By identifying which barriers prevent families from accessing services and which supports aid families in accessing services, researchers can more effectively create targeted interventions.

Prior qualitative studies have examined barriers and supportive factors impacting the access of several types of services, including EI services (e.g., Evans et al., 2016; Jimenez et al., 2013; Little et al., 2015), specific disability services such as those for children with autism spectrum disorder (e.g., Pearson & Meadan, 2018; Zuckerman et al., 2014), and a home-visiting intervention program (Jean-Baptiste et al., 2017). However, additional qualitative studies are also needed to examine the specific factors that impact whether primary caregivers successfully access ECSE services. Given the differences between EI and ECSE (Danaher et al., 2004) and the differences observed between the two groups in study 1, the assumption cannot simply be made that the same barriers impact both types of service access. Once a child turns three years old, the child's school district becomes responsible for providing services and determining eligibility for services, and this system might have different gaps or limitations than EI. Additionally, primary caregivers might have different experiences trying to access these services than they do trying to access EI services because of the differences in the process of obtaining these services, the distinctions in agencies who are in charge of these services, and the variable criteria for eligibility (Danaher et al., 2004). By interviewing primary caregivers of children who are eligible for ECSE services, it is possible to acquire current and accurate information about their experiences obtaining these services. Although inferences as to the potential barriers to ECSE can be gained from other bodies of literature, like EI as discussed below, learning about barriers unique to ECSE has great merit.

Barriers to Accessing EI Services

Specific barriers in accessing EI services identified through qualitative research include factors at different levels of the social ecological disparities model. By interviewing parents and service providers, researchers were able to identify certain barriers that could then be addressed through interventions. The barriers identified across studies ranged from the individual level (e.g., family denies services) to the community (e.g., services not being available) or even potentially policy level. However, as previously mentioned it is important to re-examine these barriers within different regions to determine if universal roadblocks emerge or whether distinct trends will arise in different geographical regions.

Individual factors that have been identified as impacting EI access include variables ranging from not understanding services (e.g., Barlow et al., 2005; Evans et al., 2016) to parents feeling like too much was going on in their lives already (e.g., Barlow et al., 2005). For example, research suggests that when a referral is made, but the family does not accept these services this can be in part attributable to parent denial of delays or due to a lack of understanding of services (Little et al., 2015). Another study which included interviews of parents who had a child referred for EI services identified some differences in experiences between parents with high health literacy and parents with low health literacy (Jimenez et al., 2013). Those parents with low health literacy faced several barriers that were not as prominent for those parents with higher health literacy (Jimenez et al., 2013). Additionally, this study found that parents also had some difficulty staying with one pediatrician (Jimenez et al., 2013), which may be an Individual level factor or an Interpersonal factor. A study conducted in the United Kingdom (UK) interviewing 19 women who qualified to receive in-home services but declined them also identified individual barriers to obtaining services; the barriers discussed by these women included misunderstanding of the services, not trusting the services, and already having existing support (Barlow et al., 2005). Some of these barriers also need to be assessed at the interpersonal and organizational levels (e.g., clearer and more appropriate explanation of the services). Because of the health care disparities experienced by certain groups of children, a final study specifically examined the experience of 10 black or African American mothers who had a child with a diagnosed disability and eight of whom were accessing early intervention services (Evans et al., 2016). As opposed to examining barriers, this study used "The Family Strengths Model" as the theoretical framework and identified themes that related to positive views of their child's disability. The five themes identified were the child's father being involved, experiencing a "positive spiritual connection," having good social supports, understanding EI services, and the parents having a positive experience of disabilities from their own childhood (Evans et al., 2016). Although some studies took a barriers approach to examining families' experiences at the Individual level, other studies approached this level with a more positive or strengths-based perspective. Future research should continue to examine these barriers or supports in other geographical areas.

Additional barriers have been identified at the Interpersonal level as well. One systemic barrier results from referrals not occurring even though they would be appropriate, which can happen because service providers might not have a complete understanding of the EI process or have not connected families with EI services successfully (Little et al., 2015). Additional Interpersonal barriers included trouble getting in touch with service providers or staff members of early intervention and either having pediatricians who did not provide a thorough explanation of early intervention or not having access to helpful written materials (Jimenez et al., 2013). These barriers occur at the Interpersonal level between caregivers and service providers, but additional research in other geographical areas is still needed.

Furthermore, prior research has identified barriers at the Organizational and Community levels also. Based on interviews conducted with parents and service providers of very low birth weight infants, children might not be identified as eligible because of inadequate tools to assess for delay (e.g., a tool that cannot be used for children younger than 4 months; Little et al., 2015). A final gap identified occurs when a child is evaluated for services, the child is determined to be eligible, and the family accepts the services but the services are not available or are not of high quality (Little et al., 2015). Organizational and Community level barriers are frequently out of the control of families trying to access services thus, it is important for policy makers to have a strong sense of what these are to aid in making the system more successful and equitable.

At the Policy level, some children can lose eligibility status because of changes in eligibility criteria resulting from funding variability (e.g., creating stricter criteria to ensure fewer children are eligible; Little et al., 2015). If any of these gaps occurs in the EI process, the child is unlikely to receive the services they need. To plan effective interventions, the barriers should be considered in the context in which they were identified, and the interventions should specifically address the identified barriers. Family perspective as to what these policy level barriers might be can provide unique and helpful insight.

Families face barriers at all levels of the model, and researchers have identified a variety of barriers at each of the levels. The literature, however, does not seem to be presenting a comprehensive picture. Many of the studies conducted have been qualitative and have been conducted on small samples. To learn more about the local area, additional research is needed specific to the experiences of families in this local county. Furthermore, other barriers and supports have been identified for health and educational services, so more research should examine if some of these barriers and supports are present at the EI age range as well.

Refinement of Educational Disparities Model

Although some barriers and supports overlap between the experience of caregivers attempting to access EI services and the experience of caregivers attempting to access ECSE services, additional research is needed examining the experience of families trying to access ECSE services. Some research has assessed the barriers to and supports for accessing EI services, yet limited research exists in the area of caregivers accessing ECSE services. In addition to previously examined EI barriers, other educational barriers can be hypothesized, such as parents experiencing stigma from their child being classified as having a disability or being placed in special education (Ali et al., 2012; Kauffman & Smith, 2003), parent advocacy playing a larger role due to its inclusion in IDEIA (2004), parents interacting directly with schools, and teacher self-efficacy in addition to parent self-efficacy (Little et al., 2015). Because of the differences between EI and ECSE (e.g., eligibility criteria, location services are offered), additional information should be gathered from primary caregivers with regard to accessing both types of services. Barriers identified might be different for accessing ECSE services as compared to accessing EI services based on difference in referral process, location of services, service providers, and criteria to access services. Thus, research examining barriers for each age range is necessary to ensure that the model of educational disparities developed for this study includes barriers relevant to EI and ECSE.

This study will use a social ecological based model of educational disparities to guide the interviews, and the responses obtained from families in this study will inform future actions to address barriers identified. This model was created by combining existing models of barriers leading to health disparities in a range of other fields as well as adding factors associated with barriers in accessing EI services but has not benefited from the inclusion of ECSE specific factors. To emphasize what education specific factors have been added to the original health disparities model, an updated version of the model (with EI factors and education factors hypothesized added) is displayed in Figure 3.1. Information obtained from primary caregivers of children who could qualify for EI or ECSE services will be analyzed and used to inform model refinement to illustrate a comprehensive list of barriers to obtaining educational services, which might likely lead to disparities.

Aims of Current Study

While some qualitative research has examined barriers to EI service access, additional research in this area is still needed and much less research has been conducted on the experiences of primary caregivers and service providers at the ECSE age range. Although some barriers to and supports for obtaining EI and ECSE services overlap, future research should be conducted to identify specific barriers to receiving ECSE services as differences in the referral process and the intervention context, among others, can differ.

This study aims to address the lack of research examining the experience of families attempting to access both EI and ECSE services. The first goal of this study is to identify barriers to accessing EI and ECSE services by interviewing families who have been successful in obtaining these services as well as interviewing families who have not been successful in obtaining these services but whose children would likely qualify. The second goal of this study is to identify supports for families in obtaining ECSE services and to determine what families find helpful by interviewing the same two groups of families.

Method

Sample

Using purposeful sampling (Creswell, 1998), families were recruited for the study if they met two criteria at the time of recruitment: 1) had a child 6 years or younger and 2) had a child enrolled at some point in EI or ECSE services or with some type of developmental or learning concern but who had not received services. The second group consisted of families that had any concerns about their child's development and families referred for an evaluation but never scheduled an appointment for their child to be evaluated. Primary caregivers knowledgeable about their child's background were interviewed. Twenty-five interviews were conducted with a single individual (one parent or one grandparent), and three interviews were conducted in pairs (either two parents or a parent and grandparent). General information about the participants is included in Table 3.1.

A review examining sampling practices as well as sample size among education studies indicated qualitative researchers interviewed between 6 and 134 participants for a grounded theory study (Guetterman, 2015). Based on the wide range of number of participants interviewed, thematic saturation (Morse, 1995) was used to help determine the final acceptable sample size of 28 participants. As the study was being conducted, the interviews were transcribed and analyzed to code themes.

Measures: Interview Development

Given the exploratory nature of this study, the questions developed for the interview were written broadly to allow for families to give an account of their experiences with the EI and ECSE referral process and with accessing EI and ECSE services. Additionally, some questions from the interview were developed by referencing interviews from prior research studies (i.e., Dababnah & Bulson, 2015; Little et al., 2015; Samadi et al., 2011; Zuckerman et al., 2014), but the overall structure of the interview and the majority of questions were taken from or adapted from the Samadi et al. (2011) study. The interview was semi-structured to allow researchers some flexibility in the questions they asked and to ensure the questions were relevant to each family. The interview was developed using the framework described by Mason (2018) which presents steps in the interview process that start with considering one’s primary research questions broadly and then moving toward more specific questions. Broad questions focused on asking caregivers to describe the delay or disability of the child and moved toward asking more specific questions about the experience of the family with the referral process, evaluation process, and enrollment process in EI or ECSE services. The interview included questions about any supports the family had during the process of obtaining EI or ECSE services, as well as any barriers they experienced in trying to obtain these services. Additionally, specific questions addressed hypothesized barriers/supports from each level of the socioecological model discussed earlier. Additional open-ended questions were included to help probe for original themes not included in the hypothesized model (Figure 3.1). Each section of the interviews included an intent which reflected the purpose for including that section's questions. Each section of the interview document contained a statement of intent for the purposes of increasing consistency among interviewers regarding the desired information for that section. Sample intents include: 1) *The purpose of this section of the interview is to build rapport and allow the family to share information about their child that we may not explicitly ask about* and 2) *The purpose of this section is to determine if the child has ever had an evaluation or assessment for their learning or developmental difficulties, and if so, we want to know more information about the experiences parents had in participating in the evaluation process. Additionally, we want to know how they found out about the evaluation and how they felt after the evaluation took place.* The complete semi-structured interview is included in Appendix A, but this was a fluid guide. Interviewers omitted irrelevant questions or included additional questions as necessary. For example, one of the questions from the interview was, "Has your child ever been assessed by a psychologist or the schools for a potential developmental or learning concern?" If the participant responded "yes," then a set of questions was asked, but if the participant answered "no," then that set of questions was skipped.

Procedure

The participant contact information was obtained from both broad recruitment efforts in the community and through the office of preschool special education at a local school district. The researchers collaborated with the Special Education Coordinator to obtain a list of all students being served through early childhood special education services in the local school district. Those identified through the local school district received a letter in the mail notifying them of their eligibility for the study. Additionally, researchers broadly recruited in this local county by posting flyers in the community (specifically targeting doctor and therapist offices), publishing advertisements in the newspaper, and sharing information about the study online. For those individuals who called or emailed to participate in the project, a researcher conducted a phone screening with the potential participant to determine eligibility. Criteria to participate in the study included: 1) Parent or primary caregiver of a child 6 years or younger and 2) Caregiver report that someone (including parent) has expressed some concern about their child's development, learning, or behavior, or their child has an identified delay or disability (including those that have and have not received services). Once determined to be eligible for the study, the researcher set a date, time, and location for the interview with the participant. All interviews were conducted in the lab at a local university or in the participant's home. Interview location was determined based on participant preference.

Before the interview began, the researcher reviewed the consent form with the eligible participant and did not begin the interview until consent had been obtained and any participant questions answered. This study has approval from the university Institutional Review Board. The interviews were conducted either by a doctoral candidate or the candidate's faculty mentor. All interviews were audio recorded except one based on the parents' preference to participate in the study without being audio recorded. The interviewer also took notes during all interviews. Additionally, participants completed a demographic questionnaire to provide additional information about their child and family. Domains assessed in the demographic questionnaire included: 1) those pertaining to both the child and caregiver or the household (i.e., date of birth, race, ethnicity, birth country, primary and other languages spoken in the household, number of adults and children living in the household, who contributes the most money to the household, total household income from all sources, whether or not the household income stays the same month to month, whether or not the family owns a home), 2) those pertaining to the child alone (i.e., child's primary language, location child currently lives, and school status), and 3) those pertaining to the caregiver alone (i.e., relationship of participant to child, whether or not the participant has ever served in the military, participant's number of children, participant's marital status, participant's highest level of education, participant's usual occupation, participant's employment status, and participant's school status). Additionally, all information collected about the participant was also collected for the child's second caregiver if applicable.

All interviews were conducted in English, and the interviews lasted 34 minutes and 14 seconds on average, with the shortest interview having a duration of 19 minutes and 6 seconds and the longest interview having a duration of 67 minutes and 3 seconds.

Data Analysis

The interviews were transcribed by the doctoral candidate or a research assistant. All transcriptions were double-checked for accuracy and cleaned to ensure all information was de-identified. All research assistants were trained and given explicit instructions on the formatting of the transcriptions. In cases where the interview was inaudible, research assistants would contact the doctoral candidate for her to review and make a final transcription decision.

An initial codebook was developed to align with the tiers of the socioecological model and the initial proposed barriers and supports derived from the literature (Barlow et al., 2005; Betancourt et al., 2003; Birkin et al., 2008; Evans et al., 2016; Horn & Beal, 2004; Kilbourne et al., 2006; Jimenez et al., 2013; Little et al., 2015; McLeroy et al., 1988;). Additionally, 10% of the transcriptions (i.e., three transcriptions) were reviewed by the doctoral candidate and faculty mentor to verify the initial codes, add new codes, and to finalize the codebook. This approach aligned with a deductive approach to thematic analysis, whereby themes were identified based on the participants' responses and organized into the theoretical framework provided by the socioecological model: 1) Individual (caregiver) factors, 2) Interpersonal factors, 3) Organizational factors, and 4) Community factors. Prior research has described the methods of thematic analysis and the use of a coding framework (Nowell et al., 2017) in a similar way to the current study in using a theoretical framework to guide theme selection.

Interrater Reliability

Once the initial codes were identified and the codebook was created, an additional 10% of the transcriptions (i.e., three transcriptions) were coded by the doctoral candidate and the faculty mentor to establish interrater concordance. The doctoral candidate identified the "meaningful units of analysis" by highlighting a section of text and indicating the number of codes she used for that text (Campbell et al., 2013, p. 304). This method of determining interrater concordance was chosen based on the varied lengths of responses and the frequency with which more than one code was needed for a section of text.

Agreement was determined by comparing the subcategory codes from each rater for each meaningful unit of analysis. For example, the subcodes within one theme "has accurate knowledge about symptoms," "has accurate knowledge about treatment/disability services," "has accurate knowledge about etiology," and "has accurate knowledge about typical development" were all collapsed into one code of "has accurate knowledge." Additionally, some codes were collapsed into one category even across themes for the purposes of calculating interrater concordance and theme analysis because they represented a similar/overlapping construct. For example, positive interaction between provider and parent *and* parent having positive attitude/feeling/perception of provider were originally in two theme areas but collapsed into one code with an overarching theme of caregivers having positive interactions with and attitudes about providers. This approach was used because during consensus conversations it was not uncommon for the raters to discuss and come to the agreement that both codes were applicable to that section. Using this method, raters agreed approximately 73.8% of the time on average across the three transcriptions they both coded after consensus conversation. Finally, after discussing any meaningful units of analysis where the two raters disagreed, the two raters reached 100% agreement.

Following this method of coding varying meaningful units of analysis as opposed to lines of text or sentence by sentence, the doctoral candidate coded the remaining transcriptions. New codes were developed and added to the codebook during the process of coding the remaining transcriptions. The interviewers continued conducting interviews until saturation was reached (Morse, 1995). Thematic saturation was reached when the last two interviews were coded and no new codes were added to the codebook.

Based on differences between EI and ECSE services, it was necessary for these two types of services to be examined separately. Thus, codes were separated into those that applied to EI specifically (from 21 participants), ECSE specifically (from 15 participants), and both EI and ECSE (from 6 participants) by placing them into these groups based on what the participant was discussing at that time in the interview. As an example of an interview which included EI and ECSE codes, this interview could have codes specific to EI (e.g., convenience of Babies Can't Wait appointments), codes specific to ECSE (e.g., attending an evaluation for ECSE services at a school), or codes that could apply to both (e.g., age at which child first received services). After all transcriptions were coded, the doctoral candidate organized the codes into themes and identified quotations to support the themes for EI and ECSE.

The themes that are included as meaningful results were endorsed by "many" participants (i.e., more than half of the participants for that age group) or by "several participants" (i.e., more than one-fourth and less than half of participants for that age group). This method of theme selection was chosen to provide consistency in how themes were selected without depending too much on the numbers themselves which could lead to the overgeneralization of themes (Maxwell, 2010). Additionally, using a numerical basis for choosing themes helps to identify themes that may not have been obvious (James, 1984 and Sadker & Sadker, 1995, p. 2 in Maxwell, 2010) and to avoid picking only those themes that fit what the researcher was expecting to find (Maxwell, 2010). Furthermore, the semi-structured nature of the interview resulted in each interview being unique and some participants getting questions that other participants did not get. Thus, the researchers perceived it would be misleading in some cases to report exact percentages based on the way questions were asked.

Results

The doctoral candidate and faculty mentor conducted 28 interviews with caregivers of children 6 years and younger with some type of developmental, behavioral, or learning concern. Because one parent declined to be audio recorded, only 27 of the 28 interviews were transcribed; however, all interviews were coded and analyzed, with the non-recorded interview coded and analyzed from handwritten notes made by the interviewer. No sample quotations in the remainder of this paper were taken from the participant who declined to be audio recorded.

The themes that emerged during analysis of codes were organized around the following four factors in alignment with the socioecological model: 1) Individual (caregiver), 2) Interpersonal, 3) Organizational, and 4) Community. Although the themes are organized into these four factors, many factors interact with and overlap with other factors in the socioecological model. The results are organized according to the themes that emerged for both EI and ECSE services, EI services alone, or ECSE services alone. All themes are discussed in the context of their role as a barrier (a factor that likely caused difficulty in receiving services or prevented services altogether) or a support (a factor that likely aided in receiving services) suggested by a review of the literature or directly stated by participants. Additionally, the most commonly reported or most seemingly meaningful themes in each age group are discussed in more detail below. Though this does not include a discussion of all themes that were reported, all themes discussed by "several" or "most" participants in each age group are included in Table 3.2 and Table 3.3.

Themes for Both Early Intervention and Early Childhood Special Education

Individual Factors

Barrier: Inaccurate or Limited Caregiver Knowledge (Endorsed by Many). Many participants either reported having limited knowledge about symptoms, treatment, etiology, or typical development or these participants demonstrated a lack of knowledge by reporting inaccurate knowledge. For example, one participant reported not having knowledge of the variety of delays that may exist, "*I feel like my understanding of kind of the- the general message of what I think everybody knows is that I was only aware of like the really, really severe bad* *levels of things"* (Participant 19- EI). Participants also described not knowing about delays or about services. One participant discussed how, "*Um, I had the- I feel like I don't know a lot. Um, what I know is there are a lots of things out there that I don't know about,"* (Participant 27- ECSE) and another reported,

> *Well, you know, I'm going to be honest with you, I don't know…You know, uh, sometimes you don't know what's out there until you actually research what's out there…So when you don't know what's actually out there, then you don't know what's not out there.* (Participant 14- ECSE)

These participants indicated not knowing, in some cases, even what to look for because they did not know what was available. Not having knowledge can contribute to families experiencing more difficulty in accessing services because they might not know their child needs services or know where to go once they recognize a delay. Prior research has indicated how parents with lower health literacy had more difficulty with referrals for EI than parents with higher health literacy (Jimenez et al., 2013), which provides evidence for low or lack of knowledge likely making the process of service access more difficult.

Support: Caregivers Seeking Knowledge (Endorsed by Many). In many cases, participants who reported not knowing about a service or about developmental delays or disabilities also indicated a desire to learn more about services or developmental delays and disabilities. One participant described,

> *I need to know more because or else I go through social media, YouTube and all that. I see a lot of you know some conspiracy theories like oh autism is caused by shots, immunizations. Or things like that. I need to know more. … I need to know more and I need to know if there's anything that I'm missing that could add to what I'm already*

> *doing, just to make sure that he gets – he's uh – he get everything that may help…him in order to reach his maximum potential*. (Participant 23- ECSE)

Valid sources of information are important for families in knowing what developmental milestones their child should be reaching as well as what to do in the case their child might have a delay. Another participant, in response to a question about anything else that would be helpful for people who have young children reported,

> *Classes, frequent, uh, seminars to update them on information 'cause information- we live in a changing world. Information is always changing…They're always upgrading…And so, since we're in a world that's full of upgrades, we need to upgrade the parents as well. Let them know…And keeping the parents informed.* (Participant 14-ECSE)

Caregivers who reported seeking knowledge seemed to benefit from their own desire to learn more about child development and services available. Because lack of knowledge likely results in a more difficult time accessing services, then caregivers seeking knowledge can help to remediate some of the challenges associated with low knowledge. Caregivers seeking knowledge presumably aids in the process of accessing services.

Support: Accurate Caregiver Knowledge (Endorsed by Many). With regard to having accurate knowledge, many caregivers reported having knowledge of services that existed or having knowledge about signs of developmental delays or disabilities. This knowledge appeared to be a support for families in getting services. Participants sometimes specifically reported the delays they noticed, how they learned about developmental delays or disabilities, or their source of knowledge. For example, one participant reported, "*… I'm an RN without an active license… RN, but I still have my degree, and, um, bachelor's degree, Bachelor of Science degree in* *nursing, so I knew what a developmental delay was*" (Participant 18- ECSE). This caregiver shared how she was familiar with developmental delays due to her education, and her familiarity with developmental delays might have aided in her recognition of her own child's delay. Other caregivers described more generally their knowledge of the importance of early intervention. For example, one caregiver emphasized the importance of EI when she expressed, "*I mean, like, with anything with kids, like, early intervention is a good thing*" (Participant 7- EI). Participants being aware of EI and ECSE services and knowing how to get connected to these services appeared to be helpful in the process of accessing services. Specifically, one participant reported generally, "*I mean I think just knowing what exists is the biggest thing"* (Participant 9- EI). Participants appeared to use the knowledge they had to help identify when their child had a delay and then to get access to services for their child. As Participant 9 also expressed, when "*you know better, you do better*." As caregivers are more aware of delays and services available, they likely use that information to help their child get what is needed.

Barrier: Caregivers Expressing Negative Feelings or Attitudes About Services and Providers (Endorsed by Many). Although the negative feelings or attitudes expressed by caregivers did not necessarily prevent participants' children from getting services, these feelings and attitudes could have contributed to a more difficult experience overall in accessing services. Participants expressed negative feelings and attitudes about both their providers (e.g., pediatricians, service providers) and the services themselves. For example, one participant described, "*His pediatrician just would always say he's fine, like he's fine, um but sort of well, I guess charitably we could call him "old school." I think he was just wrong and kind of ugly"* (Participant 19- EI). This participant described how she had to return to the doctor more than one time and she had to work with another doctor to get help for her baby. This experience likely delayed care for her child and made her experience more negative.

One of the participants who was unsuccessful in getting her child access to any services indicated,

> *They kinda just, I don't know, I feel like they just kinda singled him out and didn't really know how to handle a child like that, so they wanted to just put him into another class, put him into a behavioral cl..., where other kids with behavioral problems and behavioral problem kids are all together, you know, they're never gonna learn, they're gonna be stuck in the behavioral vicious cycle.* (Participant 3- ECSE)

This participant's experience with her child's preschool was very negative, and she also had negative opinions about potential services. In this case, the participant did not pursue additional services for her child in the form of ECSE. Her views of these services likely impacted her decision not to pursue those services. Other participants might not have been prevented from getting their children services, but they might have described more negative experiences overall in getting services. In some cases, caregivers' views or attitudes about special education services impacted their decisions related to those services (Palmer et al., 2001).

Support: Caregiver Positive Attitudes About Providers and Services (Endorsed by Many). Many participants also reported having positive feelings or attitudes about their providers or about their child's services, which likely contributed to a more positive experience overall. One participant simply indicated how, *"...the pediatrician referred us to Babies Can't Wait, and they came and were awesome"* (Participant 7- EI). Another participant who had very positive things to say about services and providers described, "*I see a big jump from the time he started pre-K. So pre-K has done wonders for him"* (Participant 14- ECSE). A different participant described how she was hesitant to try to get Babies Can't Wait services at first, but ended up feeling really positive about the services her child received, "*After being with the program, if I had known how, how great it is and how much it would have helped like I probably would have signed up earlier"* (Participant 5- EI). Caregivers who express belief in the effectiveness of services and demonstrate a positive understanding of the services (Evans et al., 2016) might be more likely to try to continue with services or begin services. Another participant described her Babies Can't Wait provider,

> *Oh, Ms. [EI PROVIDER] was amazing…I adore her. Because, um, any questions I have for her she answered… like she was amazing at working, at integrating it with my family and then [CHILD] has a little brother so he would come and of course he wanted to watch…She never like just was like 'this is for [CHILD]!' and pushed him away. She was very warming, heart-giving and like loving…to just both kids, any kid that was there; and she interacted well with like everybody and my child – and my dog.* (Participant 17- EI)

Having positive feelings about providers or about services in general appeared to lead to a more pleasant experience for caregivers who accessed services. Believing the services made a difference in their child's life also likely contributed to caregivers wanting to continue services or having the opinion that they would have started services earlier if they had the opportunity. Many healthcare organizations value patient feedback, but systems need to be in place to plan the utilization of feedback to improve care (Kaipio et al., 2018). If programs implement a system for caregivers to provide feedback, then EI and ECSE service providers can utilize this information to improve caregiver satisfaction related to these services.

Interpersonal Factors

Support: Caregiver Action or Advocacy (Endorsed by Many). Many participants reported they took action even without their provider giving a specific recommendation or advocated for their child to begin receiving services. In one case, a caregiver indicated, "*I think at that point he was used to me bugging him enough that he really didn't hesitate, um, about going ahead and referring me to Babies Can't Wait"* (Participant 7- EI). This participant clearly expressed how her persistence with the pediatrician resulted in her ability to get a referral to Babies Can't Wait more easily. Additionally, a participant noted her advocacy for her child by explaining, "*And so, just very passionate one to make sure that he got the best. So, I've given my life to take him back and forth to doctors, back and forth to get him evaluated.*" (Participant 14-ECSE). Another participant expressed what she would want to tell other families of young children, "*I would tell them to be strong, to be their child's advocate, to keep hitting the walls and doors until it opens, to never give up, and to dedicate their time in to making sure that their child gets all the services and they shouldn't – they should keep trying*" (Participant 23- ECSE). The advocacy displayed by these parents reveals how their actions frequently led to ensuring their child initiated access to services. In these cases, the advocacy on the part of caregivers and the actions taken by caregivers helped get children connected to services. These examples of parent advocacy demonstrate how parents played a role in obtaining crucial services earlier.

Throughout the interviews, some caregivers described advocacy as helping their child to initially receive services, but in other cases, caregivers expressed how advocacy helped their child maintain or continue services. More specifically, one caregiver explained how her advocating for her child helped him to continue getting services that the service providers tried to discontinue,

> *So she brought me this paper for me to sign to terminate [CHILD]'s enrollment. And I'm like, "Wait, wait, wait, wait, wait- what-" I said, "I never agreed to pulling [CHILD] out." ... I said, "But I'm not agreeing to take my child out because he needs to be here. I need this program. I need this program." ...from September to November, I called. I had a meeting with everybody I could have a meeting with…I went from one stage whoever was with them, I went over their head. Whoever was with them, I went over their head. Whoever's with them, I went over their head. I told 'em, "I'm not signing to pull my child out of this program."* (Participant 26- ECSE)

This caregiver's advocacy and persistence helped continue receipt of services. Although this caregiver reported other children had been removed from this program, her advocacy likely resulted in a different outcome for her child. Overall, participants had success both accessing services in the first place and maintaining service access for their children through their advocacy and action.

Support: Presence of a Supportive Social Network (Endorsed by Many). Caregivers reported that their social network provided reassurance and encouragement, advice, support, connection to services, and positive interactions with their children. One participant discussed getting connected to someone whose child experienced some of the same challenges her daughter experienced,

> *You know I would say I need to find someone who's like-minded and so, I just, emailed this parent, and we've been best friends ever since. Um...so finding her and someone who was just a little bit farther ahead...in the journey, um, really helped.* (Participant 25- ECSE)

This social connection helped this parent feel better and provided a friendship for this parent. In the case of the social network providing positive interactions with the child, this same caregiver described her family's support for her daughter through observing her family celebrating milestones her daughter had reached,

> *But man, like, just seeing the way our whol- 'cause we were at my parents' house for Memorial Day weekend when she started jumping. And so, just seeing like my whole family like getting so excited, like my parents who are in their sixties jumping with her.* (Participant 25- ECSE)

Having a support system in place was more commonly described in the positive context (e.g., as support, as advice) than in the negative context. Support systems can contribute to families staying positive and potentially reducing stressors, which aligns with literature showing the positive role a support system plays (e.g., Evans et al., 2016).

Support: Parent Knowledge Obtained from Professional Source (Endorsed by Many). As reported above, high caregiver knowledge played an important role in service acquisition. Importantly, the source and accuracy of this knowledge can positively impact service access. Caregivers successful in accessing both EI And ECSE services reported providers (e.g., pediatricians, teachers, therapists) as their source of knowledge, as opposed to alternative sources such as friends, family, or the Internet. One participant reported, "*…you know, [SCHOOL] was really good at making sure that I had the, um, helpin' me with, um explaining and making sure I had the knowledge to have him talk further, so they kinda gave me...like more educational things"* (Participant 18- ECSE). Some caregivers also described how they learned about services from their providers (e.g., "*for Babies Can't Wait, um, I only knew because the pediatrician* *recommended it"* (Participant 6- EI)), and other caregivers discussed learning both about development as well as about services from their providers,

> *At two years old, she wasn't saying more than like mama and dada and maybe one other, maybe [sibling name] or [sibling name], one of my other children's names. And I kind of felt like, so okay you know she's just taking her time. She'll catch up, but her pediatrician said at that point, that at 2 years old that she probably should have a larger vocabulary, that she should be able to, um, to verbalize more and so she recommended we go to Babies Can't Wait* (Participant 5- EI)

Providers with knowledge of child development and available services who families trusted most often provided support for families trying to access services. In the case of one caregiver whose child did not receive any services, the caregiver reported,

> *Yeah, we see a group of pediatricians, so I think the last three check-ups, we may have seen three different pediatricians. They've mentioned it every time. Um, and mentioned that we can do speech therapy if we want to* (Participant 1- EI)

Even in this case of the parent not seeking out services, the provider was still a valuable source of knowledge. Sources of knowledge are important to consider, especially when some sources are not as reliable as others. Although much information exists regarding health and development online and in the media, it is frequently recommended that individuals talk to their doctor about concerns or before starting treatment. In the case of these participants, many reported their provider as a source of knowledge leading to connections to services or recognition of a delay.

Barrier: Providers Displaying a Low Level of Skills/Knowledge (Endorsed by Several). Although many participants reported their provider as a source of knowledge, several participants shared information about their provider displaying a low level of skills or knowledge. In one case, a participant explained, "... *it was something the pediatrician missed but it was pretty obvious to me"* (Participant 6- EI). Had this participant not been aware of child development, then she may not have been connected to services as quickly. She described how the pediatrician did not notice the concern, but the participant did. This participant was not as impacted by the provider missing something important, but if this participant was not aware of the concern and her child's pediatrician also missed it, this child may not have received needed services until later. Other cases of low provider knowledge and skills related to telling caregivers to wait and see when they may have qualified for services had they been referred, and some research has discussed taking a different tactic to the "wait-and-see" approach (Scherr et al., 2020). Caregiver knowledge significantly impacts their ability to get services for their children, and provider knowledge can contribute to making the process more difficult.

Organizational Factors

Support: High collaboration among providers (Endorsed by Several). Many participants indicated that high collaboration existed among providers (e.g., between a pediatrician and an EI service provider, between an EI service provider and the school district) and that this was beneficial in learning about and accessing services in a timely manner. More than one parent explained the role that an EI service provider or coordinator played in helping them get connected to the ECSE system. For example, one participant indicated, "*Mm-hm, yeah, the coordinator from Babies Can't Wait actually, um, she scheduled it and, um, and she actually was there at his initial evaluation"* (Participant 6- EI) in reference to her child's ECSE evaluation. This aided in a seamless transition into ECSE services. Other participants described simpler collaborations or communication among providers, such as their pediatrician making a referral directly to Babies Can't Wait. These collaborations and communications seemed to make the referral processed clearer and did not put as much responsibility on the caregiver following through for every step. If service providers more frequently communicate and collaborate with each other, the opportunity for a need to be missed or to not follow up on services is lessened. Healthcare professionals have reported collaborating with each other frequently and most of these professionals view interprofessional collaboration as "very helpful" (Felix et al., 2016, p. 2). Collaboration can also help lead to "optimal health services" (World Health Organization, 2010, p. 9). More communication and collaboration can lead to better care for children and their families.

Community Factors

Support: Low Wait Time for Services (Endorsed by Several). Several caregivers indicated that they did not have to wait long for appointments. For example, when asked about her experience from the time she realized they needed an appointment until she got in touch with them and got the evaluation, one mother responded,

> *It was within two weeks. Very fast, and they kept on top of it, would tell me be expecting this in the mail on this date, um, have it back to us by this date or we will come, you know, or would you rather us come this date and pick it up and they were very fast…and wanting to get him in as soon, to see what to do, as possible.* (Participant 12- EI)

As shown in the quotation above, lower wait times appeared to be associated with a more positive experience accessing services. Additionally, with the importance of interventions starting as early as possible (Bailey, 2005; Moeller, 2000; Rickards et al., 2009; Zwaigenbaum et al., 2015), shorter wait times would lead to quicker service access and more time to intervene.

Barrier: Needed Treatment and Assessment Services Unavailable (Endorsed by Many). Several participants described wanting services that did not exist or were not available in affordable or accessible way in their local area. In some cases, participants described services they wish existed that were unrelated to Babies Can't Wait services or ECSE services but that could serve as a precursor to accessing these (e.g., diagnostic services). Other participants discussed a desire for an increase in the diversity of services offered related to EI services. One participant discussed her wish for a greater variety in the types of services Babies Can't Wait provides,

> *I mean I guess it would be nice if they had feeding at Babies Can't Wait because Babies Can't Wait the great thing about them is if your insurance can't pay they pick it up but because they don't have a therapist we just get our 20 visits through someone else and then after insurance doesn't pick it up we pay out of pocket. But that's why Babies Can't Wait is so great because it just continues.* (Participant 8- EI)

If services do not exist through Babies Can't Wait, they are sometimes not accessible to a family due to insurance coverage, a family not being able to afford it, or the services themselves not being prevalent.

Additionally, other participants specifically indicated concerns with the number of service providers available. Specifically, another participant expressed concerns with the amount of time a Babies Can't Wait service provider was able to spend with her due to the large caseload, "*Um, the main thing was that- I mean I know they have like such an enormous caseload…but my personality is such that, it would've been great if we could have twice as much time"* (Participant 19- EI). Concerns with caseloads point to participants feeling as though not enough service providers are available to meet needs of wanting more time with the provider. Another participant raised a similar concern related to the amount of special education services allocated to their child. This participant discussed how more special education services specifically should be available.

> *Um, I think that they are a beneficial and good service to students in need. I think that more services could be given…And I don't know the answer to that. I don't know if it's a we don't have enough providers. I don't know if like there's not enough funding or if it's just you're taught that they only need to be seen so many times a week or something like that, whereas I don't know, but there are many times where I think that more services could be given to special ed students.* (Participant 15- ECSE)

This participant indicated that she would like to see more special education services available. Additional providers can help to reduce the burden on existing service providers. In the cases where participants described needing additional services, the lack of services prevented families from accessing services.

Barrier: Accessibility of Program Information (Endorsed by Several). For caregivers to find out about programs (e.g., Babies Can't Wait, ECSE services), it is important for information to be available in the community. Program materials should be widely available and comprehensive so as to inform caregivers of services in their local area. Several participants also reported limited advertisements informing parents about services or more generally about how to look for developmental delays or disabilities. Although the lack of posted information might not have prevented participants from accessing services entirely, it might have delayed service access or made services more difficult for families to find. A participant described the difficulty she had in finding out how to contact Babies Can't Wait,

> *I think just more information to people on what the process is on how to contact…um, I think I did, now that I'm remembering, had to dig a little bit through, like I couldn't just*

> *find it on a Babies Can't Wait website. I had to dig a little bit through my Facebook group to find like a direct phone number.* (Participant 15- EI)

Other participants described needing more information about the services or how to get in touch with the services but not knowing where to obtain this information.

Similarly, participants in the ECSE age range also indicated the need for greater accessibility to information about services. One participant explained,

> *Um, maybe if there was more, I guess, advertisement about it. Um, I don't see a lot of, um, information just, you know, in doctors' offices or anything that's, you know, concerning. Um, developmental delays and all…Um, it's just something that has to be brought up. It's not, um, just I guess readily available.* (Participant 2- ECSE)

This participant also specifically mentioned the need for additional materials with information about developmental delays. In these cases, the lack of posted or readily available information made the process of learning about delays and about services available more difficult for some families.

Early Childhood Special Education Specific Themes

Whereas the previous section discussed themes that arose across both EI and ECSE, this section will specifically review only those topics and themes that were reported by multiple participants during conversations about ECSE. These topics also arose during conversations with participants of EI-aged children, but they did not emerge as frequently for this group.

Interpersonal factors

Barrier: Inconsistency in Care or in the Child's Life (Endorsed by Many). Many participants reported concerns related to inconsistency in their child's care (e.g., changing pediatricians) or in their child's life (e.g., moving states frequently). Participant 3 reported concerns related to inconsistency in her child's care and indicated her child never received services. Specifically, she described, "*He's been to maybe 4 or 5 different schools, daycares. He's only 5, so he's been around*" (Participant 3). This mother describes her son attending multiple child care centers or schools, but other participants described having to change pediatricians. In another case, a participant described their child moving states about four times within the same year. Each of these cases of inconsistency appeared to make the process of getting services more difficult.

Barrier: External Stigma (Endorsed by Many). Although some participants described stigma more generally, others discussed stigma in the context of potentially influencing their decisions. One participant described generally the fear of others stigmatizing their child or unfairly judging their child,

> *I guess seeing your kid with a hearing aid you don't want people to pick on 'em, or people to stare or thinks or try to label her as being slow just 'cause she has a hearing aid. And I have some teachers that have tried to label her as slow and do tests to see she's not slow, she just has hearing loss - she has no problem with learning.* (Participant 20)

Another participant described generally how individuals in their country treated those with special needs,

> *Um, it was really hard, I couldn't believe it because first um in my country autism is not so common…And of course there are people with disabilities but I don't remember seeing or hearing anything about autism at all until when I started Googling and learning about all that and it was really painful because where I come from uh people with special needs are not accepted. They are instead hidden behind doors.* (Participant 23)

When asked if this mother felt similarly about the United States, she indicated that she also experienced difficulty here as well, which has impacted her even taking her children to the park now. Another participant whose child never received services reported, "*My friends told me not to put him in a special education class because, um, just doesn't look good in the future, you know, like they need, he needs to be in a regular class"* (Participant 3). The stigma surrounding special education in this case appeared to support this mother's decision not to pursue a special education evaluation for her child. Previous literature has demonstrated the negative impact of stigma on individuals with autism spectrum disorders (e.g., Obeid et al., 2015; Shtayermman, 2009), and these results also demonstrate the negative impact of stigma on the experience of these individuals.

Organizational factors

Support: A Clear or Easy Referral Process (Endorsed by Several). Several participants reported the referral to services was clear or easy. The referral process for ECSE involves the family going through Child Find to be evaluated for services. Families can be referred to Child Find in a number of ways, and one of these ways involves collaboration between the EI and ECSE service providers (discussed in more detail in the section on "High collaboration among service providers"). One participant responded to a question asking about the referral process by saying, "*Um, it was really, really easy. Um, they were really easy. It was really fast"* (Participant 27- ECSE). Caregivers appeared to view a clear or easy referral process as a positive thing. Previous studies have discussed a difficult intake process as a barrier to health care services (e.g., Flores et al., 1998), so a clear referral process likely acts as a support for families accessing ECSE services.

Community factors

Barrier: Systems not working to support families (Endorsed by Several). Systems here refer to programs put into place intended to aid families (e.g., income-based programs). Within the ECSE age range, several parents discussed how the systems in the community or state did not always work to support the families as intended. For example, when one participant described her experience with getting her child into ECSE services, her view of that system did not emphasize supporting her child but rather on meeting system requirements.

> *And so, um, it was a position- it was a- a space open up there as they say a number 'cause your child become a number…Uh-huh, which is, you know, heart-wrenching…because that means they're not looking at the child. They're looking at trying to keep the numbers.* (Participant 26)

This participant expressed how this system did not appear to work to the benefit of her child and also later described the difficulty she had with the ECSE providers. Another participant expressed the difficulty of trying to get her child enrolled in a special education program or an early school program due to her income,

> *… I had a lot of problems. I like literally had to fight for it because they felt like what am… I wasn't, like my income wasn't low enough that she didn't deserve it. And it's not that my income isn't low but I'm not - I'm not lazy enough to sit around and like not work to support my children…So I felt like that. I think they, they take income into too much consideration… 'Cause it's not a daycare, it's a school system, no matter what. And I feel like if they took the whole process of well like you make this much money, no it's not about how much money the parent makes, it's about what the child needs.* (Participant 17)

This participant's view of the system reflects a system working against her and her child.

Several other participants also discussed related systems outside the context of ECSE specifically. Several participants mentioned these complements to ECSE as being a stressor and impacting other service access. For example, one participant discussed the difficulty in getting the Katie Beckett waiver, *"Like the Katie Beckett. Their requirements are just too harsh – like they expect you to have to do maybe – not maybe but five therapies a week to qualify for that…and sometimes imagine going for therapy five days a week and it's a lot and overwhelming"* (Participant 23). These participants described how certain systems which are supposed to be in place to support families did not seem to support their family. These experiences reflect how some of the systems in place may act as challenges families have to overcome to get their child the help he or she needs.

Early Intervention Specific Themes

Given the differences between EI and ECSE (Danaher et al., 2004), it is important to examine barriers specific to each context. The themes included in the early intervention section are those themes that were discussed specifically regarding the experience families had in trying to access Babies Can't Wait services in Georgia or in missing out on this opportunity. Only one theme emerged in the Organizational Level unique to participants accessing EI services.

Organizational Factors

Support: Access to Affordable and Convenient Appointments (Endorsed by Many). Many caregivers indicated that the appointments took place in their home, and often these appointments were described as affordable and convenient. One participant expressed, "*…the services are free, they come to my house, I don't have to drag two babies off the second floor"* (Participant 12- EI). Another participant explained, "*Everyone was responsive and showed up* *and having the therapy in our home was invaluable to me"* (Participant 7- EI). A third participant commented on the cost and the convenience of appointments, "*I mean we didn't pay anything, um, and we didn't have to drive anywhere for it"* (Participant 5- EI). Another participant discussed her experience after having another baby with wanting to continue to have the Babies Can't Wait appointments, "*Like, come, like please, there's no reason to skip because this is like the easiest thing ever. You literally come to me"* (Participant 21- EI). These participants and others described the support of not having to leave their home and for the services being covered by insurance or based on a sliding scale. Another participant even went as far as to describe how she may not have pursued services had they not been so convenient:

> *…'cause he, you know, he has [INSURANCE], and they said that it would be covered, but I mean if I was having to pay like the dollar amount for like a therapeutic visit every week that probably, honestly would not have happened …And I probably would- just would not have done it to be honest…if it hadn't been so kind of like "here you go."* (Participant 19- EI)

Overall, the consensus appeared to be that caregivers appreciated service providers coming to their homes and being free or affordable. In some cases, the services being convenient and affordable resulted in more participants accessing services, so these logistical factors should be taken into consideration when planning for services in the future.

Discussion

The purpose of this study was to identify both barriers to and supports for families accessing EI and ECSE services by interviewing caregivers of children with developmental delays or disabilities. The themes identified in this study were mapped onto the developed socioecological model of educational service access disparities. Although these themes were organized into four of the socioecological factors, many of these factors interact with and overlap with each other, so this organizational approach may oversimplify some of the connections among the factors. Many outcomes from this study overlap with prior research examining parental perspectives on access to early intervention services, thus confirming previously identified barriers and supports; however, this research also identified novel factors that appeared to both positively and negatively impact service use.

Novel Themes Organized by Their Role as Barriers or Supports

This study identified several themes highlighting novel barriers and supports that impact EI and ECSE access. Barriers were hypothesized based on a wide array of literature from other fields, but this study specifically confirms some of these hypothesized barriers or supports within the EI/ECSE fields. Within the Interpersonal level of the socioecological model, caregivers of children both in the EI and ECSE age ranges indicated the important role parents advocating for their children played in them getting services. Parents discussed the importance of following up with doctors to obtain referrals, attending meetings to discuss continuation of services, and initiating calls to service providers to both begin and maintain services. These findings confirm the hypothesis that parent advocacy was a meaningful barrier to service access as it is likely closely linked with other factors previously identified in the literature. For example, parents with a higher self-efficacy (Little et al., 2015) or with more knowledge may be more likely to advocate for their children because they might feel like they can be successful and know what their child needs. Additionally, many caregivers of children in the EI and ECSE age range also discussed their seeking of knowledge, which likely contributed to their ability to advocate for their children. Previously, “lack of knowledge about disability,” “lack of knowledge of educational opportunities,” and “difficulty in interfacing with school officials and complying with procedural requirements" have all been cited as challenges caregivers face in effectively advocating for their child in the special education process (Phillips, 2008, p. 1829-1832). As reported in this study, this pattern of under action or limited advocacy is related to stigma and negative attitudes about services. Although only two participants reported information related to this topic, in a larger sample this topic may arise more frequently. Furthermore, the majority of the participants in this study had accessed services for their children, and thus were less likely to report not taking action to get their child services. Though we specifically targeted families that were not and had not been enrolled in EI or ECSE services, they were not as likely to enroll in this study compared to those that had accessed these services. This theme provides evidence for the importance of creating more parent-to-parent organizations or helping caregivers get connected with existing organizations. These organizations can help teach caregivers how to advocate for their children. For example, organizations such as Parent to Parent of Georgia ("About P2PGA," n.d.) help caregivers connect with other caregivers to be supported and to learn more about their own rights and their children's rights.

Another novel theme that emerged for both the EI and ECSE age ranges was the importance of high collaboration among providers to facilitate service access. This theme had not been previously discussed in depth in the literature but aligns with research documenting the importance of provider skills (e.g., McLeroy et al., 1988, Horn & Beal, 2004), as providers with higher skills are more likely to appropriately collaborate. This theme was discussed in the context of pediatricians communicating and collaborating with service providers as well as Babies Can't Wait providers communicating with and collaborating with the providers of ECSE services to aid in transitions at the age of three. Most caregivers discussed these collaborations and communication resulted in faster and effective referrals. When planning interventions, it may be helpful to consider how to increase collaboration among various providers, which may involve more trainings being available for a range of providers (e.g., pediatricians, teachers, therapists). Interprofessional collaboration might be impacted by interprofessional education programs, so an increase in focusing on these interprofessional education programs can provide healthcare workers with the training needed to have better collaborations (World Health Organization, 2010). By helping to increase provider awareness of other services and provider familiarity with referral process, providers are able to help families get connected with services at higher rates.

Barriers and Supports Replicated from Previous Literature

This study served as an important replication of several themes from the socioecological model levels already documented in the previous literature. For example, a meaningful theme that arose repeatedly throughout interviews for caregivers discussing EI services and ECSE services was the importance of caregiver knowledge of what services existed and how to access these services. Knowledge acting as either a barrier (i.e., lack of knowledge) or as a support (i.e., has knowledge or awareness) has been previously identified as having an impact on access to health-related services (e.g., Birkin et al., 2008; Kilbourne et al., 2006; McLeroy et al., 1988) and to early intervention services (e.g., Barlow et al., 2005; Evans et al., 2016; Jimenez et al., 2013) and has thus, been a primary target of previous interventions designed to increase EI service access (Daniel et al., 2009). Future research should review how to tailor knowledge interventions particularly to groups' experiences disparities in service access.

In these interviews, the importance of knowledge source became apparent. Caregivers reported a variety of sources of knowledge (e.g., friends, family, the internet), but many specifically reported service providers as an important source of knowledge for them. With misinformation being spread about autism spectrum disorders through the Internet, from person to person, and through some advocacy groups (Savoy, 2014), it is important to have reputable sources of knowledge to inform parents of services. Caregivers having trust in their providers (e.g., Barlow et al., 2005), caregivers having good communication with providers (e.g., Jimenez et al., 2013), and providers having knowledge (e.g., Little et al., 2015) have also previously been reported as factors contributing to service access, and these factors play a role in caregivers effectively receiving information from providers. With this information in mind, it is important to consider designing courses or presentations for caregivers to learn how to be better consumers of information. Additionally, campaigns against misinformation prove valuable in spreading the word about evidence-based interventions. These campaigns would need to be targeted at caregivers of young children and would need focus on common misconceptions.

Although providers might be one of the most credible sources of diagnostic and referral information, this study revealed that friends and families can serve as a supportive factor through the provision of a social network. This emerged as a theme for caregivers of children in both age ranges related to the importance of families having a social network or social support from friends, family, and providers. Participants indicated several different areas of social support including, friends telling them about services to family members giving support and advice. This theme encompasses a couple of barriers previously identified in the literature in the following domains: network/capital (e.g., Barlow et al., 2005; Birkin et al., 2008; Horn & Beal, 2004; McLeroy et al., 1988) and family support (e.g., Barlow et al., 2005; Evans et al., 2016). The absence of a social network was also reported by several participants in the ECSE age range specifically and appeared to act as a barrier. Although some studies indicated EI providers were not sources of support (e.g., Evans et al., 2016), the current study revealed support from family, friends, and service providers. These results can be used to provide evidence for a need for an increase in actions service providers can take to help families feel supported.

Caregivers in both age groups also reported a range of attitudes and feelings that appeared to act as barriers (in the case of negative ones) and as supports (in the case of positive ones). Attitudes (Barlow et al., 2005; Birkin et al., 2008; Evans et al., 2016; Jimenez et al., 2013; Kilbourne et al., 2006; McLeroy et al., 1988) and beliefs (Birkin et al., 2008; Kilbourne et al., 2006; McLeroy et al., 1988) have previously been identified as barriers to families getting services. In some cases, parents reported negative attitudes or beliefs about services made the process of getting services more difficult. To address the concerns of families having negative attitudes about a provider or a service, organizations and communities should make patient navigators more readily available (e.g., Guevara et al., 2016). These patient navigators are individuals who give support to families by assisting them in accessing services and providing them with education. Specifically, they provide explanations of services as well as help families get connected with other providers if they are not satisfied. To help with this, service providers should also consider reaching out for feedback on their services more often. Providers who do more regularly monitor their families' views of their services might be able to change their practice to better serve families and meet their needs, but it is important that providers determine ways of utilizing the feedback received to make changes for those they serve (Kaipio et al., 2018).

A final overlapping theme that surfaced from the interviews in the Community level was the importance of resources and services and providers being available and advertised for in communities. This barrier of a lack of service availability has been previously documented in the literature (Little et al., 2015). Just as important as the services themselves existing, is making information about these programs available to families. If a service exists without families knowing about it, these families might be just as likely not to access them as if they did not exist. Although several participants reported their pediatrician informed them of Babies Can't Wait Services, others indicated not knowing about them or only being vaguely aware of them. Overall, there seems to be a need for additional posted or circulated information about these services with a particular emphasis on culturally targeted this information to reach families who otherwise may not find out about services. Developmental delay information in the form of campaigns such as the previously mentioned "Learn the Signs. Act Early" may help increase caregiver knowledge of signs of delays as well as how to act early (Daniel et al., 2009).

Other themes emerged as unique either among caregivers of EI-aged children or among caregivers of ECSE- aged children. Specifically among participants with EI-aged children, the convenience of Babies Can't Wait appointments with providers coming to families' homes was frequently discussed as a meaningful support. Families generally seemed to appreciate the convenience that the home visit aspect of Babies Can't Wait provides. In the county this study was conducted, Study 1 demonstrated how the EI service access rates were better than the state and national averages while the ECSE service access rates were similar to state and national averages. When using this as the measure for success, EI service access rates seem to be better than ECSE service access rates. These practical factors help explain some of these differences. Next steps may include identifying ways of making ECSE services more accessible through addressing logistical barriers (e.g., families having to travel to the school to be evaluated). One way of approaching this barrier might be to offer services at more locations

In addition to the convenience of appointments, participants of EI-aged children discussed the cost of the services changing based on a family's income or the services being covered by insurance as a support. With regard to finances, two participants specifically indicated they would not have participated in services had they not been covered by insurance. Although the cost of appointments being free did not arise as a theme among participants of ECSE-aged children, ECSE services are also free to families. Future campaigns could be designed to increase awareness of the ECSE services not costing anything.

A final theme that emerged for caregivers of children in the ECSE age range only was inconsistency in care or in their child's life. In some cases, this inconsistency led to delays in receiving services, but in other cases this inconsistency prevented the children from being able to obtain services. This theme had previously been identified in the literature review (Jimenez et al., 2013), and it might be closely related to caregiver stress (e.g., Barlow et al., 2005). If caregivers are having to change pediatricians or preschools, this may be indicative of increased life stressors. Previous research has also indicated how caregivers who do not have adequate health literacy were more likely to lack consistency in provider (Jimenez et al., 2013). Additionally, inconsistency in care likely creates a more difficult context for caregivers to raise concerns because their relationship with their provider might not be as strong as someone who has had the same service provider.

Limitations and Future Directions

Although this study has many strengths, such as the inclusion of participants with children in the EI and ECSE age ranges, there are also several limitations. The researchers attempted to include both families who had and had not been successful in accessing services, but this latter group was more difficult to target in recruitment and to identify for inclusion. 14.28% of the sample had not accessed EI or ECSE treatment services. More specifically, two families included had not accessed any type of service, another only received an assessment from a university but had no follow-up intervention, and a fourth one was included that only participated in private speech services. All other families had accessed EI, ECSE, or both. The lack of participation of families who had limited access to these services may be indicative of families not knowing about delays or disabilities or might point to a difficulty in participation in general. Although, families that had initiated some interaction with ECSE but did not subsequently pursue services were intentionally recruited, we knew this was going to be a group with unique recruitment challenges due to their previously exhibit lack of service pursuit. As a result, the population included is likely more representational of those families successfully accessed services and who might not have experienced the same level of challenges in finding services as families not accessing services. Even though not as many families who were not accessing services were included as originally anticipated, this study did still include several of these families as well as a number of families who had accessed services but with significant challenges. Given the difficulty of finding this sample, additional research might focus on mixed methods or quantitative research that examines what factors delays treatment receipt.

A second limitation arose with the use of a semi-structured interview where questions became more specific at times. The interviewer typically started with broad questions, but these questions narrowed if participants failed to include certain needed information. In these cases, there could be some risk of steering multiple participants to report on similar areas that might not have been as meaningful or significant to them. Additionally, some questions were written in a way to provide several examples (e.g., asking about logistical factors such as finances or transportation), and these questions might have also have made participants more likely to report on certain topics. Although these limitations with the interview exist, the researchers created the interview by adapting questions from existing reputable sources (i.e., Dababnah & Bulson, 2015;

Little et al., 2015; Samadi et al., 2011; Zuckerman et al., 2014) which examined similar topics to the current study. Furthermore, the semi-structured nature of the interview allowed for broader and more spontaneous responses before leading into the more specific questions.

Another limitation of this study was that it did not employ a method of using triangulation with study participants. This study did not use member checking (Creswell, 2000) where researchers review the raw data for accuracy with participants or to confirm that they agree with themes. Instead, as described in detail in the method, two researchers had consensus conversations to development of the codebook, determine how to create meaningful units of analysis, and to resolve coding differences. Additionally, this study only included interviews with caregivers, but no interviews with service providers, pediatricians, policymakers, or others who are more familiar with the process of accessing services were included. The purpose of this study was to more closely examine the experience of caregivers, but information from additional sources might be helpful in identifying a broader and more comprehensive understanding of barriers and supports. Future research should provide a more comprehensive coverage of views from different stakeholders by expanding the participant pool to others who might be familiar with EI or ECSE services (e.g., pediatricians, special education preschool teachers).

Two novel emerging themes for ECSE were described by participants and need to be examined in more depth in future research due to not reaching saturation. The two emerging themes that warrant additional research related to barriers were: 1) low level of acculturation and 2) parent inaction. One mother born outside of the United States who enrolled a child in Babies Can't Wait services and ECSE services reported not having full awareness of American culture and the services available as a barrier. Research supports that acculturation (McLeroy et al., 1988), match with providers (e.g., language, culture, race; McLeroy et al., 1988), and culturally targeted distribution (e.g., Birkin et al., 2008) have all been previously identified as barriers to service receipt. Future research should enroll additional participants born outside the United States to examine if this theme of acculturation is common for this population and to potentially inform intervention development. Both of these themes should be further examined by recruiting more participants who were not born in the United States and more participants who did not access services.

A final limitation relates to the way the themes were analyzed and organized. Although the themes were separated based on the two age ranges, the themes were not analyzed by race. In this sample, 13 participants identified as Black or African American and 13 participants identified as White. Future research should examine the themes that emerged with each of these groups of participants separately to identify if unique challenges emerge for either group.

Conclusion

The goal of this study was to explore factors in a family's ability to access early intervention and early childhood special education services in a timely way with ease. Ultimately, this study was meant to address the second step in health disparities research presented by Kilbourne and colleagues (2006). The first step (previously completed as part of Study 1) was to detect disparities if they exist, and the second step (completed as part of the current study) was to identify barriers to accessing services. The third step is to create interventions to address these barriers. Study 1 revealed an underutilization of services across the EI and ECSE age ranges as well as variation in sociodemographic groups' rates of accessing services. With that information in mind, the interviews in the second study helped to identify some themes for factors contributing to underutilization of services and challenges getting access to services across many groups of children in a local county. To begin to address the third step in health disparities research, these themes, along with the ideas from participants about ways of addressing potential barriers, are included in Table 3.4. Although some of the barriers and supports for accessing EI services differ from those barriers and supports for accessing ECSE services, the majority of barriers and supports also overlapped. For this reason, the ways of improving service access have been combined into a single group of interventions that may be beneficial across both age ranges.

Through interviews of 28 families about their experience accessing services, families from a similar geographic region reported a variety of challenges and supports in this process. These challenges and supports ranged from originating at the Individual level to the Community level, and participants frequently shared ideas for improving the process for other families. Although the majority of the families in this study had successfully accessed services, they were still able to share valuable information about the challenges they faced in getting timely services and appropriate resources. Additionally, for families to receive access to any services, they reported having a number of supports (e.g., having the knowledge of services, having support from others, advocating for their child, appointments being convenient, services being available). This study was able to compare some of the similarities and differences across early intervention and early childhood special education services. This information can be used to help plan interventions to increase service utilization in this community.

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Figure 3.1

Model of Mechanisms (Including Those Identified and Confirmed by this Study) that may Contribute to EI and ECSE Service Disparities

Note. Underlined factors are those that were newly identified in this study. Bolded factors are those that were hypothesized and confirmed by this study.

Table 3.1

General Information About Participants

	n	%
Parent/Guardian participating in interview		
Mother	22	78.6
Father	1	3.6
Mother and Father	2	7.1
Grandmother	2	7.1
Mother and Grandmother	1	3.6
Child Gender		
Male	20	71.4
Female	8	28.6
Age of child at time of interview		
Birth-2 Years	5	17.9
3 Years-5 Years	21	75
6 Years	2	7.1
Participation in either BCW or ECSE services		
Yes	24	85.7
No	4	14.3
Type of services received or receiving		
Babies Can't Wait and not Early Childhood Special Education	12	42.9
Early Childhood Special Education and not Babies Can't Wait	6	21.4
Babies Can't Wait and Special Needs Preschool	6	21.4
Other	10	35.7
Race/Ethnicity		
American Indian or Alaska Native	0	0
Asian	1	3.6
Black or African American	13	46.4
Native Hawaiian or Other Pacific Islander	0	0
White	13	46.4
Other	1	3.6
Income		
<$25,000	10	37
$25,000- $75,000	14	51.9
>$75,000	3	11.1
Primary language		
English	28	100
Language Other Than English	0	0
Ethnicity		
Hispanic or Latino	1	3.6
Not Hispanic or Latino	27	96.4

Table 3.2

Themes that Emerged for the EI Age Range

Topics	**Supports**	**Barriers**
Individual	• **Caregivers having accurate knowledge about services or symptoms of a delay or disability (many)** • **Caregivers having positive feelings or attitudes about or high trust in their services and their providers (many)** • **Caregivers seeking knowledge (several)**	• **Caregivers having inaccurate knowledge or lacking knowledge about symptoms or treatment (many)** • **Caregivers having negative feelings or attitudes about their services and their providers (many)** • Caregiver reporting high levels of stress (several)
Interpersonal	• **Providers being a reported source of knowledge and displaying high skills/knowledge (many)** • **Presence of a supportive social network (many)** • **Caregivers taking action or parental advocacy being present (many)** • Consistency is reported in child's care or in child's life (several)	• **Providers displaying low skills/knowledge (several)**
Organizational	• **Having access to affordable appointments in the home and that were convenient (many)** • **High collaboration among providers (several)**	*No themes emerged that were reported by "several" or "many" participants*
Community	• **A low wait time to schedule appointments (several)**	• **Needed services (e.g., treatment services) and providers being unavailable (many)** • **Materials/advertisements for services unavailable (several)**

Note: Bolded themes are those that are described in more detail in the results.

Table 3.3

Themes that Emerged for the ECSE Age Range

Topics	Supports	Barriers
Individual	• **Caregivers having accurate knowledge about services or symptoms of a delay or disability (many)** • **Caregivers having positive feelings or attitudes about or high trust in their services and their providers (many)** • **Caregivers seeking knowledge (many)**	• **Caregivers having inaccurate knowledge or lacking knowledge about symptoms or treatment (many)** • **Caregivers having negative feelings or attitudes about their services and their providers (many)** • Caregiver reporting high levels of stress (several)
Interpersonal	• **Providers being a reported source of knowledge and displaying high skills/knowledge (many)** • **Presence of a supportive social network (many)** • **Caregivers taking action or parental advocacy being present (many)** • Consistency is reported in child's care or in child's life (several)	• **Inconsistency in child's care or in the child's life (many)** • **External stigma being present (many)** • **Providers displaying low skills/knowledge (several)** • Limited interactions with providers (several) • Absence of a social network (several)
Organizational	• **A clear or easy referral process (several)** • **High collaboration among service providers (several)**	• **An unclear or difficult referral process (several)**
Community	• **A low wait time to schedule appointments (several)**	• **Needed services (e.g., treatment services) being unavailable (many)** • **Materials/advertisements for services unavailable (several)** • **Systems do not work to support family (several)** • A high wait time to schedule appointments (several)

Note: Bolded themes are those that are described in more detail in the results.

Table 3.4

Themes that Emerged During Interviews with Potential Ways of Addressing These Barriers

<table>
<tr><th>Theme</th><th>Ways of Addressing Potential Barrier</th></tr>
<tr><td>Individual Factors (e.g., having knowledge that services exist, knowing about developmental delays and disabilities)</td><td>• Classes, seminars, or courses that could be provided for parents with information about typical development and potential developmental concerns as well as services available (Participant 14 & 17)
• Courses designed to help caregivers become better consumers of information
• More information available about what “the range of normal is” for parents and caregivers (Participant 19)</td></tr>
<tr><td colspan="2">Quotation from participant: “Um, I think they should have um, I guess I feel like they need a class of parents of special needs children like it doesn’t have to be like a required 10-week course or anything but some kind of class to help you get through it. To show you the signs and symptoms, the signs and the symptoms to look for, to like, you know, what you need to do as a process to start making sure your child’s needs are met or if your child has any delays.” (Participant 17)</td></tr>
<tr><td>Interpersonal Factors (e.g., having social support, being connected to providers with high levels of skills, parents effectively advocating for their child)</td><td>• Creating more parent support groups or mentor programs for children and families (e.g., Participant 3)
• Mentors or other parents in similar situations being connected to each other more regularly (Participant 25 & 26)
• Having more readily available social workers or patient navigators in hospitals and other locations to help families coordinate services for families and to help parents advocate for their children (Participant 8)
• Parents consistently receiving more information on disability rights (Zuckerman et al., 2014)
• Connecting parents to organizations such as Parent to Parent of Georgia
• More outreach from healthcare professionals about early signs and available resources (Zuckerman et al. (2104)
• Providers giving parents ideas for what they can do at home to help with intervention goals (Participant 15)</td></tr>
<tr><td colspan="2">Quotation from participant: “The only thing is I think that everybody that’s in the NICU should have like a social worker assigned to them that sets all this up. Um because it’s just, I can really see how a baby could how some people could just wait till their kid is 3 and be like oh we didn’t know. Because it just happens, like if you miss that phone call then or you lost the flyer from the NICU.” (Participant 8)</td></tr>
<tr><td>Organizational Factors (e.g., convenience of appointments, long wait times) play a role in ease of accessing services and a family’s ability to access services</td><td>• Creating one place or location for families to find out about services to allow families to be on multiple waitlists at the same time or find the service provider that is most convenient for them (Participant 17)
• Campaigns to address misinformation</td></tr>
<tr><td colspan="2">Quotation from participant: “I wish they had some just one general resource, either you could sign up online, you can go to the office and sign up or something; some kind of resource to make it where it’s easier to access.” (Participant 17)</td></tr>
<tr><td>Community Factors (e.g., resources and services being available, advertisements available for resources and services)</td><td>• More readily available advertisements (e.g., information in schools, medical practices, daycares, mail, social media) (Participant 15 & 17)- for example, Learn the Signs. Act Early</td></tr>
<tr><td colspan="2">Quotation from participant: “Yeah, um, well of course at the pediatrician’s office like having maybe flyers or something like that but even maybe at daycares or um, in the mail, like those like flyers that people get in the mail… if like the family doesn’t leave the house or something just something in their mailbox that they’d be able to see… um, that might be kind of helpful, I think, um and of course just like their webpages and… social media.” (Participant 15)</td></tr>
</table>

Appendix A

Interview: Parent and Caregiver Experience with Early Intervention and Early Childhood Special Education Services

- Materials:
    - Two recorders
    - Extra batteries
    - Pen and paper for note-taking
    - Consent form
    - Paper copies of questionnaires or iPad

- Welcome and Introduction:
    - *Review Consent*
        - When you get to the part of the consent that is titled "Audio Recording," review the information in the consent and then follow the prompts below before having them initial.
            - *Audio Recording:*
            1. **Your thoughts and feelings are very important to us. Therefore, we would like to record what you say, so that we can go back and remember it later.**
            2. **We will go back later and write down exactly what you have said but without writing down any names. Then we will store this information in a secure location and destroy the original audio file.**
            3. **The researchers are the only ones who will be able to see this file, and they will not know any names associated with each story.**
            4. **Do you have any questions about this?**
            5. **Is it okay to record what we say today?**
            6. Have them initial the line next to the choice they made.
        - Finish reviewing consent after going over the Audio Recording prompts.
    - *Housekeeping:*
        - Provide the following information to families before beginning the interview.
        1. **You can take a break or ask us to turn off the recorder at any time during the interview.**
        2. **You are encouraged to tell me if you feel uncomfortable for any reason.**
        3. **You can ask us to stop the interview at any time, and you are never required to continue answering questions.**
    - *Questions:*
    1. **Do you have any questions?**

****If participant has signed consent, has agreed to have their interview recorded, and does not have any further questions, TURN ON AUDIO RECORDER NOW and record your (the interviewer) name, the date, and the participant number****

-
    - *Interview:*
    1. **Now I am going to start the interview. Please be honest with your responses. There are no right or wrong answers.**

2. *Examiner Note- Potential additional probes to use throughout:* **Can you describe this in more detail? Can you tell me a little more about that?**

Interview

Information on Developmental Delay:

Intent: The purpose of this section of the interview is to build rapport and allow the family to share information about their child that we may not explicitly ask about.

I. **Tell me a little bit about your child.** (Zuckerman et al., 2014)

Intent: The purpose of this section is to find out the parent or caregiver's perception of their child's learning or developmental delay or difficulty. We want to know if they noticed any difficulties their child has had and if they knew at that time that their child was potentially delayed. We also want to find out their attitudes toward these difficulties and to find out if anyone else has put a name to their child's difficulties.

II. **Tell me a little bit about your child's development.** (Samadi et al., 2011)

Potential probe: **Some kids have some learning or developmental difficulties. Do you believe that your child has any learning or developmental difficulties?** (Samadi et al., 2011)

→*If learning or developmental difficulties noted (include in study & proceed with follow-up questions)*

1. **Why do you think this?**

2. **What were some first signs you noticed that indicated your child was having difficulties?** (Samadi et al., 2011)

3. **How do you feel about these difficulties?** (Samadi et al., 2011)

→ *If no learning or developmental difficulties noted*

1. Has anyone else every told you they suspect your child has any learning of developmental difficulties?

Potential Probe: **How do you feel about this?**

Intent: The purpose of this section is to determine if the child has ever had an evaluation or assessment for their learning or developmental difficulties, and if so, we want to know more information about the experiences parents had in participating in the evaluation process. Additionally, we want to know how they found out about the evaluation and how they felt after the evaluation took place.

III. **Has your child ever been assessed by a psychologist or the schools for a potential developmental or learning concern?** (*refer to parent response above as applicable*)? Note: if they mention above in part II that they received an evaluation, skip this intro question and move to "if, yes" below

→ If no, skip to section IV

→If yes

1. **When your child received the assessment, how old was your child?** (Samadi et al., 2011)

2. **Who conducted the assessment?** (Samadi et al., 2011)

3. **Tell me about your experience from the moment you determined your child needed an evaluation.** (Little et al., 2015)

Specific prompts (as necessary):

(1) **How did you know it was time to get your child evaluated?** (Samadi et al., 2011)

General areas to evaluate:

Did someone tell you that you needed to get an evaluation? If so, who?

(2) **How did you know what steps to take get your child evaluated?** (Samadi et al., 2011)

(3) **Tell me about the process of scheduling the appointment.** (Zuckerman et al., 2014)

General areas to evaluate:

- **How long did it take to schedule your appointment?** (Zuckerman et al., 2014)

(4) **Please tell me about the day of your appointment.**

General areas to evaluate:

- **Where was the appointment?** (Dababnah & Bulson, 2015)
- **How was your relationship with your provider?** (Zuckerman et al., 2014)
- **How was your experience at the evaluation appointment?** (Zuckerman et al., 2014)

4. **Did your child receive a diagnosis? Tell me about that diagnosis.** (Samadi et al., 2011)

5. **Were you given any information about what the next steps would be?**

   General areas to evaluate:

   - **Were you told or notified in some way that your child would be eligible for special education services after your child's evaluation?**

   - **What services would your child be eligible for?** (Samadi et al., 2011)

6. **How did the results of the evaluation make you feel?** *If appropriate ask:* **How did it make your partner feel? Other people close to you?** (Samadi et al., 2011)

   a) Can you describe how you think and feel about your child's difficulties? (Samadi et al., 2011)

Intent: The purpose of this section is to learn more about parent's knowledge of developmental or learning delays or disabilities. Our goal is to find out how they learned about their child's development and how they obtained this information.

IV. What general information do you know about developmental/learning delays or disabilities? (Samadi et al., 2011)

→ *If applicable because child has been clearly identified as having some delay or diagnosis, ask the following:*

How has your knowledge of developmental delays changed since going through the evaluation process? What changed this? (Samadi et al., 2011)

General areas to evaluate:

- **How did you get this information?** (Samadi et al., 2011)

- **Where did you get this information?** (Samadi et al., 2011)

- **Do you think you need to know more about it?** (Samadi et al., 2011)

Support and Services (Formal & Informal)

Intent: The purpose of this section is to find out information about any difficulties parents or caregivers experienced in trying to access services. At this point in the interview, we want to know about anything the parents and caregivers consider to have made their experience difficult, challenging, or impossible. Specific probes are provided, but we are interested in any and all barriers or difficulties families provide.

V. **Can you describe any challenges you have experienced trying to seek services for your child?**

Specific Probes:

(1) **Can you describe your communication with service providers, with individuals scheduling the services, or with school personnel?**

(2) **Did any practical considerations negatively or positively impact your ability to obtain services (e.g., finances, transportation, family support, available materials)?**

(3) **What are your views of special education services*?*** (Samadi et al., 2011)

2. **Is there anything you did not like and feel should be improved in the process of trying to access services?** (Samadi et al., 2011)

3. **What additional type of support do you think is necessary for your child and your family?** (Samadi et al., 2011)

4. **If you had a friend whose child seemed to have a similar problem, what advice would you give to this friend to help them get services?**

VI. What have you found to be helpful in the process of finding services for your child?

Intent: The purpose of this section is to determine whether or not the family is receiving services. If so, we want to learn what services families are accessing and how families obtained services. If families are not receiving services, we want to find out if the families believe their child should be receiving services and what their process was like of trying to obtain services in the past if they have tried. Also, we want to learn about services families would find helpful if they existed.

VII. Is your child currently receiving or has your child ever early childhood special education services?

A. *→If families receive services:*

1. **What type of formal or informal services are/were provided for your child?** (Samadi et al., 2011)

2. **Tell me about the process of how your child began receiving services.**

General areas to evaluate:

- **What did you like about the process of accessing services?** (Samadi et al., 2011)

B. *If family does not receive services:*

1. **Do you believe your child needs services?** *[To probe parent beliefs]*

2. **Have you tried to access services for your child?**

   →If yes

   - **Can you tell me about that process?**

   - **Who have you talked to about your child's problem?**

3. **Are there services that do not exist in this area that you feel would be beneficial for your child?** (Dababnah & Bulson, 2015; Samadi et al., 2011)

<u>Community Response</u>

Intent: The purpose of this section is to find out more about the way the community, the family, and the friends of the parent or caregiver treat the parent or caregiver's child.

VIII. How do people in your family/community act toward your child? (Samadi et al., 2011)

Specific Probe:

- **How does this make you feel?** (Samadi et al., 2011)

Finish the interview by thanking the family for their time and their willingness to share so openly

CHAPTER 4

GENERAL DISCUSSION

The two studies in this dissertation contributed to the literature examining patterns of children accessing early intervention (EI) and early childhood special education (ECSE) services. These two studies extended the literature by thoroughly examining access patterns at a local level for both the EI age range and the ECSE age range. This study focused on comparing local rates to expected rates based on eligibility estimates as well as to actual state and national rates. Although much research has been conducted on the importance of children receiving services early in life (e.g., Bailey et al., 2005; Moeller, 2000; Rickards et al., 2009; Zwaigenbaum et al., 2015) and research has revealed underutilization of both EI services (e.g., Rosenberg et al., 2008) and ECSE services (e.g., Paff, 2017) at the national level, less is known about who is under accessing these services. This lack of information makes it difficult to develop tailored intervention plans to effectively serve more children generally but also all children equitably. This study aimed to examine both EI and ECSE service access patterns to determine if these patterns were distinct and to prevent the assumption that these two programs would show similar trends.

Some of the underutilization of services is likely a result of certain groups of children being more or less likely than other groups to access these services. Specifically, studies have revealed variable results in terms of sociodemographic groups accessing services at different rates for the EI age range (e.g., Barfield et al., 2008; Clements et al., 2008; Fefferman et al., 2017; Feinberg et al., 2011; Litt & Perrin, 2014; Mann et al., 2008; Rosenberg et al., 2008;

Shapiro & Derrington, 2004), the ECSE age range (e.g., Morgan et al., 2012; Morrier & Gallagher, 2012), and the school age range (e.g., Hosp & Reschly, 2003). Thus, more research examining these patterns at a local level is necessary to elucidate service access trends and to inform next steps. This step of fully documenting sociodemographic differences in service access aligns the first step of a model developed by Kilbourne et al. (2006) when conducting disparities reduction research. This model describes the importance of 1) identifying the disparities, 2) examining barriers that may be contributing to these disparities, and 3) creating interventions to reduce these disparities. By inspecting sociodemographic patterns in accessing services in several distinct ways, researchers were able to map out the patterns of these groups and inform to whom interventions should be tailored.

In addition, to working toward local disparity identification in Study 1, the second study in this dissertation, aimed to explore barriers and supports families experienced in accessing these services. This study helped to address the second step in the disparities reduction model (Kilbourne et al., 2006). The contributions to each step in the disparities reduction framework these studies provided will be reviewed in detail.

Study 1: Examining Local Rates and Disparities in Accessing EI and ECSE Services

Through Study 1, the researcher examined patterns and rates of EI and ECSE service access. Specifically, these patterns and rates were explored through examining how a local county was performing with regard to both EI and ECSE service access when compared to national rates, state rates, and rates of children who might be eligible. Overall, results of this study suggested this local county is performing similar to or better than national or state rates for both the EI and ECSE age ranges. Although this county demonstrated strong performance compared to the rest of the country and the rest of Georgia, there was still documented room for improvement. Compared to the number of children who might be eligible for services based on studies examining direct assessment data with children in these age ranges (i.e., Rosenberg et al., 2008 and Paff, 2017), this local county continues to show a statistically significant underaccess of services across both EI and ECSE services. To help conect more eligible children with freely available services that can make a meaningful impact on their educational trajectory, the goal of the second study was to try to determine if specific groups of children are less likely to receive services. To this end, researchers also examined patterns of service access among various sociodemographic groups of children.

Furthermore, patterns across sociodemographic groups were also examined by comparing the various sociodemographic groups to each other using risk ratios, as well as to the number of children within that sociodemographic group that are predicted to be eligible for services. Through this examination and in alignment with our hypothesis, several groups were identified that were disproportionately underrepresented in both EI and ECSE services (i.e., Asian children, American Indian and Alaskan Native children, and children with race classified as Other). However, demonstrating a different pattern, Black or African American children and Hispanic or Latino children were disproportionately overrepresented in both EI and ECSE services. These findings align more closely with the school age literature (Hosp & Reschly, 2003)

To examine if these risk ratios were indiciative of district wide success with enrolling families in services, we conducted additional analyses to contextualize these findings within the expected or predicted rates of access for each demographic group. For the EI and ECSE age range, White children, Black or African American children, and Asian children were all still statistically significantly underaccessing these respective services compared to the children in each of these groups who might be eligible. Thus, these results indicate that particular groups might be driving the overall underaccess of services for this county.

This study also expanded upon the existing literature through examining usage patterns for groups of children based on primary language and insurance status in addition to race/ethnicity. Finally, children from families whose primary language is not English were significantly more likely to access services than children from families whose primary language is English, and children from families who had private insurance were less likely to access services than children who had public insurance or no insurance. Overall, children whose primary language group was English and children in all insurance status groups were significantly under accessing services in the EI age range. These findings give a more detailed overview of service access patterns and indicate the need to target all insurance status groups when planning interventions.

Although the results of Study 1 reveal a pattern of service access including an overall underutilization of services, additional research is needed to determine why some families are successful in accessing services while others are unsuccessful. To do this, Study 2 was designed to learn about the expereinces families have in the process of accessing services.

Study 2: Identifying Barriers in Accessing EI and ECSE Services

In the second study, researchers wanted to delve more deeply into the second step in the disparities reduction framework (Kilborne et al., 2006). This seemed important because although the district examined in Study 1 perfomed well in terms of enrollment compared to state and national rates, the rate of access was still largely under the expected rate based on prevalence estimates (Rosenberg et al., 2008; Paff, 2017). This study more closely examined barriers and supports that exist for families trying to access EI and ECSE services by conducting interviews with caregivers of children with delays or disabilities. This is particularly important in a district that is performing so well because the barriers and supports may be different or less obvious than in districts where access rates are extremely low. Caregivers of children who accessed services successfully and caregivers of children who did not access services successfully were both included to contribute to a more comprehensive picture of the barriers and supports in accessing EI and ECSE services.

A number of themes emerged to elucidate barriers and supports in accessing services that were reported by “several” participants (i.e., at least 25% of participants but less than 50% of participants in that age group) or by “many” participants (i.e., at least 50% of participants in that age group). Themes were organized into barriers or supports at each of the following levels based on the socioecological model: Individual, Interpersonal, Organizational, and Community. Many themes that emerged aligned with previous literature on barriers (e.g., lack of knowledge or having inaccurate knowledge, unclear or difficult referral process as a barrier, needed services and providers being unavailable, a lack of advertisements/materials) or supports (e.g., having accurate knowledge, clear or easy referral process). Other novel themes that emerged included parents taking action or advocating for their child as a support, presence of stigma as a barrier, and high collaboration among service providers as a support.

Through identifying these themes, the researchers were able to begin to explore the experiences families have in a local county when accessing EI and ECSE services. Many of the participants included had successfully accessed services, but they were still able to contribute information about supports as well as information about the challenges they experienced. Information obtained from these individuals might allow interventions to be put into place to prevent delays for others in the future. Furthermore, participants were also included who had not accessed services, and these participants were able to shed additional light on some of the factors that contributed to them not getting services. For example, one participant who was unsuccessful in accessing services expressed concerns related to having negative attitudes about services. The identified barriers and supports contributed to ideas for future directions for researchers to plan interventions to increase service access.

Future Directions

With Study 1 revealing an overall underutilization of EI and ECSE service usage and Study 2 identifying barriers and supports associated with caregivers accessing services for their children, the researchers have a better idea of future directions to head. Specifically, the researchers hope to design interventions to increase service access across both of these age ranges to ensure children are getting the services they need. These interventions will be aimed to increase service access for all children due to the overall underutilization of services in the county in this study.

Although some barriers that were identified in Study 2 are more systemic and difficult for the current researchers to directly change, other barriers would be easier to address through direct action. For the more systemic changes, an example of a change that could be made tied to the results of Study 2 would be for additional services and service providers being available in the local community.

To address barriers through direct action on the part of the researchers, several intervention ideas were proposed. For example, participants having accurate knowledge as well as lacking knowledge were frequently discussed in the context of contributing a participant's ability to get services for their child. One idea for an intervention that could be put into place would be for the researchers to design a course or class for caregivers of children to provide information on appropriate and delayed developmental milestones as well as steps to take in the case of a caregiver noticing a delay. More specifically, a course could be designed around how and when to raise concerns with a child's pediatrician and how to contact local service providers. Additionally, other interventions (e.g., campaigns against misinformation) were discussed in more detail.

The supports identified also contribute to the researchers' understanding of the experience of families accessing services. In particular, a social network being present was most commonly discussed in the context of being a support. The researchers could help create more parent support groups or mentor programs to increase social support for children and their families. Additionally, patient navigators being available at pediatrician offices may help families get connected to services more easily. These specific interventions, as well as others based on identified barriers and supports, may be helpful in increasing service access across all groups of children in the EI and ECSE age ranges.

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