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Caregivers of Children Enrolled in Georgia's Early Intervention Program: The Influence of Rural or Urban Residence on Knowledge of Rights, Community Resources and Social Supports

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CAREGIVERS OF CHILDREN ENROLLED IN GEORGIA'S EARLY INTERVENTION PROGRAM: THE INFLUENCE OF RURAL OR URBAN RESIDENCE ON KNOWLEDGE OF RIGHTS, COMMUNITY RESOURCES AND SOCIAL SUPPORTS

by

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ABSTRACT

The purpose of this study was to establish the baseline for understanding the impact of place of residence on socio-demographic factors for caregivers of children enrolled in Georgia's Early Intervention (EI) program. This study is a secondary analysis of nine questions from the Family Outcomes Survey (FOS) collected between January of 2006, and May of 2010 (N=15,474). The Kruskal-Wallis Statistic and the Samawi–Vogel Overlap Coefficient were used to examine the relation between the rural or urban classification of county of residence, the health district in which participants reside, and the participant's knowledge of rights, access to community resources, and social support systems. Results demonstrated that while the responses to the selected questions from the FOS were highly positive overall, significant differences were found in responses from participants based on their place of residence. Participants located in urban areas responded significantly less positively when compared to their rural counterparts. Findings from this study may serve to facilitate an improvement in the delivery of EI programs throughout the State of Georgia.

INDEX WORDS: Early intervention, Developmental delay, Disability, Rural, Urban, Knowledge of rights, Access to community resources, Social supports.

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DEDICATION

This dissertation is dedicated to my son, Owen. I hope this achievement is proof that with hard work and resolve anything is possible. Whatever your dreams may be, just remember that without love in a dream, it will never come true.

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BACKGROUND, SIGNIFICANCE, AND LITERATURE REVIEW

Introduction

The relation between socio-demographic variables such as knowledge of rights, social support systems, and community resources for families enrolled in early intervention programs has been extensively researched, especially in regard to race, family income, gender, and qualifying condition. However, research is lacking when examining the relation between socio-demographic variables and early intervention regarding rural or urban residence. This study used data from the Family Outcomes Survey, a questionnaire administered as a part of Georgia's Early Intervention (EI) program, to examine differences in knowledge of rights, the availability of community resources, and support systems based on the rural and urban status of the county in which participants reside. The following research question was addressed in this study:

What is the relation between rural and urban residence and socio-demographic variables such as knowledge of rights, community resources and social supports for families of infants and children enrolled in Georgia's EI program between January of 2006 and May of 2010?

Because Georgia's EI program is administered at the health district level, further analysis of the data was conducted at the district level to explore the relation between the above described outcomes and the health district in which participants reside.

Finally, recommendations and policy implications are discussed in order to facilitate an improvement in the delivery of EI programs throughout the State of Georgia.

Background

The early years of childhood development provide the foundation for an individual's cognitive and physical abilities for the rest of his or her life. These early years, (generally considered birth to five years of age), are marked by developmental milestones. Children with developmental problems progress through the same genetically programmed sequence of development; however, because of disability their brains may not mature in the same manner as a typically developing individual (Anastasiow, 1990). Because the achievement of each milestone relies upon the abilities obtained at a previous milestone, any delays will have a direct effect on the accomplishment of subsequent milestones. For this reason, it has been noted that developmental problems in infants and toddlers can set a child on a trajectory that will result in lifelong disability (Shonkoff & Meisels, 1990). Further, certain developmental milestones may only be met during finite windows of time. Abilities unattained during these crucial windows will result in unattained abilities for a lifetime.

Severe developmental problems are referred to as developmental disabilities. Developmental disabilities are defined as delays in mental or physical functioning which manifest before the age of 18, and are likely to continue indefinitely (Center for Disease Control and Prevention, 2010c). Developmental disabilities may result from a variety of causative factors including mental retardation, neuromuscular disorders such as cerebral palsy, blindness and deafness, learning disabilities, epilepsy, genetic disorders, chronic medical conditions, trauma, premature birth, nutritional problems or environmental factors and autism (Decoufle, Yeargin-Allsopp, Boyle, & Doernberg, 1994).

Surveillance of developmental disabilities presents a challenge for a number of reasons. Exact prevalence estimates for children with developmental disabilities will vary depending on the type of disability, the age group included, and the survey method used (Decoufle, et al., 1994). While there are a wide range of studies estimating the prevalence of selected developmental disabilities in the United States (Hauser, 2007; Rosenberg, Zhang, & Robinson, 2008; Steinkuller, et al., 1999; Tomblin, Records, Buckwalter, Zhang, & Smith, 1997; Winter, Autry, Boyle, & Yeargin-Allsopp, 2002; Yeargin-Allsopp, et al., 2003), studies estimating the prevalence of multiple conditions in one sample are less frequent. Large population based data sets such as the Metropolitan Atlanta Developmental Disability Surveillance Program (MADDSP), and the National Health Information Survey (NHIS), have been used by researchers to estimate prevalence rates for all developmental disabilities. Research using data from these studies has resulted in varying prevalence estimates ranging from as low as 2% of the general population, to as high as 14% (Boyle, Decoufle, & Yeargin-Allsopp, 1994; Center for Disease Control and Prevention, 2004, 2006, 2010c; Larson, et al., 2001; Rice, 2009).

Because of a pattern of increased prevalence which has become apparent since the 1990's, Autism Spectrum Disorders (ASDs) have become an area of particular interest to researchers. ASDs refer to a range of developmental disabilities related to the core disorder of autism, including Asperger Syndrome. ASDs are characterized by impairments in social and emotional understanding, all aspects of communication, and flexibility of thinking and behavior (Jordan, 2005). Depending upon severity, ASDs can impact a person's functioning at different levels, from very mildly to severely (Center for Disease Control and Prevention, 2010b). A strong genetic link to these disorders has been well

established (Bailey, et al., 1995; Rutter, 2000), as well as a strong gender bias, with ASDs affecting males more often than females (Rice, 2009). There are three different types of ASDs:

- Autistic disorder, also called "classic autism",
- Asperger Syndrome, and
- Pervasive Developmental Disorder also called "atypical autism".

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a large scale prevalence study of ASDs. ASDs have been of particular interest to researchers since the early 1990s when a pattern of increased prevalence began to emerge. A 2006 study of eleven states using ADDM data found that one child in every 110 was classified as having an ASD. This marked an increase in prevalence of 57% from the 2002 to the 2006 ADDM surveillance year (Rice, 2009). Research suggests that the rising prevalence of ASDs may result from multiple factors including changes in diagnostic criteria, changes in diagnostic practices, increased community awareness, and a true increase in symptoms in the population (Center for Disease Control and Prevention, 2010a). The rationale behind the theory that there has been a true increase in ASD symptoms in the population stems from research comparing ASD prevalence to that of other developmental disabilities over time. These comparisons have shown that ASD prevalence is increasing at a higher rate than other disability categories.

In order to minimize the negative impact of developmental disabilities, including ASDs, a field of childhood education has emerged designed specifically to identify children with special needs in the early years of life and to provide appropriate and early intervention services. These programs, commonly referred to as EI programs, exist to

provide a coordinated array of intervention services designed to assist children with developmental disabilities reach their maximum potential. EI services are intended for both the family and child and can include physical therapy, occupational therapy, speech and language therapy, special education, special instruction, and patient advocacy (Shonkoff & Meisels, 1990). Although the term early intervention can be used broadly to refer to services for children up to the age of eight years old, this study refers to early intervention as the provision of services from birth to age three. This definition is consistent with eligibility requirements for the Georgia statewide EI program (Georgia Department of Human Resources Division of Public Health, 2006).

It has been well established that EI programs are capable of preventing, or minimizing, the short and long term effects of delayed development that would occur in the absence of intervention during the first years of a child's life (Bailey, Nelson, Hebbeler, & Spiker, 2007; Black, Dubowitz, Krishnakumar, & Starr, 2007; Guralnick, 1998; Infant Health and Development Program, 1990; Lovaas, 1987; McCormick, et al., 2006; Ramey & Ramey, 1998; Rauh, Achenbach, Nurcombe, Howell, & Teti, 1988; Simeonsson, Cooper, & Schelner, 1982). In 1986, the United States Congress recognized the importance of providing EI services to infants and children with disabilities and their families by establishing the Program for Infants and Toddlers with Disabilities (Part C of the Individuals with Disabilities Education Act [IDEA]). Part C of IDEA established a federal grant program to assist states in operating a comprehensive statewide EI program (H.R. 1350--108th Congress, 2003). Today, EI programs operate in fifty states, the District of Columbia, the Commonwealth of Puerto Rico, and four outlying areas (U.S. Department of Education, 2010a). Georgia's EI program is called Babies Can't Wait (BCW), and is administered

through the Georgia Department of Community Health, Division of Public Health (Georgia Department of Community Health Division of Public Health, 2010). The program has no financial requirements for participation, and anyone can refer a child to BCW. Participation in the program is voluntary (Georgia Department of Human Resources Division of Public Health, 2006).

It has been widely accepted that socio-demographic variables impact childhood development (Bronfenbrenner, 1974). Research in this area has also demonstrated that certain socio-demographic variables can negatively impact children with developmental delays or disabilities by resulting in unmet needs. Some characteristics which have been shown to result in unmet needs include poverty, insurance status, lower levels of provider supply, and the general pediatrician/population ratio (Mayer, Skinner, & Slifkin, 2004). Parents of children with special needs rely upon a complex system of medical, educational and social services to meet the needs of their children, and rural or urban residence can impact the availability to these services. It has been demonstrated that a number of home-care problems are common to both urban and rural settings, including nursing coverage, respite care, school services, coordination of medical resources, and emergency response protocols (Wheeler & Lewis, 1993). Research has also demonstrated that urban and rural populations differ in terms of access to services for children with special needs (Farmer, Clark, Sherman, Marien, & Selva, 2005; Montes, Halterman, & Magyar, 2009; Sontag, 1993). However, comprehensive studies on the diverse needs of rural versus urban families related to the implementation of EI services have yet to emerge.

In an effort to equalize access between populations, experts in the field of EI have identified certain key factors to facilitate access to services and ultimately improve

outcomes (Brewer, McPherson, Magrab, & Hutchins, 1989). Included among the identified factors are knowledge of rights, community resources, and social support systems.

Parental knowledge of rights is vital to ensure equitable access to EI services, and to guarantee the quality of those services. Foremost among those rights is the right of families to access EI services. Part C of the IDEA requires that all infants and toddlers with disabilities receive EI services from birth through age three, regardless of personal or family characteristics. Procedural safeguards included under part C of the IDEA ensure that families are informed about and involved in the decision making process for services for their child and family. Families who are not familiar with the EI system may not be fully aware of these rights, and for this reason the local lead agency must provide information to assist families in understanding their rights. The BCW program is designed to maximize family involvement and ensure parental consent in each step of the process from the determination of eligibility through service delivery. Parents must be informed about these rights and safeguards in order to assume a leadership role in ensuring services to their children.

It has been widely demonstrated that the composition of a community, including the resources present in that community, is an important factor in human development. Researchers have observed that formal structures such as police, schools, and clergy provide linkages between society and the development of individual children and youth (Coulton, 1995). Concern among professionals over the erosion of institutional resources in urban neighborhoods has directed growing attention to the potential negative impact of the inability of families to access community resources on child development (Earls & Buka, 2000). EI models which incorporate integration with community resources are able

to assist families in addressing their priorities in the context of available community resources. Multiple studies examining community based EI program models have clearly demonstrated the positive impact of these models on developmental outcomes (Halpern, 1990). Resource-based models of EI have been widely regarded as best practice for a number of years. In 1987, C. Everett Koop, the U.S. Surgeon General at the time called for professionals involved in the care of children with special health care needs to work together to build community-based service systems (Brewer, et al., 1989).

Access to community resources has also been shown to be of particular concern to families of children with ASDs. Research has also shown that families of children with ASDs are more likely than parents of other children with special health care needs to report difficulties accessing community resources, and more likely to experience dissatisfaction with the resources available in their community (Montes, et al., 2009).

It has been demonstrated that parents of a child with a developmental disability have lower rates of social participation than parents without a child with a disability (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). This is concerning as a link between social supports and positive outcomes for EI programs has been clearly established. Research has consistently shown that families with strong support systems are able to handle challenges more effectively than families with few supports (Bailey, et al., 2007; Dunst, Trivette, & A.G., 1994; Vincent, Slisbury, Strain, McCormic, & Tessier, 1990). Acknowledging this link, many experts now encourage the adoption of a behavioral-ecological model for service delivery.

Purpose of the Study

The Family Outcomes Survey (FOS) is an ongoing survey of the knowledge, attitudes and beliefs of caregivers of children who participate in the BCW program. The survey is administered by the child's service coordinator upon his or her discharge from the program at three years of age. Results from the FOS were analyzed to investigate differences between caregivers regarding three categories: (1) how well caregivers know their rights and are able to advocate for their child, (2) access to community resources, and (3) support systems for caregivers. Because the FOS is administered upon discharge of the client from the program, it is unlikely that survey participants will directly benefit from this research; instead, the information gained will benefit future BCW participants by assisting program administrators to direct the allocation of resources for future participants.

By comparing responses to the previously mentioned categories with the rural or urban classification of county of residence, it is anticipated that these data will be used to highlight differences between caregivers of children who participate in the BCW program. Moreover, it is anticipated that this study will establish the baseline for understanding differences between the impact of urban or rural classification on knowledge of rights, access to community resources, and social supports. By providing program administrators with this information, this study will facilitate an improvement in the delivery of EI programs throughout the State of Georgia. In turn, this information will allow program administrators, at both the state and federal level, to better address the diverse needs of target populations through the allocation of resources to target areas. Examples of these resources include advertising materials, contracted and full time therapists, special instructors, service coordinators, and family education and support services.

Significance of the Study

Georgia consistently ranks among the bottom ten states in the United States in terms of child health. Based on ten key indicators of child health, Georgia was ranked 42nd out of 50 states in 2009(Annie E. Casey Foundation, 2009). The infant mortality rate in Georgia (8.1/1,000 live births) is well above the national average (6.7/100 live births). Additionally, Georgia's rate of sudden infant death syndrome (1.1/1,000 live births), exceeds the reported national average (0.59/1,000 live births) for the same year (Georgia Children's Health Alliance, 2010)).

Georgia also lags behind the rest of the nation in regard to certain characteristics of healthy families. Data from 2007 indicate that 22% of Georgia's children ages 1 to 5 live in households where family members read to them less than three days per week, compared to a national average of 16%. Data from 2008 indicate that 28% of Georgia's children are living in families where no parent has full time, year round employment (Annie E. Casey Foundation, 2009).

Unfortunately, Georgia also consistently fares poorly in terms of EI when compared to the rest of the nation. In 2008, available data show that Georgia served 1.19% of its population ages birth to two years old, compared to a national baseline of 2.53%. The percentage of Georgia's population served through EI ranks below every state and territory in the U.S. except American Samoa and the District of Columbia (U.S. Department of Education, 2006).

In June 2010, the U.S. Department of Education released state determinations on implementation of the IDEA for fiscal year 2008. This document represents a summary of an evaluation of each state and territory's efforts to implement the requirements and

purposes of the IDEA. Programs are compared based on fourteen indicators such as; ensuring positive outcomes for infants and toddlers with disabilities, timely provision of services, meeting evaluation timelines, and provision of services in natural environments (U.S. Department of Education, 2010b). Programs are then ranked into one of five categories from meets requirements to needs intervention. According to the Department of Education's findings, Georgia fell under the category of needs intervention for the third consecutive year. This places Georgia at the bottom of the national rankings, out ranked by every state and territory in the union with the exception of the District of Columbia

In July 2010, the Commissioner of the Georgia Department of Community Health received a determination letter from the Acting Director of the U.S. Department of Education's Office of Special Education and Rehabilitative Services outlining Georgia's noncompliance with the requirements of Part C of the IDEA. This letter states that "based on the totality of the State's data and information . . . Georgia must submit a corrective action plan to the U.S. Department of Education." (Posny, 2010, p. 1). In response to the letter of determination, Debbie Cheatham, the Program Director of Children and Youth with Special Needs for Georgia's Department of Community Health Division of Public Health, posted a letter to BCW stakeholders and interested parties conceding that "Georgia's Part C EI program, BCW has been determined to be in needs intervention status for a third consecutive year" (Cheatham, 2010). If Georgia intends to address the areas outlined by the U.S. Department of Education and move beyond the needs intervention classification, state program administrators will need to examine the manner in which the BCW program operates at both the state and local levels.

Section 504 of the Rehabilitation Act of 1973, establishes that an agency that receives federal dollars may not "afford a qualified handicapped person an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to . . . and as effective as that provided to others." (2006, p. 1). As the diversity of families within Georgia continues to increase, and laws such as IDEA continue to emphasize the importance of fairness and equity when offering services to children with disabilities, it is urgent that challenges related to the diverse needs of both rural and urban families of children with disabilities are identified and addressed.

Literature Review

Developmental Disabilities

Developmental disabilities are defined as delays in mental or physical functioning which manifest before the age of 18, and are likely to continue indefinitely (Center for Disease Control and Prevention, 2010c). Developmental disabilities may result from a variety of causative factors including mental retardation, neuromuscular disorders such as cerebral palsy, blindness and deafness, learning disabilities, epilepsy, genetic disorders, chronic medical conditions, trauma, premature birth, nutritional problems or environmental factors and autism (Decoufle, et al., 1994).

Prevalence of Developmental Disabilities

Accurate surveillance of developmental disabilities is challenging because case definitions for developmental disabilities often rely on clinical examinations and clinical judgment rather than on results from laboratory reports or pathology findings. Also, because these conditions evolve over time and are related to the maturation of the nervous

system, a child may be several years old before a definitive diagnosis of a developmental disability can be made (Decoufle, et al., 1994).

In order to estimate prevalence rates for developmental disabilities in the U.S., researchers commonly use data from the MADDSP, and the NHIS. In 1984, the Center for Disease Control (CDC) initiated the Metropolitan Atlanta Developmental Disabilities Study (MADDS). MADDS was funded by the Agency for Toxic Substances and Disease Registry through a cooperative agreement involving the CDC, and the Georgia Department of Human Resources. From 1984 to 1990, MADDS monitored the prevalence of four serious developmental disabilities – mental retardation, cerebral palsy, vision impairment, and hearing impairment – among children three to ten years of age (see Table 1) (Center for Disease Control and Prevention, 2004). The MADDS represented the first population based study of multiple disabilities among U.S. school-aged children (Decoufle, et al., 1994).

Using data from the MADDS, researchers were able to show that rates for developmental disabilities varied by age, race, and sex. The study found the overall crude rate of cerebral palsy in children was 2.4 per 1,000 children, and that the rate was higher among black children (3.1 per 1,000 children) as compared to white children (2.0 per 1,000 children). Researchers also reported that the MADDS data showed the rate of moderate to severe hearing impairment among the study population was 1.1 per 1,000 children, and the rate of vision impairment was 0.8 per 1,000 children. The same researchers also found that rates of hearing impairment were higher among black male children as compared to other race and sex groups, whereas rates for vision impairment varied only slightly between these group (Boyle, et al., 1996).

A critique of the MADDSP study is a lack of adjusting for confounding variables. According to the author of the study; "... in this study rates were not adjusted for possible confounding factors; consequently, the variation in rates may reflect social or other characteristics unique to the study population" (Boyle, et al., 1996). This criticism implicitly acknowledges the possible importance of social characterizes on developmental disabilities.

In order to continue the work of MADDS, the MADDSP was established in 1991 by the CDC as an ongoing program. Beginning in the 1996 study year, MADDSP added autism spectrum disorders as a fifth disability. Also in 1996, MADDSP began to focus on a narrower age range. By changing the inclusion criteria to include children who are 8 years old at any time during the study year of interest, administrators hoped to make the surveillance program timelier (Center for Disease Control and Prevention, 2004).

Table 1

MADDSP Case Definitions

Autism Spectrum Disorders	A child is included as a confirmed case of ASD if he or she displays behaviors (as described by a qualified professional) consistent with the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV) diagnostic criteria for Autistic Disorder, Pervasive Developmental Disorder- Not Otherwise Specified (including Atypical Autism), or Asperger's Disorder. A qualified professional is defined as an educational, psychological or medical professional with specialized training in the observation of children with developmental disabilities.
Cerebral Palsy	Confirmed cases of cerebral palsy include children whose conditions are diagnosed as cerebral palsy by a qualified physician or who are identified by other qualified professionals as having this disability on the basis of physical findings noted in source records. A qualified professional is defined as a physician, physical therapist, occupational therapist, nurse practitioner, or physician's assistant.
Hearing Loss	Hearing loss is defined as a measured, bilateral, pure-tone hearing loss at frequencies of 500, 1,000, and 2,000 hertz averaging ≥40 decibels (dB), unaided, in the better ear. In the absence of a measured, bilateral hearing loss, the conditions of the children met the case definition if their source records include a description by a licensed or certified audiologist or qualified physician, of a hearing loss of ≥40 dB in the better ear.
Intellectual Disability	An intellectual disability is defined as a condition marked by an intelligence quotient (IQ) of ≤70 on the most recently administered psychometric test. In the absence of an IQ score and in the context of testing, a written statement by a psychometrics that a child's intellectual functioning is within the range for intellectual disability is acceptable.
Vision Impairment	Vision impairment is defined as a measured visual acuity of 20/70 or worse, with correction, in the better eye. In the absence of a measured visual acuity, a child is considered a patient if a source record indicates a functional description, by a qualified physician or vision professional, of visual acuity of 20/70 or worse (e.g., light perception only), or a statement by a qualified physician or vision professional that the child has low vision or blindness.

(Center for Disease Control and Prevention, 2004)

Using MADDSP data derived from the 2000 surveillance year, researchers found that approximately 2% of eight year old children had at least one of the five developmental disabilities monitored (Center for Disease Control and Prevention, 2006). Using combined data from 1996 and 2000, researchers were able to estimate prevalence rates over time. They found that during the 1996 surveillance year, the prevalence of mental retardation was 15.5 per 1,000 children aged 8 years, however; it decreased to 12.0 per 1,000 in 2000.

The overall prevalence of cerebral palsy was 3.6 per 1,000 in 1996 also decreasing to 3.1 per 1,000 in 2000. Prevalence rates of both hearing loss and vision impairment also decreased from 1.4 per 1,000 in 1996 to 1.2 per 1,000 in 2000. Minimal differences by study year were observed in the prevalence of all four disabilities when examined by sex, race and severity, but the prevalence of mental retardation and cerebral palsy was highest among males and black children (Bhasin, Brocksen, Avchen, & Braun, 2006).

The NHIS is an ongoing survey of U.S. households, which uses a multistage probability sampling procedure to obtain a nationally representative sample of the civilian, non-institutionalized population (National Center for Health Statistics, 2009). Using NHIS survey results from 1994 and 1995, researchers estimated the combined prevalence of persons of all ages with mental retardation and/or developmental disabilities in the United States to be 14.9 per 1,000 (Larson, et al., 2001). Another commonly cited prevalence study which used data from the 1988 Child Health Supplement to the NHIS incorporated multiple conditions to examine the prevalence of developmental disabilities among children ages 0 through 17 years. In this study, researchers examined deafness or trouble hearing, blindness, epilepsy or seizures, stammering and stuttering, other speech defects, cerebral palsy, delay in growth or development, learning disabilities and emotional or behavioral problems. The results of the research suggest a prevalence rate of 16.7% for all developmental disabilities among children less than 17 years old. Hearing impairment, speech defects, delays in growth or development, learning disabilities, emotional or behavioral problems were all exceptionally common, ranging in prevalence from 3.5% to 6.5% (Boyle, et al., 1994)

When discussing the limitations to this study, the authors acknowledge that delay in growth or development encompasses a wide range of possible disorders, and can be seen as an overly broad category resulting in an overestimation of the overall prevalence rate. Also, the rate for deafness or trouble hearing may have been higher than those seen in other studies because the NHIS survey included unilateral and bilateral hearing loss of any severity, whereas only moderate to severe bilateral hearing loss had been captured in most previous studies (Boyle, et al., 1994).

Autism Spectrum Disorders

ASDs refer to a range of developmental disabilities related to the core disorder of autism including Asperger Syndrome (Center for Disease Control and Prevention, 2010b). Autism spectrum disorders are characterized by impairments in social and emotional understanding, all aspects of communication, and flexibility of thinking and behavior (Jordan, 2005). The symptoms of ASDs typically are present before age 3 years and often are accompanied by abnormalities in cognitive functioning, learning, attention, and sensory processing (Center for Disease Control and Prevention, 2009). The term "spectrum disorders" is used to indicate that ASDs encompass a range of behaviorally defined conditions, which are diagnosed through clinical observation of development. These conditions include autistic disorder (i.e., autism), Asperger disorder, and pervasive developmental disorder--not otherwise specified (PDD-NOS). Persons with Asperger disorder or PDD-NOS have fewer diagnostic symptoms of ASDs compared with autism, and the symptoms often are indicative of more mild impairment (Center for Disease Control and Prevention, 2009).

While the exact cause of autism is yet unknown, a strong genetic link to these disorders has been established. When researchers first examined autism prevalence rates in the 1960s, they found that the 2% rate of autism in siblings was far above the general population base rate, suggesting a possible high genetic liability. This realization led to the first small-scale twin study of autism which indicated strong genetic influences (Rutter, 2000). A 2009 British twin study examined a combined sample of monozygotic and dizygotic pairs. Sixty percent of the monozygotic pairs were concordant for autism versus no dizygotic pairs. Ninety percent of monozygotic pairs were concordant for a broader spectrum of related cognitive or social abnormalities versus 10% of dizogotic pairs (Bailey, et al., 1995). The findings of both these studies indicate that autism is under a high degree of genetic control. Further, the unraveling of the human genome has added scientific evidence to the case for a genetic link to autism. Medical and chromosomal findings indicate genetic heterogenity based on genome-wide scans of affected relative pair samples (Rutter, 2000).

Research has also shown strong gender bias when examining ASD prevalence. Using ADDM data from 2006, researchers found that autism spectrum disorders affect approximately 1 in 70 males compared to 1 in 315 females (Rice, 2009). According to the CDC, the prevalence of ASDs among eight year old boys is estimated to be 7.3 to 19.3 per 1,000 as compared to a range of 1.0 to 4.9 per 1,000 among 8-year-old girls (Center for Disease Control and Prevention, 2009).

The ADDM Network is a group of programs funded by the CDC to determine the number of people with developmental disabilities and ASDs in the United States. The most recent prevalence report from the ADDM Network studied data collected from 11 ADDM

Network sites (areas of Alabama, Arizona, Colorado, Florida, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, South Carolina, and Wisconsin) for 2006.

ASDs have been of particular interest to researchers since the early 1990s, when a pattern of increased prevalence began to emerge (Rutter, 2000). To analyze changes in identified ASD prevalence, researchers compared 2006 ADDM data with data collected from 10 sites (all sites noted above except Florida) in 2002. They found that the average prevalence of ASDs identified among children aged 8 years increased 57%. Although improved ascertainment accounts for some of the prevalence increases documented in the ADDM sites, a true increase in the risk for children to develop ASD symptoms cannot be ruled out (Rice, 2009).

If improved ascertainment cannot be credited for the entirety of the increase in prevalence, how can the increased prevalence be explained? Research suggests that multiple factors may explain the rising prevalence of ASDs including changes in diagnostic criteria, changes in diagnostic practices, increased community awareness, and a true increase in symptoms in the population (Center for Disease Control and Prevention, 2009). However, some research has shown that the increased prevalence of autism cannot be solely attributed to improved diagnosis and reporting of developmental disabilities. Using annual report data from the Office of Special Education Programs (OSEP), researchers developed cohort curves showing ASD prevalence to be increasing over time at a higher rate than other disability categories. This suggests that the increasing prevalence of children with the autism classification is not the result of across-the-board increases in special education classification (Newschaffer, Falb, & Gurney, 2005).

The Importance of Early Intervention

Ideally, EI is a holistic approach designed to offer a wide range of services to all those affected by the child's delay or disability. EI services are intended for both the family and child and can include a range of services such as physical therapy, occupational therapy, speech and language therapy, special education, special instruction, and patient advocacy (Shonkoff & Meisels, 1990). In a 1998 journal article, Michael Guralnick, the director of the Center on Human Development and Disability at the University of Washington, defined EI as ". . . . a system designed to support family patterns of interaction that best promote children's development." (Guralnick, 1998, p. 319). Renowned educational psychologist Sheila Wolfendale further reinforced the importance of a holistic approach when she wrote that early childhood intervention has several goals: "To provide support to families to support their children's development; to promote children's development in key domains such as communication or mobility; to promote children's coping confidence, and to prevent the emergence of future problems." (Wolfendale, 1997, p. 147).

The rationale concerning children with developmental disabilities is that their modes and rates of learning are likely to require specialized strategies to ensure healthy development, and children will experience improved competency when they participate in intensive, systematic EI programs. The success of EI is typically defined broadly in terms of more positive intellectual and social-emotional development relative to the expected outcomes in the absence of EI (Ramey & Ramey, 1998). Figure 1 illustrates the theory that children's experiences can alter their intellectual competence over time.

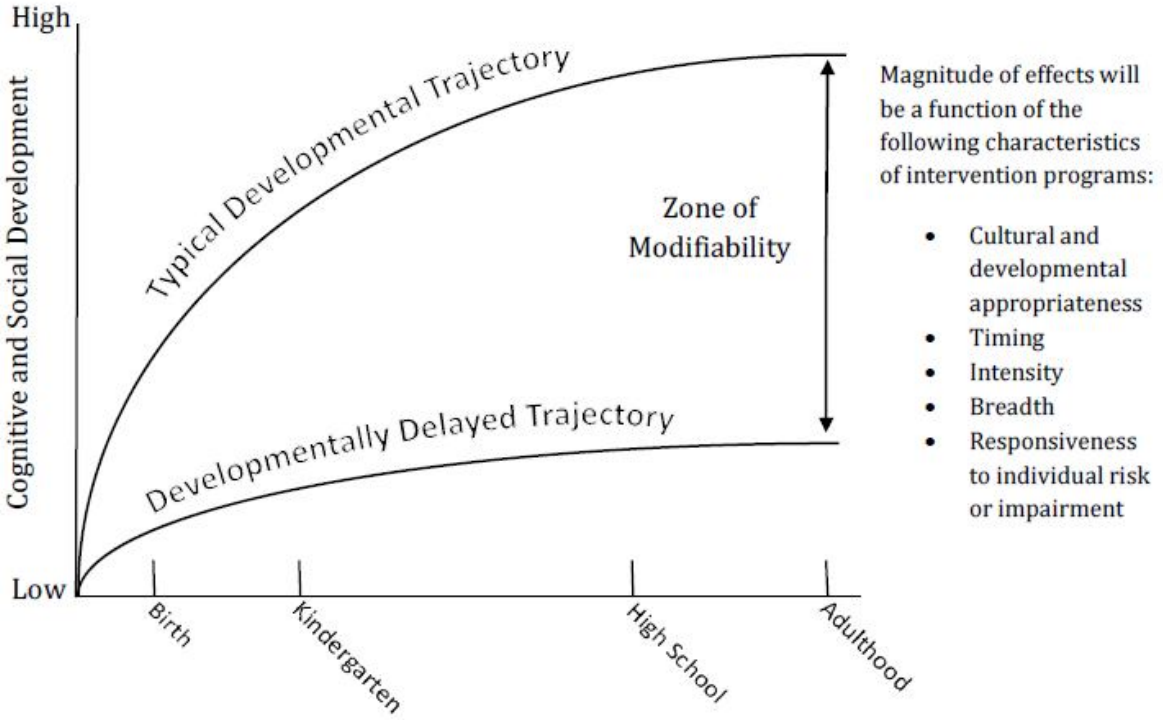

Figure 1. Ramey's Hypothetical Range of Reaction for Experience-Driven Cognitive Neurodevelopment (Ramey & Ramey, 1998)

Ramsey's figure graphically depicts the developmental trajectory for a typically developing individual, and that of an individual with a developmental delay. Over time, as the two trajectories diverge, the area between them (the zone of modifiability) grows increasingly large. The earlier a child receives EI services, the more likely that they will be able to be placed on a normative developmental trajectory, and continue to show optimal development after EI ends. Given the framework outlined in Figure 1, the obvious question is, can the trajectory of development through EI programs be effectively altered? Decades of research has indicated that the answer to this question is undeniably affirmative.

A 1982 review of twenty seven studies describing EI for infants and young children concluded that "the research does provide qualified support for the effectiveness of early

intervention" (Simeonsson, et al., 1982, p. 638). Later in the same decade, a randomized controlled trial of EI services targeted at low birth weight infants found a progressive divergence between the low birth weight experimental and low birth weight control children on cognitive scores. In this study, an experimental group of low birth weight children received EI services, and showed a significant improvement in cognitive scores compared to their peers in the control group who did not receive EI services. Scores obtained by the low birth weight control group were significantly lower than those of the low birth weight experimental children ($F = 4.42$, $p < .05$) (Rauh, et al., 1988). In 1990, the Infant Health and Development Program examined the effectiveness of EI in reducing the developmental and health problems of low-birth-weight and premature infants. This eight-site clinical trial randomly assigned 985 infants to an intervention group which received an educational curriculum focused on child development, as well as family support and pediatric follow-up, and to a control group of infants receiving only pediatric follow-up. After correcting ages for premature birth, the children were tested at the age of 36 months. Results showed the intervention group had significantly higher mean IQ scores than the control group. In addition, the intervention group had significantly fewer maternally reported behavior problems, and a small, but statistically significant, increase in maternally reported minor illnesses for the lighter-birth-weight group (Infant Health and Development Program, 1990). In 1994, follow-up data were obtained 4 to 7 years after an EI program ended. Subjects were randomly assigned to one of four intervention conditions: education treatment from infancy through three years in public school (up to age 8), preschool treatment only (infancy to age 5); primary school treatment only (age 5-8 years), or an untreated control group. Researchers concluded that "Results generally

supported an intensity hypothesis in that scores on cognitive and academic achievement measures increased as duration of treatment increased" (Campbell & Ramey, 1994).

EI has also been shown to be effective for children diagnosed with autism. In 1987, the results of a behavior modification treatment for two groups of similarly constituted, young autistic children were reported. These results demonstrated that the intensive, long-term experimental treatment group showed that 47% achieved normal intellectual and educational functioning, with normal-range IQ scores and successful first grade performance in public schools. Another 40% were mildly delayed and assigned to special classes for the language delayed, and only 10% were profoundly delayed and assigned to classes for the autistic/retarded. In contrast, only 2% of the control group children achieved normal educational and intellectual functioning; 45% were mildly retarded and placed in language-delayed classes, and 53% were severely delayed and placed in autistic/delayed classes (Lovaas, 1987).

History of Early Intervention Programs

The origins of EI in the United States can be traced to as far back as 1912, when President William Howard Taft signed into law a bill creating the Children's Bureau in the Department of Labor (Shonkoff & Meisels, 1990). The stated purpose of the new Bureau was to investigate and report "upon all matters pertaining to the welfare of children and child life among all classes of our people" (U.S. Social Security Administration, 2010b). However, it soon became clear that the focal point of the Children's Bureau would be children with special needs. In its first annual report, the Bureau noted that particular attention would be focused on "those who were abnormal or subnormal or suffering from physical or mental ills"(Lesser, 1985, p. 592). As the first official acknowledgement of a

federal responsibility for children's welfare, the establishment of the Children's Bureau provided a foundation for governmental data collection and federal grants to promote the health and development of the nation's most vulnerable children (Shonkoff & Meisels, 1990).

In 1935, with the ratification of the Social Security Act, the Children's Bureau received a significant amount of additional funding and support. Title V of the Act, Grants to the States for Maternal and Child Welfare, was assigned to the Children's Bureau and gave the Bureau equal status with the unemployment compensation and old-age provisions of the Social Security Act (U.S. Social Security Administration, 2010b). Title V of the Social Security Act was divided into five parts, the second part entitled Services for Crippled Children created the first federal program to provide matching funds for states to deliver medical services to a targeted patient group (Shonkoff & Meisels, 1990). $2,850,000 was appropriated to be made available to states for " . . . services for locating crippled children and providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization and aftercare for children who are crippled or who are suffering from conditions which lead to crippling . . ." (U.S. Social Security Administration, 2010a).

Funding for these programs continued throughout the 1940s and 1950s, but few changes were made until the 1960s which were marked by substantial growth and modernization in the field of early childhood intervention. In 1961, President Kennedy appointed a presidential commission to explore current knowledge in this area and develop a national strategy of prevention (Shonkoff & Meisels, 1990). As a result, in 1963 the enactment of Public Law 88-156 provided new federal funding under Title V of the Social Security Act for Special Projects for Children with Mental Retardation. In 1965, Head

Start began as a pilot program for children in more than 2,500 communities across the country. The founders of Head Start were convinced that compensatory programs in the preschool period could facilitate better school adjustment and performance for children who were disadvantaged by the consequences of poverty and social disorganization (Zigler & Valentine, 1979). Head Start provided a coordinated array of professional services to provide educational, medical, dental, nutritional, psychological, and social services, and "provided a bold and dramatic model for the field of early childhood intervention that continues to the present day" (Shonkoff & Meisels, 1990, p. 16).

In 1965, the Medicaid provisions of the Social Security Act (Title XIX) were signed into law mandating programs that reflected federal interest in early childhood intervention for poor children. One of the best known of these efforts is the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT). EPSDT mandated the early and periodic medical, dental, vision and developmental screening, diagnosis and treatment of all children, and youth under 21 years of age whose families qualified for Medicaid. Later in the late 1960s, President Johnson capitalized on the momentum created by President Kennedy and signed Public Law 90-538, the Handicapped Children's Early Education Assistance Act, which authorized funds to stimulate the development, evaluation, refinement, and dissemination of model demonstration programs for the education of disabled infants, preschoolers, and their parents.

Throughout the 1970s, EI programs in the United States experienced changes brought about by both litigation and legislation. In 1972, Public Law 92-424 (the Economic Opportunity amendments) mandated that all Head Start centers reserve at least 10% of their enrollment for children with identified disabilities. In 1975, the passage of Public Law

94-142 (the Education for All Handicapped Children Act), guaranteed the right to a free and appropriate public education for all children of school age, regardless of the presence of a disability. This legislation mandated the development of individualized education plans (IEPs). Supportive legislation, multiple successful class-action suits, and a rising public consciousness about the injustice of discrimination against people with disabilities characterized much of the legacy of the 1970s (Shonkoff & Meisels, 1990).

While in office, President Ronald Reagan took a special interest in programs for disabled children, facilitating some major steps forward for the field. In fact, according to some experts, the Education for All Handicapped Children Act Amendments of 1986 (Public Law 99-457) is the most important legislation ever enacted for developmentally vulnerable young children (Shonkoff & Meisels, 1990). The amendments, signed into law by President Reagan, reauthorized the Education of the Handicapped Act and include a rigorous national agenda pertaining to more and better services to young special needs children and their families. Specifically, the act calls for "a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all handicapped infants and their families"(PL99-457, 1986). Part H of the bill established the new discretionary program for states to facilitate the development of comprehensive systems of EI services for infants and toddlers with developmental delays or disabilities. The bill also required states, by the early 1990s, to provide free and appropriate public education and related services for all eligible children with disabilities from ages 3 to 5 in order to receive any federal preschool funds. Finally, the law reauthorized a number of discretionary programs under the Education of the Handicapped Act, such as services for deaf-blind children, early childhood research institutes, and grants for personnel training. In order to

receive Part H funds, each state is required to select a lead agency to administer its service system and must appoint an Interagency Coordinating Council to assist in its planning, development, and implementation. In the first year, about one-third of the states chose departments of education as their lead agency, slightly fewer states chose departments of health, and the remainder designated other agencies, such as departments of mental health or human services as their lead agency (Garwood, Fewell, & Neisworth, 1988).

The 1990s marked a period of polarized debate about the balance between public and personal responsibility for the health and well-being of children and families. The decade began with the passing of Public Law PL101-476 in 1990 which amended the Education for All Handicapped Children Act and renamed it as the "Individuals with Disabilities Education ACT" (IDEA). In contrast to PL-99-457, the Omnibus Personal Responsibility and Work Opportunity Reconciliation Act of 1996 replaced the Aid to Families with Dependent Children (AFDC), with a new law which offered temporary Assistance to Needy Families (TANF). Critics of this new law said that for families of children who are disabled or developmentally at risk, TANF's sanctions and limitations impose considerable burdens on poor families who are already stressed significantly (Ohlson, 1998). Examples of these greater hardships include the following: 1) reductions in funds available for Supplementary Security Income (SSI) insurance and redefined eligibility criteria that have resulted in the termination of cash allowances for many children who had qualified previously; 2) greater difficulty for poor families to qualify for Medicaid coverage because of changes in the application process and modifications in the SSI eligibility guidelines; and 3) elimination of federal child-care assistance for families who take part in welfare-to-work programs. There have been numerous reauthorizations

to the IDEA, in 1999, and most recently in 2004, when some changes were made to the section of the bill which addresses services for infants and toddlers birth to age three years (called Part C). In 2004, IDEA was reauthorized and amendments were made to the original legislation, but the regulations for part C were not finalized, so coordinators are currently operating using regulations from the 1999 reauthorization.

Early Intervention in the United States Today

In the United States today, Part C of the IDEA provides grants statutory formula to fifty states, the District of Columbia, the Commonwealth of Puerto Rico, and to the Secretary of the Interior to assist in maintaining and implementing statewide systems of EI services for infants and toddlers with disabilities and their families (U.S. Department of Education Office of Special Education Programs, 2009). Throughout the nation, IDEA governs how states and public agencies provide EI, special education, and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities (U.S. Department of Education Office of Special Education Programs, 2009). Federal regulations guide the implementation of Part C of IDEA from state to state under the federal lead agency of the Office for Special Education Programs (OSEP). The Governor of each state is required to identify a lead agency to oversee the system. It is the responsibility of each state's lead agency to meet the federal requirements and answer to the OSEP. The OSEP ensures that each state is in full compliance with all federal requirements through supervision and monitoring, and providing enforcement and technical assistance to correct deficiencies and improve results (Office of Special Education Programs Technical Assistance and Dissemination Network, 2011). The OSEP uses fourteen indicators to measure implementation (see Table 2).

Table 2

Part C Performance Indicators

1. Timely Service Delivery	Percent of infants/toddlers with IFSPs receiving EI on their IFSPs in a timely manner.	8. Early Childhood Transition	Percent of all children exiting Part C who received timely transition planning by their 3rd birthday.
2. Settings	Percent of infants/toddlers receiving EI in the home or programs for typically developing children.	9. Part C monitoring System	General Supervision system identifies and corrects no later than one year from identification.
3. Child Outcomes	Percent of infants/toddlers demonstrating improved positive social-emotional skills; acquisition and use of knowledge and skills; use of appropriate behaviors.	10. Administrative Complaints	Percent of signed written complaints with reports issued that were resolved within 60-day timeline.
4. Family Outcomes	Percent of families reporting EI services have helped the family know their rights; effectively communicate child's needs; and help their children develop and learn.	11. Due Process Hearings	Percent of due process hearing requests that were fully adjudicated within applicable timeline.
5. Child Find, Ages Birth to 1	Percent of infants/toddlers birth–1 with IFSPs compared to other States with similar eligibility definitions and national data.	12. Resolution Agreements	Percent of hearing requests that went to resolution sessions that were resolved through resolution session settlement agreements.
6. Child Find, Ages Birth to 3	Similar to Indicator 5 for B–3.	13. Mediations	Percent of mediations held that resulted in mediation agreements.
7. Timeliness of IFSP	Percent of eligible infants/toddlers with IFSPs within 45-day Part C timeline.	14. Data Accuracy	State reported data are timely and accurate.

(Regional Resource and Federal Center Network, 2009)

In 2004, Part C EI served 282,733 children in the United States. This represents 2.3% of children in the U.S. who are younger than three years old (U.S. Department of

Education, 2006). This represents significant growth, up from 1.5% of children less than three years of age in 1995 (see Figure 2).

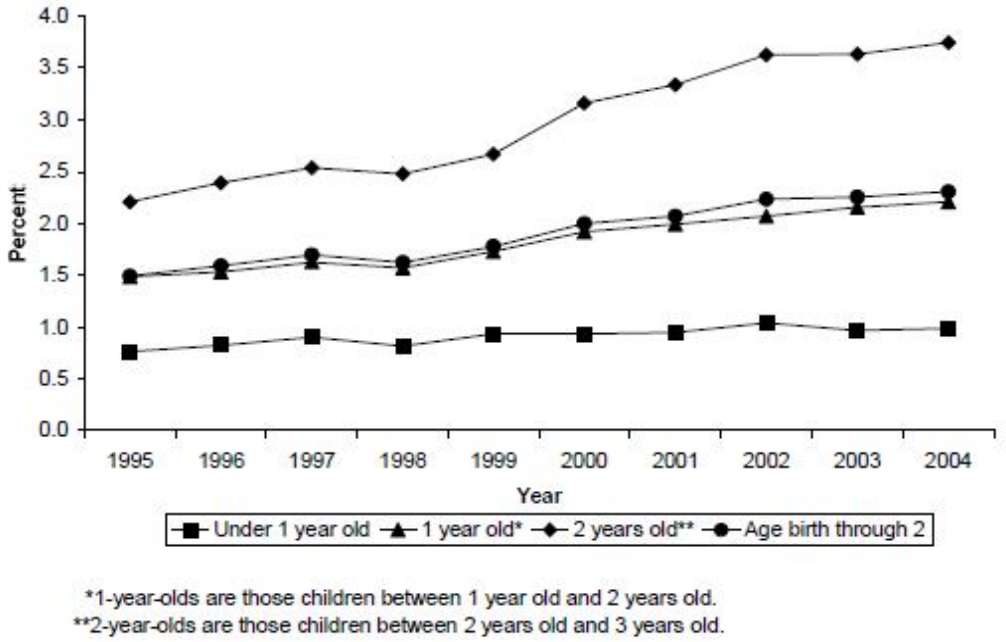

Figure 2. Percentage of the population birth through age 2 served under Part C of IDEA by age: Fall 1995 through fall 2004 (U.S. Department of Education, 2006)

While commendable, some research has shown the number of children who could benefit from EI services to be much higher than the percentage currently served. In 2008, researchers used a nationally representative longitudinal sample of children born in the United States in 2001 to estimate rates of eligibility for Part C EI. Data for this study was collected as part of the Early Childhood Longitudinal Study, Birth Cohort, which obtained data from participants when children were nine and twenty four months of age. Results indicated that approximately 13% of children in the sample had developmental delays that would make them eligible for Part C early interventions (Rosenberg, et al., 2008).

Research has also shown marked discrepancies in the racial and ethnic backgrounds of children served under Part C (see Table 3). Black (non Hispanic) children have a risk ratio of 1.0 indicating that these children were as likely as children in all other racial/ethnic groups combined to receive EI services. American Indian/Alaska Native children and white (not Hispanic) children had a risk ratio of 1.5 and 1.3, respectively, indicating that these children were somewhat more likely to receive EI services than were children of other racial/ethnic groups. Asian/Pacific Islander children and Hispanic children had a risk ratio of 0.6 and 0.7, respectively, indicating that these children were less likely to receive EI services than children of other racial/ethnic groups (U.S. Department of Education, 2006).

Table 3

Risk ratios for infants and toddlers served under Part C of IDEA, by race/ethnicity: Fall 2004

Race/ethnicity	Child count[a]	U.S. population, ages 3 through 5	Risk index[b]	Risk index for all other[c]	Risk ratio[d]
American Indian/Alaska Native	9,181	107,244	8.6	5.8	1.5
Asian/Pacific Islander	19,014	499,156	3.8	6.0	0.6
Black (not Hispanic)	103,332	1,748,971	5.9	5.9	1.0
Hispanic	107,080	2,454,152	4.4	6.3	0.7
White (not Hispanic	454,638	7,000,208	6.5	5.0	1.3
Total	693,245[e]	11,809,731	5.9	N/A	N/A

[a]Child Count is the number of children birth through age 2 with disabilities in the racial/ethnic group.

[b]Risk index was calculated by dividing the child count for the racial/ethnic group by the total number of children birth through age 2 in the racial/ethnic group in the U.S. population

[c]Risk index for all other was calculated by dividing the combined child count for all racial/ethnic groups except the one under consideration y the total U.S. population of all children in all racial /ethnic groups other than the one under consideration. The result was multiplied by 100 to produce a percentage.
[d]Risk ratios were calculated by dividing the risk index for the racial/ethnic group by the risk index for all other racial ethnic groups combined and rounding the result to one decimal place.
[e]The number of children reported by race/ethnicity does not match the total child count because race/ethnicity data is missing for some children.

(U.S. Department of Education, 2006)

Early Intervention in Georgia

Georgia's EI program is called BCW, and is administered through the Georgia Department of Community Health, Division of Public Health. BCW is administered through 18 District offices in Georgia, through which children and families in every county can access EI. The program has no financial requirements for participation, and anyone can refer a child to BCW. Participation in the program is voluntary (Georgia Department of Community Health Division of Public Health, 2010). According to BCW Evaluation and Assessment Standards, children are eligible for BCW in Georgia if they are:

1. Between the ages of 0 and 36 months;
2. Reside in the state of Georgia; AND
3. Meet eligibility criteria of Category 1 or Category 2 as follows:

Category 1 – Infants and Toddlers with Established Risk for Developmental Delay

Children who have an established risk of developmental delay due to a diagnosed physical or mental condition of known etiology and significant developmental consequences are considered to have a Category 1 condition, regardless of whether a delay is manifested at the time of identification.

Referrals of children with a diagnosed Category 1 condition from a physician must include a written medical diagnosis with the ICD-9 code confirming the Category 1 condition and all other medical diagnosis and accompanying code(s) available in the medical record. This written statement will be retained in the EI record.

Category 2 – Infants and Toddlers with a Significant Developmental Delay

Children eligible under Category 2 are those children who are determined eligible by the use of a variety of appropriate tools/procedures, including informed clinical opinion, to have a significant developmental delay in one or more areas of development. A delay is considered significant when standardized measures yield a score of 2 standard deviations below the mean in one or more of the five developmental domains or at least 1.5 standard deviations below the mean in two or more of the five developmental domains and/or the child's developmental issues interfere with their functional ability when compared with peers. The significant delay must be confirmed via two or more tools/procedures. One of these tools must yield a standard score. If the results of the above tools/procedures do not meet the criteria for a significant delay, an informed clinical opinion may be used to reach a determination (Georgia Department of Human Resources Division of Public Health, 2006).

In 2007, the BCW program provided services to over 11,129 children and families of children with disabilities in Georgia. Comparative data available as of 2008 showed that Georgia served 1.19% of its eligible population compared to a national baseline of 2.53% (Dif -1.33). This percentage places Georgia below every state and territory in the U.S. except American Samoa and the District of Columbia (U.S. Department of Education, 2006).

In June of 2010, the U.S. Department of Education released state determinations on implementation of the IDEA for Part B and Part C for fiscal year 2008. This document

evaluates each U.S. state and territory's efforts to implement the requirements and purposes of the IDEA based on baseline data, measurable and rigorous targets, and improvement activities for fourteen indicators. These indicators include ensuring positive outcomes for infants and toddlers with disabilities, timely provision of services, meeting evaluation timelines, and provision of services in natural environments. Based on these measures, Georgia fell under the category of needs intervention for three consecutive years. Georgia was out ranked by every state and territory in the union with the exception of the District of Columbia (See Table 4).

Table 4

Performance of Georgia's Early Intervention

Meets Requirements		Alabama, Colorado, Commonwealth of northern Mariana Islands, Connecticut, Delaware, Illinois, Indiana, Iowa, Kansas, Maryland, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, new Jersey, North Carolina, Oregon, Pennsylvania, South Dakota, Tennessee, Utah, Vermont, Virginia, Washington, West Virginia, Wyoming
Needs Assistance		Arkansas, Idaho, Nevada, New Mexico, Oklahoma, Rhode island, Wisconsin
	Needs Assistance (two consecutive years)	Alaska, Maine, South Carolina, Texas
	Needs Assistance (three consecutive years)	Arizona, California, Ohio
	Needs Assistance (four consecutive years)	American Samoa, Florida, Guam, Hawaii, Louisiana, Mississippi, New York, Puerto Rico, Virgin Islands
Needs Intervention		Massachusetts, North Dakota
	Needs Intervention (two consecutive years)	Kentucky
	Needs Intervention (three consecutive years)	Georgia
	Needs Intervention (four consecutive years)	District of Columbia

(U.S. Department of Education, 2010b)

In July of 2010, the Commissioner of the Georgia Department of Community Health received a determination letter from the Acting Director of the U.S. Department of Education's Office of Special Education and Rehabilitative Services. This letter outlined Georgia's noncompliance with the requirements of Part C of the IDEA ". . . based on the totality of the State's data and information , including Georgia's FFY 2008 APR and revised SPP, other State-reported data, the Office of Special Education Programs February 23, 2009 verification visit letter, and other publicly available information.", and required Georgia to submit a corrective action plan (Posny, 2010, p. 1). In response to the letter of determination, Debbie Cheatham, the program director of Children and Youth with Special Needs for Georgia's Department of Community Health Division of Public health posted a letter to BCW stakeholders and interested parties announcing that "Georgia's Part C early intervention program, BCW has been determined to be in "needs intervention" status for a third consecutive year" (Cheatham, 2010, p. 1).

Needs of Caregivers of Children with Special Needs

Caring for a child with special needs can be quite a challenge under the best of circumstances. Despite the best efforts of caregivers, the needs of some children will go unmet. Some characteristics which result in unmet needs have been identified and include poverty, insurance status, lower levels of provider supply, and the general pediatrician to population ratio (Mayer, et al., 2004).

In 1993 a national sample of 367 parents of children with special needs were surveyed regarding their needs. The major need that emerged was for information on how to promote the development of their children with special needs. Parents also expressed a need for information on dealing with the emotional and time demands of parenting,

identifying community resources, planning for their child's future and understanding their child's legal rights (Gowen, 1993).

Urban and Rural Classification

The purpose of this study is to uncover differences in populations based on the rural versus urban classification of their county of residence. This required a widely accepted definition of each term, along with a description of the parameters which were used to categorize each county as being either urban or rural.

According to the Miriam Webster dictionary, urban is defined as: "of, relating to, characteristic of, or constituting a city". Rural is defined as: "of or relating to the country, country people or life, or agriculture" (Merriam-Webster, 2010). Several government agencies offer differing systems for the classification of rural and urban areas within the United States including the U.S. Census Bureau, the Office of Management and Budget (OMB), and the Georgia State Office of Rural Health (SORH). While these classification systems are all based on an analysis of population density, they differ in the manner in which they draw lines for geographical boundaries, and the actual number of persons that are considered to constitute a densely populated area.

The U.S. Census Bureau categorizes geographic areas as being either an Urbanized Area, an Urban Cluster, or rural. In order to be classified as Urbanized, areas have to have an urban nucleus of 50,000 or more people, and must contain a core (one or more contiguous census block groups with a total land area less than two square miles and a population density of 1,000 persons per square mile), and may contain an adjoining territory with a minimum of 500 person per square mile and encompass a population of at least 50,000 people. An Urban Cluster must also have a core as identified above, however

may contain adjoining territory with a minimum of 500 persons per square mile and encompass a population of at least 2,500 but less than 50,000 persons. The U.S. Census Bureau classifies any territory, population, and housing units located outside of Urban Areas and Urban Clusters as rural (U.S. Census Bureau, 2009).

The OMB also defines geographic areas based on population density, but also includes consideration for outlying areas which are tied economically to core counties as measured by work commuting. The OMB categorizes geographic areas into Metropolitan Statistical Areas, Non-metropolitan Statistical Areas, and Micropolitan Statistical Areas. Metropolitan Statistical Areas are defined as central or core counties with one or more urbanized areas, and outlying counties that are economically tied to the core counties as measured by work commuting. Outlying counties are included if 25% of workers living in the county commute to the central counties, or if 25% of the employment in the county consists of workers coming out from the central counties. Non-Metropolitan Statistical Areas are outside the boundaries of Metropolitan Statistical Areas, and are further subdivided into Micropolitan Statistical Areas, and Non-core counties. Micropolitan Statistical Areas are any Non-metropolitan Statistical Area with an urban cluster of at least 10,000 persons or more. As with Metropolitan Statistical Areas, outlying counties are included if commuting to the central county is 25% or higher or if 25% of the employment in the outlying county is made up of commuters from the central county. The OMB classifies any county located outside of Metropolitan Statistical Areas, Non-metropolitan Statistical Areas, and Micropolitian Statistical Areas as a non-core county (Reynnells & John, 2008; 2010).

The Georgia SORH works to improve access to health care in rural and underserved areas and to reduce health status disparities (Reynnells & John, 2008), and works along with Public Health as a part of the Department of Community Health. The Georgia SORH defines counties in simple terms as being either Rural or Urban, based on population. Any county having a population over 35,000 in Georgia is considered by the Georgia SORH to be Urban, while any county with a population less than 35,000 is considered Rural. The Georgia SORH uses population information from the U.S. Census of 2000 (Rural Assistance Center, 2010).

This study used the Georgia SORH to classify counties as being either rural or urban. This classification system was chosen because the SORH defines geographic areas by county, which is the best fit with the available data as received from the BCW program, which also categorizes participants based on county of residence.

Residents of Urban and Rural Areas and Developmental Disabilities

Both qualitative and quantitative research into the needs differences of families living in rural and urban counties has shown a repeated pattern of concern. Those families residing in rural counties identify different needs than their urban counterparts, and often report higher levels of dissatisfaction with services.

A study published in 2009 analyzed information from over 40,000 interviews with parents of children with special needs in the United States. This study demonstrated that parents who lived in urban areas reported more difficulty accessing services (OR: 1.36 [95% CI: 1.17-1.59]). This study also reported that living in an urban area was associated with higher odds of dissatisfaction (OR: 1.21 [95% CI: 1.02-1.43]) (Montes, et al., 2009).

In 1993, a needs assessment study was completed which collected data from face to face interviews for the purpose of comparing parental concerns for infants and toddlers with special needs from rural versus urban counties in Arizona. A total of 600 parents were sampled, and differences were identified in relationship to the kinds of information parents from rural and urban counties need, as well as the source of information they are more likely to utilize. According to this study, the greatest concerns reported by parents were in "accessing information in order to make decisions regarding their child's needs" (Sontag, 1993, p. 44).

It has also been shown that intervention directed at residents of rural counties can result in improved EI outcomes. A study published in 2005 examined the primary care for children with special health care needs in rural areas. In this study, 51 parents of children with special health care needs participated in a pre-post treatment assessment of a program designed to enhance comprehensive and coordinated care. Participants were recruited from three primary care practices in a centrally Midwest state and remained in the program for twelve months. Parents involved in the study reported significant increases in satisfaction with care coordination and access to mental health services after the intervention. They also noted decreases in family needs, caregiver strain, parents' missed work days, children's school absences, and utilization of ambulatory services (Farmer, et al., 2005).

Importance of Knowledge of Rights for Early Intervention

In the EI system, knowledge of rights and safeguards assure quality and equity. For families and for the system, procedural safeguards provide the protection of an impartial system for complaint resolution. EI system personnel are legally obligated to explain

procedural safeguards to families and to support an active adherence to and understanding of these safeguards throughout the EI system (Trohanis, 2002). Personnel must provide written materials about safeguards during intake, and to review consent forms and releases with families. At that time, providers may review the materials with families who are then are asked to sign all of the informed consent forms and releases. These rights should be explained in early contacts with families, prior to evaluation and assessment, and should be reiterated throughout enrollment (Georgia Department of Human Resources Division of Public Health, 2006). Examples of these rights and safeguards include written prior notice, use of the parent's native language or preferred mode of communication, parent consent, confidentiality, release of information, examination of records, the right to accept or decline services without jeopardy, mediation, and due process procedures (Georgia Department of Human Resources Division of Public Health, 2004). Caregivers should be advised that the intent of Part C of IDEA is to enhance families' abilities to meet the special needs of their infants and toddlers by strengthening their authority and encouraging their participation in meeting those needs. The rights and safeguards are an important part of acknowledging the family's role as a primary decision maker in the early intervention process, and to strengthen and clarify the family's right to accept or reject any service without jeopardizing other services that they may want.

Importance of Community Resources for Early Intervention

Community resources are important to EI because economic, geographic and cultural factors matter in human development. It has been observed by researchers that the social organization of communities – both through formal structures and such institutions as the police, schools, and clergy, as well as through informal relationships

among neighbors, families, and peers – provide linkages between macro level changes in society and the development of individual children and youth (Coulton, 1995). The erosion of institutional resources (e.g., churches, schools, and recreational facilities) in many urban neighborhoods has directed growing attention to the potential impacts of deteriorating and stressful neighborhood environments on child development. These range from increased exposure to physical toxins with known intellectual and behavioral consequences, such as lead in soil and paint, to greater exposure to adverse social and psychological conditions as well (Earls & Buka, 2000).

A resource-based model of EI has existed in various forms for a number of years. The strength of this model is that it relies, in large part, on assisting families in addressing their priorities in the context of their existing and potential relationships with available and accessible community resources (Wolery, 2000). Results of studies examining multiple community based EI program models have clearly demonstrated the positive impact of sustained community support systems on the effectiveness of EI programs (Halpern, 1990).

In June 1987, at a conference sponsored by the American Academy of Pediatrics the Surgeon General of the US Public Health Service, C. Everett Koop, MD, ScD, issued a report concerning children with special health care needs. In the report, Dr Koop identified seven steps to improve access to care and quality of life for children with special needs. One of the steps identified was the encouragement of localities in the building of community-based service systems. In the report, Dr. Koop called for the establishment of a national agenda for families and professionals involved in the care of children with special health care needs to work together to improve the lives of these children and their families

through a system of family-centered, community-based, coordinated care (Brewer, et al., 1989).

Research has also shown that families of children with ASDs have reported difficulties accessing community resources, and experienced dissatisfaction with the resources available in their community. A study published in 2009 showed that more parents of children with ASDs reported difficulty using school and community services (27.6% vs. 9.7%) and dissatisfaction (19.8% vs. 7.9%) than parents of other children with special health care needs. Multivariate models determined that parents of children with ASDs were 3.39 times more likely to experience difficulty in obtaining services and 2.65 times more likely to be dissatisfied with services received than parents of other children with special health care needs (Montes, et al., 2009).

Importance of Social Support Systems for Early Intervention

When discussed in terms of parenting, social support systems can be defined as the social network influences that parents experience as part of their child-rearing efforts and daily lives. These social support systems can be differentiated as being either informal or formal. Informal support networks include both individuals (kin, friends, neighbors, minister, etc.) and social groups (church, social clubs, etc.) that are accessible to provide support as part of daily living. Formal support networks include both professionals (physicians, infant specialists, social workers, therapists, etc.) and social agencies (hospitals, EI programs, health departments, etc.) (Dunst & Trivette, 1990). Research has consistently shown that families with strong support systems are able to handle challenges more effectively than families with few supports (Dunst, et al., 1994). A study published in 2001 using data from the Wisconsin Longitudinal Study compared parents who had a child

with a developmental disability or serious mental health problem with a control group, and found that parents of a child with a developmental disability had lower rates of social participation than parents without a child with a disability (Seltzer, et al., 2001). There has also been a growing body of research supporting the idea of a link between support systems and child behavior and development, including early intervention (Bailey, et al., 2007). This link between social support systems and early intervention has been widely accepted by early intervention researchers who encourage the adoption of a behavioral-ecological model for service delivery (Vincent, et al., 1990).

Dunst and Trivette offer a model depicting how they believe social support directly and indirectly affects parent, family and child functioning (see Figure 3).

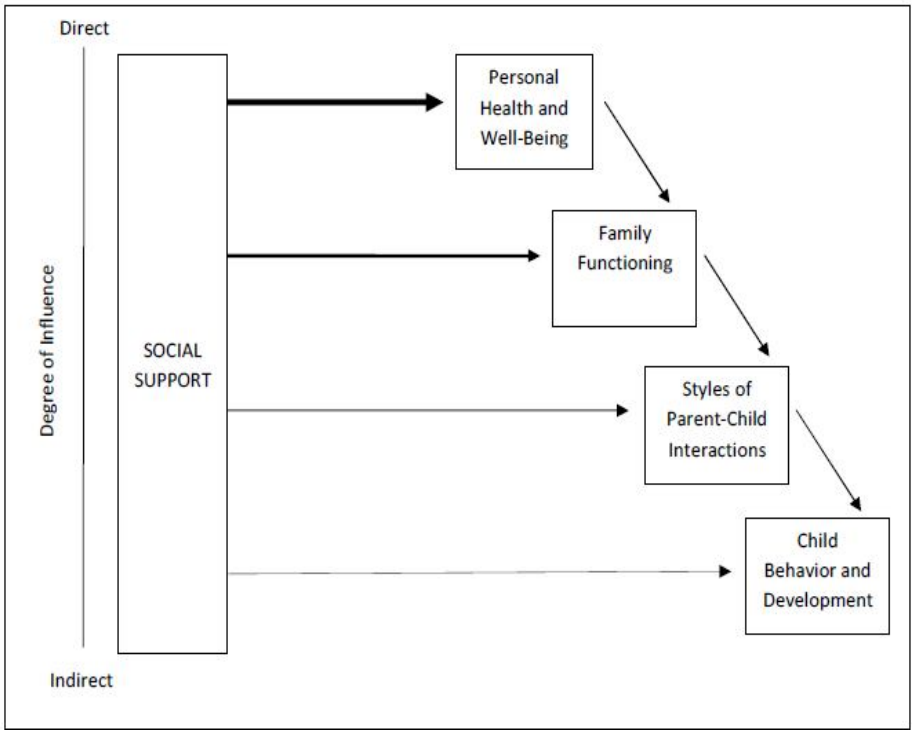

Figure 3. Dunst and Trivette's model depicting the influences of social support on parent, family, parent-child and child functioning (Dunst & Trivette, 1990)

According to this model, social support influences parent well-being and health; support and well-being influence family functioning; support, well-being and family functioning influence styles of parent-child interactions; and support, well-being, family functioning, and interactive styles influence child behavior and development (Dunst & Trivette, 1990).

Theoretical Basis for This Study

This study is founded on the work of Michael J. Guralnick, the Director of the Center on Human Development and Disability and Professor of Psychology and Pediatrics at the University of Washington. In 2005 during a plenary address to the International Association for the Scientific Study of Intellectual Disabilities, Dr. Guralnick presented a model for summarizing factors influencing developmental outcomes for children (see Figure 4).

Dr. Gularnick's model summarizes the pathways potential stressors take because of either the distinguishing traits of children with a disability (child characteristics) or because of distinguishing traits of the child's family (family characteristics). These characteristics are identified as potential stressors which effect family patterns of interaction and ultimately influence the child's developmental outcomes. Intervention components that are closely linked to these stressors will affect family patterns of interaction, and should be considered as part of the overarching EI program. That is, successful EI programs typically identify stressors (e.g. information needs, interpersonal and family distress) and then design and implement a coordinated and comprehensive EI program to mitigate those stressors. In general, those intervention components can be organized into three categories: resource supports, social supports, and information and

services (Guralnick, 2005). EI programs which consider these components are more likely to create highly individualized programs which take into consideration the family's unique needs and enhance the family's patterns of interaction.

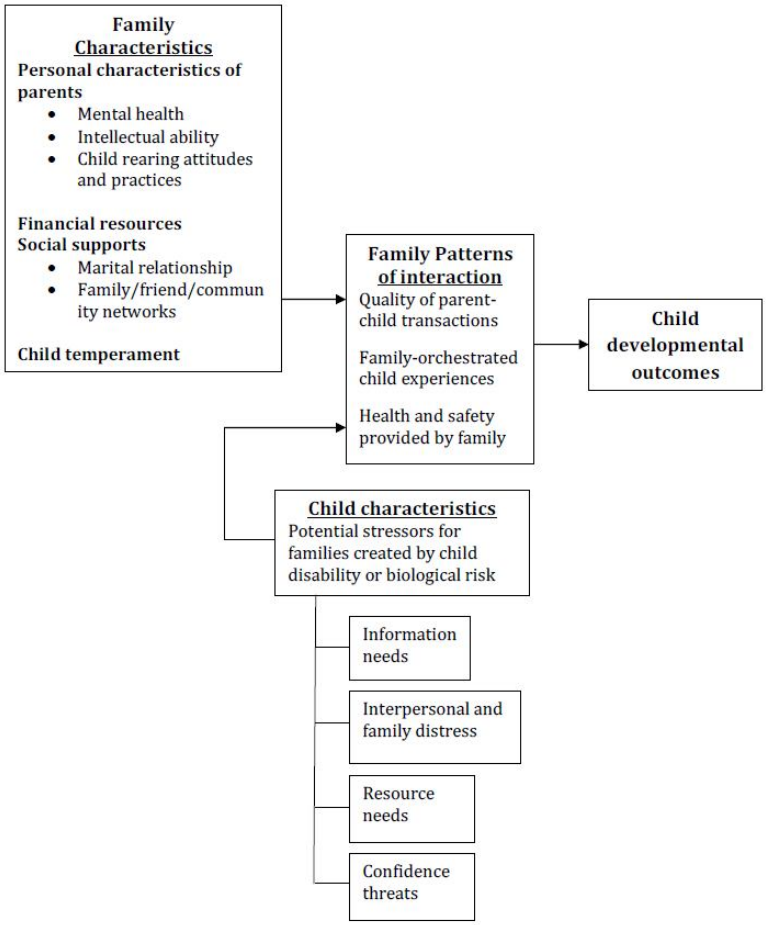

Figure 4. Guralnick's Factors Influencing Developmental Outcomes (Guralnick, 2005)

Figure 5 displays Dr. Gularnick's model, adapted to emphasize the variables under study in this research project. The three variables under study in this project (knowledge of rights, community resources, and support systems) have been isolated and are displayed as potential stressors under family characteristics. Examining how these potential stressors relate to the rural or urban classification of participant's county of residence will

identify which stressors are more likely to be present in certain populations. Once these stressors are identified, coordinated and comprehensive EI programs can be created which are designed to mitigate those stressors, thereby improving family patterns of interaction, and ultimately leading to improved child developmental outcomes.

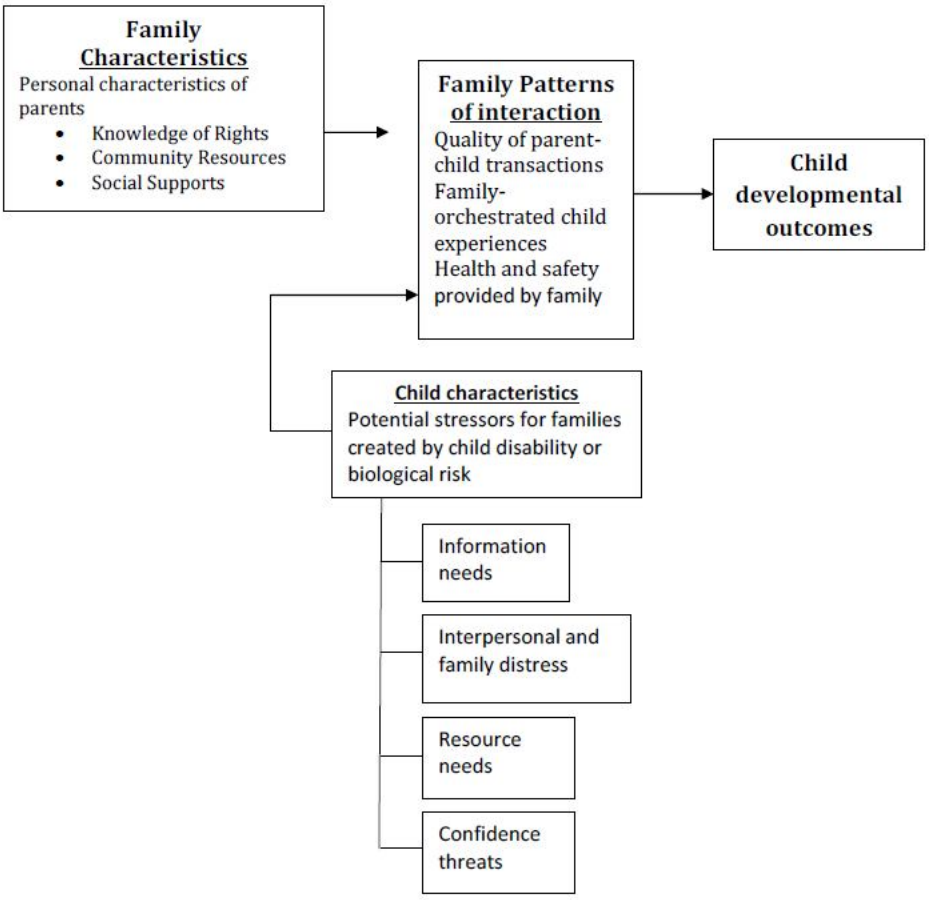

Figure 5. Adapted Model of Factors Influencing Developmental Outcomes

CHAPTER 2

RESEARCH QUESTIONS AND HYPOTHESIS

Research Questions

The following research questions were explored:

Knowledge of Rights

Research Question #1:

How do caregivers of children enrolled in the BCW program differ in regard to knowing what programs and services may be available for their child and family?

Research Question #2:

How do caregivers of children enrolled in the BCW program differ in regard to meeting with professionals to plan services and activities?

Research Question #3:

How do caregivers of children enrolled in the BCW program differ in regard to knowing their rights?

Support Systems

Research Question #4:

How do caregivers of children enrolled in the BCW program differ in regard to having someone they trust to listen and talk with?

Research Question #5:

How do caregivers of children enrolled in the BCW program differ in regard to having someone to call on when they need help with things?

Research Question #6:

How do caregivers of children enrolled in the BCW program differ in regard to being able to do things they enjoy as a family?

Community Resources

Research Question #7

How do caregivers of children enrolled in the BCW program differ in how they describe the medical care they have for their child right now?

Research Question #8

How do caregivers of children enrolled in the BCW program differ in how they describe the part-day or full-day childcare they have for their child right now?

Research Question #9

How do caregivers of children enrolled in the BCW program differ in regard to describing their child's ability to participate in social activities?

Hypotheses

In addition, the following hypotheses were tested:

$H1_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to knowing what is available for their child and family.

H1a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to knowing what is available for their child and family.

$H2_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to meeting with professionals to plan services and activities.

H2a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to meeting with professionals to plan services and activities.

$H3_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to knowing their rights.

H3a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to knowing their rights.

$H4_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to having someone they trust to listen and talk with.

H4a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to having someone they trust to listen and talk with.

$H5_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to having someone to call on when they need help with things.

H5a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to having someone to call on when they need help with things.

$H6_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to being able to do things they enjoy as a family.

H6a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to being able to do things they enjoy as a family.

$H7_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to describing the medical care they have for their child right now.

H7a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to describing the medical care they have for their child right now.

$H8_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to describing the childcare they have for their child right now.

H8a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to describing the childcare they have for their child right now.

$H9_0$: No statistical differences will be detected between caregivers of children enrolled in the BCW program in regard to describing their child's ability to participate in social activities.

H9a: A statistical difference will be detected between caregivers of children enrolled in the BCW program in regard to describing their child's ability to participate in social activities.

CHAPTER 3

METHODS

Results from the family outcome survey have been analyzed to investigate differences in three categories among caregivers of children enrolled in Georgia's EI program (BCW). The three categories are as follows: (1) how well caregivers know their rights and are able to advocate for their child, (2) support systems for caregivers, and (3) access to community resources. Differences will be compared based on the rural or urban classification of participant's county of residence.

This chapter is organized into the following section to profile study methods: (1) design of the study; (2) sampling plan; (3) instrumentation; (4) collection and treatment of data; and (5) analysis and interpretation of data.

Design of the Study

This study is a secondary analysis of data from the Family Outcome Survey (FOS) previously collected as part of the BCW program. In this survey, the State of Georgia is stratified in 18 public health districts (see Appendix C). Each district is comprised of county aggregates that range from 1 in district 3-2 to 16 in 9-2. The listing unit is a child who has been referred for services and the enumeration unit is the child's legal guardian who completed the survey. In the analysis, this study examined the results on the domains of urban verses rural. The analysis was performed using the Kruskal-Wallis test with SAS PROC NPAR1WAY. The primary endpoint of this study is to compare the outcomes of urban areas to rural areas through the use of the Kruskal-Wallis test and the Samawi-Vogel overlap coefficient (SVOC) test (Samawi, Helu, & Vogel, 2010). Counties were differentiated based on rural versus urban classification as defined by the U.S. Department

of Agriculture. Given the size of the FOS (about 3000 per year), we were able to obtain a power of 95% to detect differences between rural and urban.

Sampling Plan

The data used for this study were previously collected from surveys administered as part of the BCW program. No compensation or extra services were offered for the completion of the survey, and data collection is a native element of the BCW program. The subjects of the survey are caregivers (parents/guardians) of children with special needs who participate in the BCW program. The data set consists of 15,504 surveys completed between January of 2006 and May of 2010.

Instrumentation

This study analyzed results from the FOS. The FOS was developed by the Early Childhood Outcomes (ECO) Center for the Office of Special Education Programs as an instrument for parents to rate the extent to which they have achieved desired outcomes. The ECO Center assists states with the implementation of high-quality outcomes measurement systems for early intervention and preschool special education programs (The Early Childhood Outcomes Center, 2010a). In the fall of 2003, the Office of Special Education Programs within the U.S. Department of Education funded the ECO to promote the development and implementation of child and family outcome measures for infants, toddlers, and preschoolers with disabilities which could be used in local, state, and national accountability systems. Through an interactive process which included extensive input from stakeholders, five family outcomes were identified (The Early Childhood Outcomes Center, 2010b). The five outcomes are as follows:

- Families understand their child's strengths, abilities, and special needs.

- Families know their rights and advocate effectively for their child.
- Families help their child develop and learn.
- Families have support systems.
- Families access desired services, programs, and activities in their community.

The version of the FOS currently used by Georgia's EI program was developed in 2005. The survey is seven pages long and consists of eighteen questions separated into six categories. Each page labeled at the top by the outcome of interest. Answers are given as ordinal values 1-7 where one indicates that the responder strongly disagrees with the statement, and seven indicates that the responder strongly agrees with the statement. The portions of the FOS which were analyzed for this study are:

- Knowing your rights, and advocating for your child
- Having support systems, and
- Accessing your community

Each section is comprised of three questions; therefore, this study analyzed responses to a total of nine questions (questions 4, 5, 6, 10, 11, 12, 13, 14, and 15). The FOS can be found in its entirety in the Appendix B.

Collection and Treatment of Data

The survey is administered to the child's caregiver by the service coordinator upon the child's completion of the program at the exit interview. Survey results were retrieved from the statewide BCW database. Data was sent directly to the Children's Special Services Program Director, and principal investigator, Matthew W. Walker, via excel spreadsheet. All identifying information other than county of residence was to be removed from the data

before it was obtained. Once obtained the data were kept securely on a password protected hard drive, and were not shared.

IRB approval has been granted by all parties involved in this study including Georgia Southern University on March 16, 2010, and the Georgia Department of Community Health on May 14, 2010 (see Appendix A).

Analysis and Interpretation of Data

Analysis of the responses to the questions selected from the FOS for this study involved the use of three statistical tests, Chi Square, the Kruskal-Wallis Statistic, and the Samawi-Vogel Coefficient.

The Kruskal–Wallis test was used for each question analyzed in this study to compare urban versus rural and also to compare health districts. This test is most commonly used when there is one nominal variable and one measurement variable, and the measurement variable is not normally distributed along a bell shaped curve (McDonald, 2009b). The Kruskal–Wallis test does not make assumptions about normality. Like most non-parametric tests, it is performed on ranked data, so the measurement observations are converted to their ranks in the overall data set.

In the case of this study, the nominal variable is the rural or urban classification of the respondent's county of residence. This variable can have one of two values (rural or urban). The measurement variable is the respondent's answer to each question. Responses are Likert items with responses ranging from 1 (total disagreement) to 7 (total agreement). Due to the distribution of the measurement variable being highly skewed, it failed to meet the assumption of normality required by the ANOVA procedure.

Consequently a one way ANOVA would yield biased estimates of the p-value. A p-value of less than 0.05 is considered significant.

Questions 14 and 15 of the FOS were preceded by qualifying questions which were analyzed using the Chi Square test. Chi Square is used to compare two nominal variables, each with two or more possible values as a test of independence (comparing frequencies of one nominal variable for different values of a second nominal variable) (McDonald, 2009a). Because the answers to the qualifying questions were nominal with responses being one of two possible values (yes, no), and were being compared to a nominal measurement variable (rural, urban), the Chi Square test was selected as the most appropriate test of independence.

Finally, the Samawi-Vogel Overlap Coefficient was used to measures the similarity between the two populations with an overlap of 1.0 indicating complete agreement. For example, question four's overlap of 0.50667 means that the two populations are in only 51% agreement whereas, question five's overlap of 0.99789 means almost complete agreement. Examining these values in addition to the Kruskal -Wallis test results give a complete picture of the relation between the rural or urban residence of participants and the variables under study.

Although not everyone who completed the survey answered every question, the data had been de-identified, and there was no way of following up to collect missing data.

CHAPTER 4

RESULTS

Population Demographics

The data set examined consisted on a total of 15,474 respondent caregivers of children enrolled in BCW. Because the survey is administered at the transition meeting held when the child ages out of the program, all children were three years of age at the time their caregiver completed the survey. Of the 15,474 respondents, 10,128 were caregivers of a male child, and 5,346 were caregivers of a female child. The majority of respondents resided in counties classified as urban (13,061 or 84.4%), versus rural (2,413 or 15.6%). While a larger percentage of respondents were caregivers of male children, gender was evenly distributed between rural and urban counties with 64.6% of rural respondents being caregivers of male children, and 65.5% of urban respondents being caregivers of male children. Almost half of all respondents were caregivers of children classified as being White/Caucasian (49.3%), with the second largest racial group being Black/African American (31.4%). Other racial groups present in the sample included Hispanic (11.7%), Asian (2.18%), American Indian (0.15%), and Other (5.27%).

While Black/African American respondents were evenly distributed among rural and urban counties with 30.8% and 31.5%, respectively, other racial groups were not as evenly distributed. Among respondents residing in rural counties, 57.6% were White/Caucasian, compared to 47.8% of respondents residing in urban counties. Hispanic children were more likely to reside in urban (12.8%), as compared to rural counties (5.8%). However, the greatest discrepancy was among respondents who were caregivers

of Asian children. Among children residing in rural counties only 0.5% were of Asian descent compared to 2.5% of children residing in urban counties (see Table 5).

Table 5

Demographic Distribution

County Type	Gender	Amer. Indian	Asian	African American/Black	Hispanic	White	Other	Total
Rural	Male	3	8	443	84	928	92	1558
Rural	Female	0	4	301	58	461	31	855
Rural total		3	12	744	142	1389	123	2413
Urban	Male	12	195	2624	1064	4214	461	8570
Urban	Female	8	131	1491	605	2024	232	4491
Urban total		20	326	4115	1669	6238	693	13061
Total		23	338	4859	1811	7627	816	15474

Analysis by County Classification

Section I: Knowing Your Rights and Advocating for Your Child

Questions 4, 5, and 6 all fall under the heading: Knowing Your Rights and Advocating for Your Child. Of the three questions asked under this heading, it was found that two questions (knowledge of available programs and services, and familiarity with rights) showed a significant difference between the rural and urban groups. No significant difference was found between groups when asked how comfortable they were

participating in meetings with EI professionals. In both questions which found a significant difference, the urban population was the group with less favorable responses.

Question 4 of the FOS, asked respondents to rank how much their family knows about the programs and services that are available. Likert item responses ranged from one to seven with one indicating "We are just beginning to learn about the programs and services that are available", and seven indicating "We know a great deal about the programs and services that are available."

Of the 10,938 responses to question four, 1,790 respondents resided in counties classified as rural, and 9,148 resided in counties classified as urban. The mean response to this question was 5.7 among rural participants, and 5.5 among urban participants, indicating that both rural and urban participants were knowledgeable about the programs and services that are available. However, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 34.48, $p<0.0001$), indicating that the rural population knew more about the programs and services that were available than those residing in urban areas (see Table 6).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 51% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 6

Knowing what is Available by County Classification

Question 4: Knowing what is Available				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel OLP Coefficient:
Rural	1790	5.7	6	0.50667, p<0.0001
Urban	9148	5.5	6	
Kruskal-Wallis Statistic: 34.48, p<0.0001				

Based on these findings, we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to knowing what is available for their child and family, and conclude that a difference does exist between rural and urban populations.

Question 5 of the FOS asked respondents to rank how comfortable their family was participating in meetings with EI professionals to plan services or activities. Likert item responses ranged from one to seven with one indicating "We are just beginning to feel comfortable participating in meetings", and seven indicating "We are very comfortable participating in meetings."

Of the 10,928 responses to this question, 1,788 respondents resided in counties classified as rural, and 9,140 resided in counties classified as urban. The mean response to this question was 6.2 among both groups, indicating that both groups felt comfortable participating in meetings (see Table 7). No significant difference was found between the two groups of participants (Kruskal-Wallis Statistic: 0.2484, p=0.6182).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are 99% in agreement, confirming that there is no significant difference between groups (p-value of 0.38730).

Table 7

Meeting with Professionals by County Classification

Question 5: Meeting with Professionals				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Overlap Coefficient
Rural	1788	6.2	7	0.99789, P=<0.38730
Urban	9140	6.2	7	
Kruskal-Wallis Statistic: 0.2484, p=0.6182				

Based on these findings, we were unable to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to meeting with professionals to plan services and activities. This analysis did not detect any difference between the rural and urban groups.

Question 6 of the FOS asked respondents to rank how familiar they were with their rights, including what to do if they are not satisfied. Likert item responses ranged from one to seven with one indicating “We are just beginning to understand our rights”, and seven indicating “We understand a great deal about our rights.”

Of the 10,918 responses to this question, 1,784 respondents resided in counties classified as rural, and 9,134 resided in counties classified as urban. The mean response to

this question was 6.0 among respondents residing in rural counties, and 5.8 among respondents residing in urban counties, indicating that both groups understood a good amount about their rights. However, a significant difference was found between the two groups using the Kruskal-Wallis Statistic (43.54, $p<0.0001$), indicating that the rural population knew more about their rights than those residing in urban areas (see Table 8).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 51% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 8

Knowing their Rights by County Classification

Question 6: Knowing rights				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	1784	6.0	7	0.41956, p<0.0001
Urban	9134	5.8	6	
Kruskal-Wallis Statistic: 43.54, p<0.0001				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to knowing their rights, and conclude that a difference does exist between the rural and urban populations.

Section II: Having Support Systems

Questions 10, 11, and 12 fall under the heading: Having Support Systems. Of the three questions asked under this heading, it was found that all three showed a significant difference between the rural and urban groups. Significant differences were found when participants were asked if they have someone to talk with that they trust, if they have someone to rely on when they need help, and if they were able to do things they enjoy as a family. In each case the urban population was found to be the group with less favorable responses.

Question 10 of the FOS asked respondents to rank how often their family has someone you trust to talk with when you need it. Likert item responses ranged from one to seven with one indicating "We seldom have someone to talk with about things when we need it", and seven indicating "We almost always have someone to talk with about things when we need it."

Of the 10,890 responses to this question, 1,783 respondents resided in counties classified as rural, and 9,107 resided in counties classified as urban. The mean response to this question was 6.2 among participants residing in rural counties, compared to 6.1 among participants residing in urban counties, indicating that both groups usually had someone to talk with about things when they needed it. However, when examined by rural or urban residence, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 4.56, p=0.0327), indicating that those respondents residing in rural counties were more likely to have someone to talk about things with (see Table 9).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 32% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 9

Someone to Listen and Talk with by County Classification

Question 10: Someone to Talk With				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	1783	6.2	7	0.32232, p<0.0001
Urban	9107	6.1	7	
Kruskal-Wallis Statistic: 4.56, p=0.0327				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to having someone they trust to listen and talk with, and conclude that a difference does exist between rural and urban populations.

Question 11 of the FOS asked respondents to rank how often their family has someone they can rely on for help to provide a ride, run an errand or watch their child for a short period of time. Likert item responses ranged from one to seven with one indicating "We seldom have someone we can rely on for help when we need it", and seven indicating "We almost always have someone we can rely on for help when we need it".

Of the 10,889 responses to this question, 1,784 respondents resided in counties classified as rural, and 9,105 resided in counties classified as urban. The mean response to this question was 6.0 among respondents residing in rural counties compared to 5.8 among respondents residing in urban counties, indicating that both groups felt they had someone they could rely on for help when they needed it. However, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 36.26, $p<0.0001$), indicating that those participants residing in rural areas were more likely to have someone they could rely on (see Table 10).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 37% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 10

Someone to Help by County Classification

Question 11: Someone to Call				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	1784	6.0	7	0.37007, p<0.0001
Urban	9105	5.8	7	
Kruskal-Wallis Statistic: 36.26, p<0.0001				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in

regard to having someone to call on when they need help with things, and conclude that a difference does exist between rural and urban populations.

Question 12 of the FOS asked respondents to rank how often their family is able to do the things they enjoy. Likert item responses ranged from one to seven with one indicating “We seldom are able to do things we enjoy”, and seven indicating “We almost always are able to do things we enjoy”.

Of the 10,882 responses to this question, 1,781 respondents resided in counties classified as rural, and 9,101 resided in counties classified as urban. The mean response to this question was 5.8 among respondents residing in rural counties compared to 5.7 among respondents residing in urban counties, indicating that both groups were usually able to do the things they enjoy. However, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 8.88, $p=0.0029$), indicating that respondents residing in rural areas were more likely to be able to do things they enjoy (see Table 11).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 43% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 11

Able to Do Things They Enjoy as a Family by County Classification

Question 12: Ability to Do Things				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	1781	5.8	6	0.43301, p<0.0001
Urban	9101	5.7	6	
Kruskal-Wallis Statistic: 8.88, p=0.0029				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to being able to do things they enjoy as a family, and conclude that a difference does exist between rural and urban populations.

Section III: Access to Community Resources

Questions 13, 14, and 15 fall under the heading: Accessing Your Community. Of the three questions asked under this heading, it was found that all three showed a significant difference between the rural and urban groups. Significant differences were found when participants were asked if their medical care meets their child's needs, if their childcare meets their family's needs, and if their child was able to participate in social activities. In each case, the urban population was found to be the group with less favorable responses.

Question 13 of the FOS asked respondents to rank how well their family's medical care meets their child's special needs. Likert item responses ranged from one to seven with

one indicating “Our medical care meets few of our child’s needs”, and seven indicating “Our medical care meets almost all of our child’s needs”.

Of the 10,820 responses to this question, 1,767 respondents resided in counties classified as rural, and 9,053 resided in counties classified as urban. The mean response to this question was 6.2 among participants residing in rural counties, compared to 6.1 among participants residing in urban counties, indicating that both groups felt their medical care meets many of their child’s needs. However, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 21.12, $p<0.0001$) indicating that rural participants were more likely to feel their medical care met their child’s needs (see Table 12).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 34% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 12

Describing the Medical Care they have for their Child by County Classification

Question 13: Quality of Medical Care				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	1767	6.2	7	0.34112, p<0.0001
Urban	9053	6.1	7	
Kruskal-Wallis Statistic: 21.12, p<0.0001				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to describing the medical care they have for their child right now, and conclude that a difference does exist between rural and urban populations.

Question 14 of the FOS began with a qualifying question designed to measure whether participants either did not desire regular childcare (either part-day or full-day), or did desire regular childcare, but childcare was not available. If respondents checked either box, they were asked to skip question 14 and go directly to question 15. Of the 11,002 participants who responded to the qualifying question for question fourteen, 1,598 resided in counties that were classified as rural, and 9,404 resided in counties classified as urban (see Table 13). A higher percentage of respondents residing in urban counties indicated a desire for childcare (71.9%) compared to respondents residing in rural counties (66.2%). This represents a significant difference between participants (Chi-Square: 32.08, $p<0.0001$), indicating that respondents residing in counties classified as urban were more likely to want childcare.

Table 13

Parental Desire for Child Care by County Classification

	Question 14: Desire for Childcare		
County Type	Wanted childcare	Did not want child care	total
Rural	1598/66.2%	817/33.8%	2415
Urban	9404/71.9%	3682/28.1%	13086
Total	11002	4499	15501

Chi-Square: 32.08, $p<0.0001$

If the respondent did not answer the qualifying question (indicating that their family did receive regular childcare), they were asked to respond to question 14. Question 14 asked respondents to rank how well their family's childcare met their needs. Likert item responses ranged from one to seven with one indicating "Our childcare meets few of our child's needs", and seven indicating "Our childcare meets almost all of our child's needs".

Of the 6,023 responses to this question, 914 respondents resided in counties classified as rural, and 5,109 resided in counties classified as urban. The mean response to this question among respondents residing in rural counties was 5.7, compared to 5.5 among respondents residing in urban counties, indicating that both groups felt that their childcare met many of their child's needs. However, a significant difference was found between the two groups (Kruskal-Wallis Statistic: 6.71, p=0.0096), indicating that respondents residing in rural counties were more likely to feel that their childcare met their child's needs (see Table 14).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 40% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 14

Childcare they have for their Child by County Classification

Question 14: Quality of Childcare				
County Type	N	Mean	Median Q1, Q3 (5,7)	Samawi-Vogel Coefficient
Rural	914	5.7	7	0.40130, p<0.0001
Urban	5109	5.5	6	
Kruskal-Wallis Statistic: 6.71, p=0.0096				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to describing the childcare they have for their child right now, and conclude that a difference does exist between rural and urban populations.

Question 15 of the FOS asked respondents to rank how often their child is able to play with other children or participate in religious, community or social activities. This question also began with a qualifying question which asked respondents to indicate if their family has not wanted their child to participate in social activities. Of the 1,635 participants who responded to the qualifying question for question 15 (indicating that they did not want their child to participate in social activities), 362 resided in counties that were classified as rural, and 1,273 resided in counties classified as urban. Among respondents residing in rural counties 85% did want their child to participate in social activities, compared to 90% of respondents residing in urban counties (see Table 15). This

represents a significant difference between groups (Chi-Square: 59.82, p<0.0001), indicating that respondents residing in counties classified as rural were less likely to want their child to participate in social activities.

Table 15

Did Not Want Child to Participate in Social Activities by County Classification

	Question 15: Desire to Participate in Social Activities		
County	Wanted child to participate	Did not want child to participate	Total
Rural	2053/85%	362/15%	2415
Urban	11813/90.3%	1273/9.7%	13086
total	13866	1635	15501

Chi-Square: 59.82, p<0.0001

If the respondent did not answer the qualifying question, (indicating that they did want their child to participate in social activities), they were asked to respond to question fifteen. Question 15 asked respondents to rank how often their child participates in social activities right now. Likert item responses ranged from one to seven with one indicating "Our child seldom participates in the activities we want", and seven indicating "Our child almost always participates in the activities we want".

Of the 8,988 responses to this question, 1,399 respondents resided in counties classified as rural, and 7,589 resided in counties classified as urban. The mean response to this question was 5.3 among respondents residing in rural areas, compared to 5.0 among respondents residing in urban areas, indicating that both groups felt their child usually

participated in the activities they wanted. However, a significant difference was found between groups (Kruskal-Wallis Statistic: 16.69, p<0.0001), indicating that children residing in rural counties were more likely to participate in social activities (see Table 16).

Further analysis shows that according to the Samawi–Vogel Overlap Coefficient the rural and urban populations are only 56% in agreement. This represents a significant difference between the groups (p-value of <0.0001).

Table 16

Child's Ability to Participate in Social Activities by County Classification

Question 15: Social Activities				
County Type	N	Mean	Median Q1, Q3 (4,7)	Samawi-Vogel Coefficient
Rural	1399	5.3	5	0.56379, p<0.0001
Urban	7589	5.0	5	
Kruskal-Wallis Statistic: 16.69, p<0.0001				

Based on these findings we are able to reject the null hypothesis that no statistical differences are detected between caregivers of children enrolled in the BCW program in regard to describing their child's ability to participate in social activities, and conclude that a difference does exist between rural and urban populations.

Analysis by Health District

For each of the nine questions, a Kruskal-Wallis test was performed to test for a difference among health districts. The State of Georgia is divided into 18 health districts. Each health district is assigned a number ranging from 1-1 to 10 (see Appendix C). Each district is comprised of counties numbering between 1 in district 3-2 to 16 in 9-2.

In each case, the p-value was less than 0.0001 indicating that all health districts are not responding in the same way. In order to determine the nature of these differences, all pair wise comparisons were made between health districts for each question. In order to display differences or similarities between groups, the health districts were divided into groups of similarity. This is presented for each question using groups (A, B, C, D, or E) to denote districts that are similar or dissimilar.

Section I: Knowing Your Rights and Advocating for Your Child

Questions 4, 5, and 6 fall under the heading: Knowing Your Rights and Advocating for Your Child. Of the three questions asked under this heading, all three showed a significant difference between health districts. District 3-2 had the lowest average ranked response in each of the three questions. District 1-1 was consistently among the highest average ranked response (highest in two questions, and third highest in one question).

Question 4 of the FOS, asked respondents to rank how much their family knows about the programs and services that are available. Likert item responses ranged from one to seven with one indicating “We are just beginning to learn about the programs and services that are available”, and seven indicating “We know a great deal about the programs and services that are available”.

For this question, district 3-2 had the lowest average ranked response (4180). District 1-1 had the highest average ranked response (6383). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1074). This included health districts 3-2, 3-5, 3-4, 1-2, and 3-3 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B and C (see Figure 6). Groups B, C, D, and E were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 9-2 is a member of groups B, C, and D, but not a member of group A, indicating that district 3-2 is statistically different than district 9-2

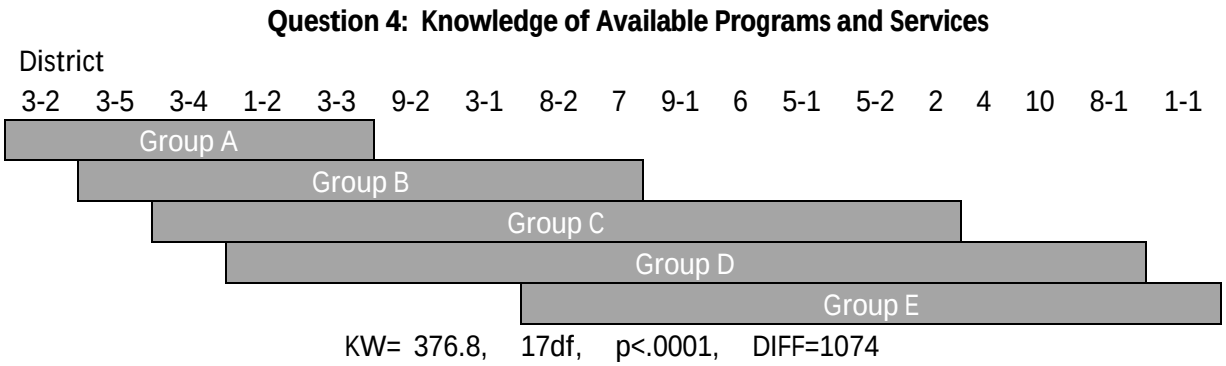

Figure 6. Knowing what is Available by Health District

Question 5 of the FOS asked respondents to rank how comfortable their family was participating in meetings with early intervention professionals to plan services or activities. Likert item responses ranged from one to seven with one indicating "We are just beginning to feel comfortable participating in meetings", and seven indicating "We are very comfortable participating in meetings".

For this question district 3-2 had the lowest average ranked response (4346). District 1-1 had the highest average ranked response (6015). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1073). This included health districts 3-2, 3-5, 8-2, 1-2, 3-3, 9-2, 3-4, and 7 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B and C (see Figure 7). Groups B and C were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 6 is a member of groups B and C, but not a member of group A, indicating that district 3-2 is statistically different than district 6.

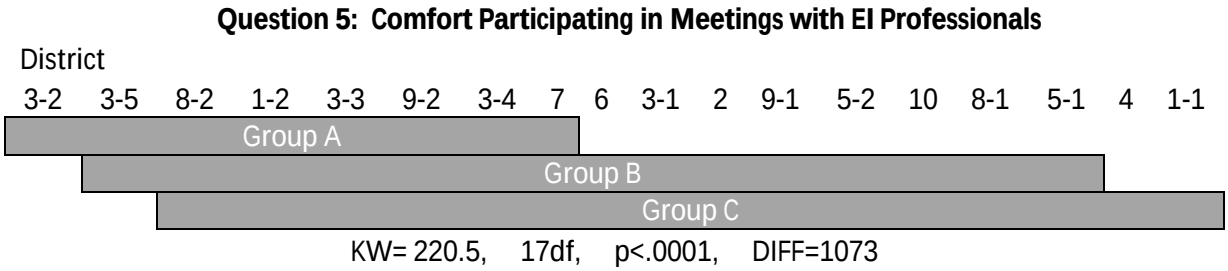

Figure 7. Meeting with Professionals by Health District

Question 6 of the FOS asked respondents to rank how familiar they were with their rights, including what to do if they are not satisfied. Likert item responses ranged from one to seven with one indicating "We are just beginning to understand our rights", and seven indicating "We understand a great deal about our rights". For this question district 3-2 once again had the lowest average ranked response (4273). District 5-1 had the highest average ranked response (6563). Group A is comprised of all groups with an average

ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1072). This included health districts 3-2, 3-5, 3-4, 7, 1-2, 3-1, and 3-3 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B, C, D, and E (see Figure 8). Groups B, C, D and E were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 6 is a member of groups B, C, and D, but not a member of group A, indicating that district 3-2 is statistically different than district 2.

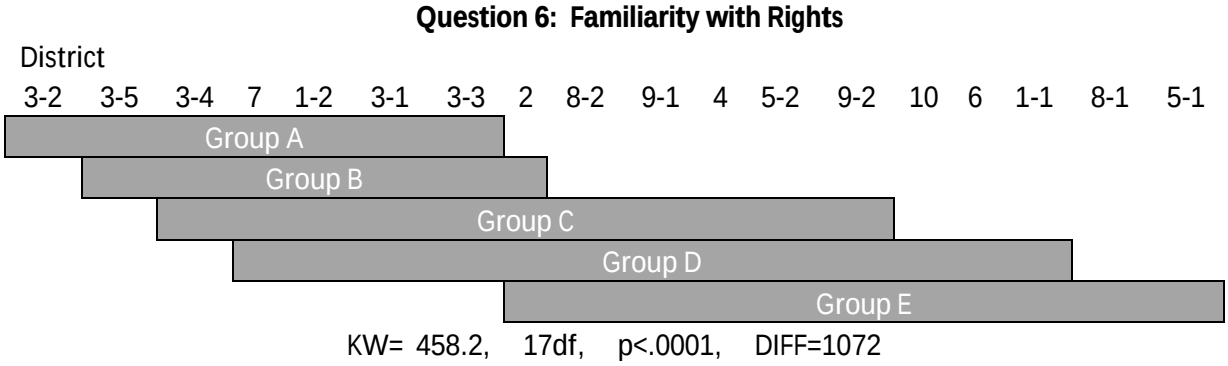

Figure 8. Knowledge of Rights by Health District

Section II: Having Support Systems

Questions 10, 11, and 12 fall under the heading: Having Support Systems. Of the three questions asked under this heading, it was found that all three showed a significant difference between health districts. District 3-2 had the lowest average ranked response in each of the three questions. District 1-1 was consistently among the highest average ranked responses (highest in two questions, and second highest in one question).

Question 10 of the FOS asked respondents to rank how often their family has someone you trust to talk with when you need it. Likert item responses ranged from one to

seven with one indicating “We seldom have someone to talk with about things when we need it”, and seven indicating “We almost always have someone to talk with about things when we need it”.

For this question, district 3-2 once again had the lowest average ranked response (4805). District 10 had the highest average ranked response (6098). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1068). This included health districts 3-2, 3-5, 3-4, 7, 3-1, 3-3, 1-2, 6, 8-2, 9-2, and 5-2 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B, (see Figure 9). Groups B and C were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 8-1 is a member of group B and C, but not a member of group A, indicating that district 3-2 is statistically different than district 8-1.

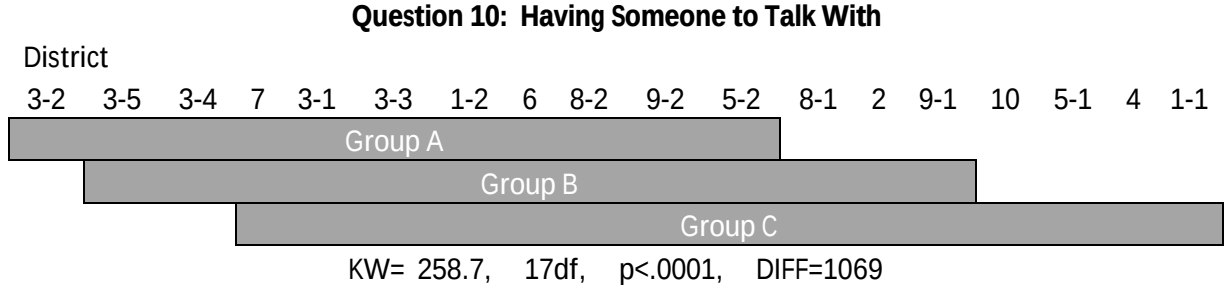

Figure 9. Having Someone to Talk With by Health District

Question 11 of the FOS asked respondents to rank how often their family has someone they can rely on for help to provide a ride, run an errand or watch their child for a

short period of time. Likert item responses ranged from on with one indicating "We seldom have someone we can rely on for help when we need it", and seven indicating "We almost always have someone we can rely on for help when we need it".

For this question, district 3-2 once again had the lowest average ranked response (4805). District 10 had the highest average ranked response (6098). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1068). This included health districts 3-2, 3-4, 3-5, 1-2, 3-3, 5-1, 9-2, 3-1, 5-2, 8-2, 6, 7, 8-1, 4, and 2 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B, (see Figure 10). Group B was formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 9-1 is a member of group B, but not a member of group A, indicating that district 3-2 is statistically different than district 9-1.

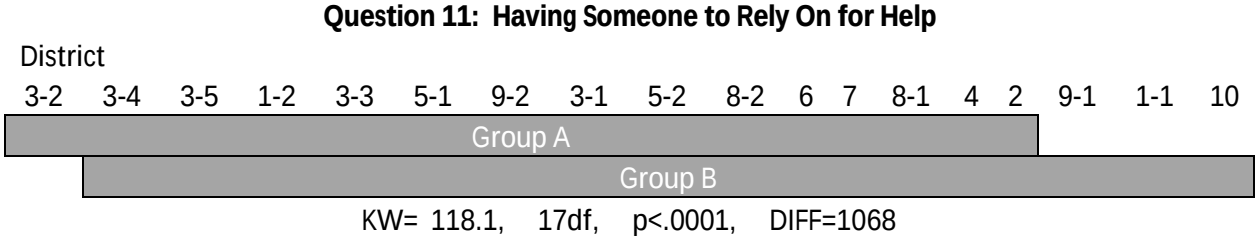

Figure 10. Having Someone to Rely On by Health District

Question 12 of the FOS asked respondents to rank how often their family is able to do the things they enjoy. Likert item responses ranged from one to seven with one

indicating “We seldom are able to do things we enjoy”, and seven indicating “We almost always are able to do things we enjoy”.

For this question, district 3-2 once again had the lowest average ranked response (4615). District 1-1 had the highest average ranked response (6094). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1069). This included health districts 3-2, 3-5, 3-4, 3-3, 8-2, 1-2, 3-1, 9-2, 7, 2, 6, and 5-1 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B, (see Figure 11). Groups B, C, and D were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 8-1 is a member of group B, C and D, but not a member of group A, indicating that district 3-2 is statistically different than district 8-1.

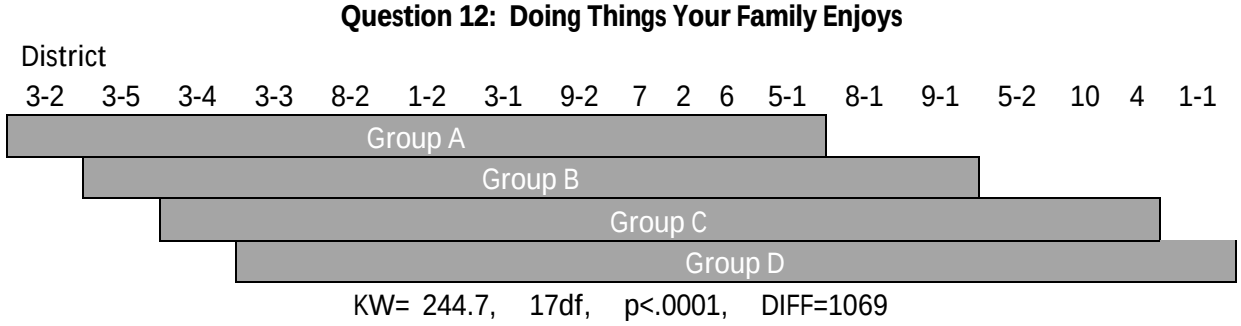

Figure 11. Doing Things as a Family by Health District

Section III: Access to Community Resources

Questions 13, 14, and 15 fall under the heading: Accessing Your Community. Of the three questions asked under this heading, it was found that all three showed a significant

difference between health districts. District 3-2 had the lowest average ranked response in each of the three questions. District 1-1 had the highest average ranked response in two of the three questions, but question 10 was consistently among the highest average ranked responses (highest in one question, second highest in one question, and third highest in one question).

Question 13 of the FOS asked respondents to rank how well their family's medical care meets their child's special needs. Likert item responses ranged from one to seven with one indicating "Our medical care meets few of our child's needs", and seven indicating "Our medical care meets almost all of our child's needs".

For this question, district 3-2 once again had the lowest average ranked response (4540). District 1-1 had the highest average ranked response (6084). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1062). This included health districts 3-2, 3-3, 3-5, 7, 3-4, 9-2, 1-2, 8-2, 9-1, 6, 3-1, and 2 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from groups B, (see Figure 12). Groups B, and C were formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 4 is a member of group B, and C, but not a member of group A, indicating that district 3-2 is statistically different than district 4.

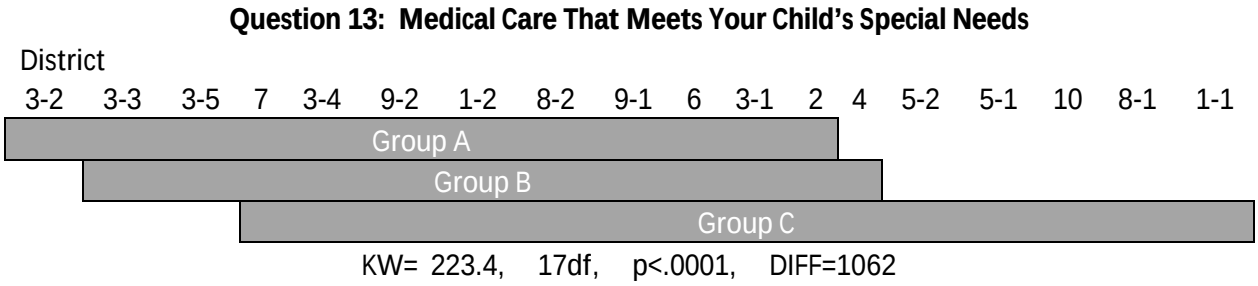

Figure 12. Quality of Medical Care by Health District

Question 14 of the FOS began with a qualifying question designed to measure whether participants either did not desire regular childcare (either part-day or full-day), or did desire regular childcare, but childcare was not available. If respondents checked either box, they were asked to skip question 14 and go directly to question 15. Question 14 asked respondents to rank how well their family's childcare met their needs. Likert item responses ranged from one to seven with one indicating "Our childcare meets few of our child's needs", and seven indicates "Our childcare meets almost all of our child's needs".

For this question district 3-2 once again had the lowest average ranked response (2527). District 1-1 had the highest average ranked response (3436). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (836). This included health districts 3-2, 3-4, 3-5, 3-3, 7, 5-1, 3-1, 1-2, 6, 9-2, 8-2, 8-1, 2, 9-1, 5-2, and 4 in group A. All responses from districts in group A are considered to be statistically similar to each other, but statistically different from group B, (see Figure 13). Group B was formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other

groups in group A. District 10 is a member of only group B, indicating that district 3-2 is statistically different than district 10.

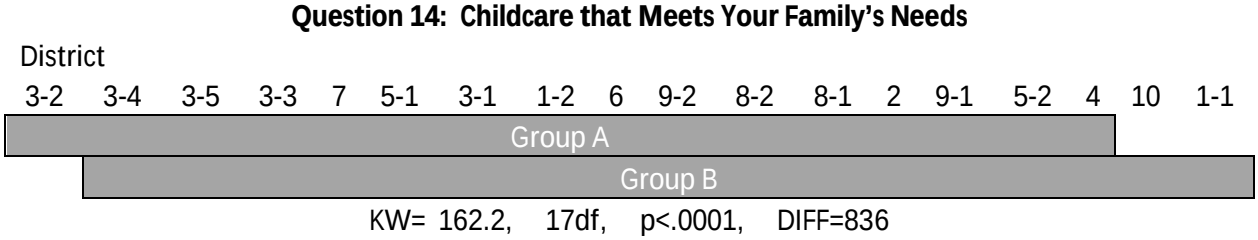

Figure 13. Quality of Childcare by Health District

Question 15 of the FOS asked respondents to rank how often their child is able to play with other children or participate in religious, community or social activities. This question also began with a qualifying question which asked respondents to indicate if their family has not wanted their child to participate in social activities. If the respondent did not answer the qualifying question, (indicating that they did want their child to participate in social activities), they were asked to respond to question 15. Question 15 asked respondents to rank how often their child participates in social activities right now. Likert item responses ranged from one to seven with one indicating "Our child seldom participates in the activities we want", and seven indicating "Our child almost always participates in the activities we want".

For this question, district 3-2 once again had the lowest average ranked response (3806). District 10 had the highest average ranked response (5036). Group A is comprised of all groups with an average ranked response lower than the lowest average ranked response plus the amount of response difference considered significant (1044). This included health districts 3-2, 3-5, 5-1, 1-2, 7, 3-3, 3-4, 9-2, 1-1, 3-1, 5-2, 9-1, 8-1, 2, 6, and 4 in group A. All responses from districts in group A are considered to be statistically similar

to each other, but statistically different from groups B, (see Figure 14). Group B was formed in the same manner. Looking at the results of this analysis, it can be seen that health district 3-2 is a member of only group A, meaning that it is statistically similar to the other groups in group A. District 8-2 is a member of group B, but not a member of group A, indicating that district 3-2 is statistically different than district 8-2.

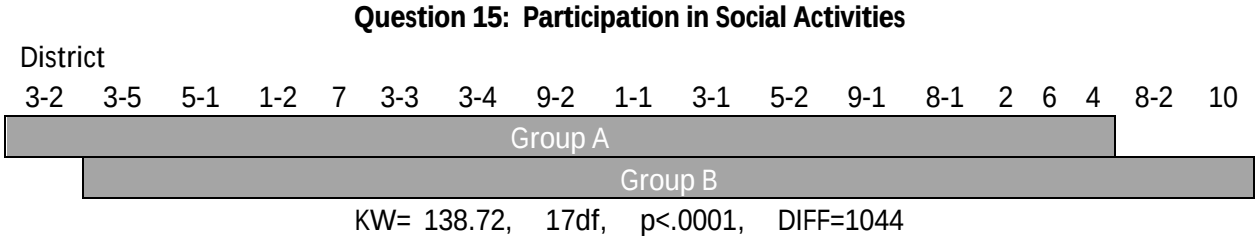

Figure 14. Participation in Social Activities by Health District

CHAPTER 5

SUMMARY, RECOMMENDATIONS, AND CONCLUSION

Summary of Findings

The purpose of this study is to establish the baseline for understanding differences between the impact of the place of residence on knowledge of rights, access to community resources, and social supports for caregivers of children enrolled in Georgia's EI program. By providing program administrators with this information, this study will facilitate an improvement in the delivery of EI programs throughout the State of Georgia.

This study found the responses to the selected questions from the FOS to be quite positive overall. With a Likert item answer of 4 indicating an average neutral response, the mean of all responses to each question were either positive or highly positive, ranging from 5.0 to as high as 6.2. These results are encouraging and show that caregivers in Georgia are, for the most part, comfortable with their knowledge of rights, social supports, and access to community resources. However, this study did find a difference in the responses from participants based on place of residence. A significant difference was found between the answers from participants based on the rural or urban classification of their county of residence, and also based on the health district in which they reside. Those participants located in urban areas responded significantly less positively to eight of the nine questions as compared to their rural counterparts. Urban respondents were also significantly more likely to desire special needs child care, and more likely to desire that their children participate in social activities than rural respondents. These differences persisted when examining participants based upon the health district in which they reside. District 3-2, an entirely urban district located in Metro Atlanta, ranked last in each of the nine questions

analyzed. Other entirely urban health districts consistently ranked among the bottom in terms of the favorability of responses. Metro Atlanta District 3-5, ranked either second or third least favorable on every question, and Metro Atlanta District 3-4 ranked either second or third least favorable on five of the nine questions. However, this trend did not hold true for all the Metro Atlanta health districts. District 3-1 consistently scored much higher than the other Metro-Atlanta health districts. This district ranked 8th or better (out of 18 health districts) on four of the nine questions, and never ranked lower than 5th. Non-Metro Atlanta health districts containing large urban centers such as District 6, which contains Augusta (Georgia's 2nd largest city by population), and district 9-1 which contains Savannah (Georgia's 4th largest city) consistently ranked in the middle or better of all health districts. However there was one exception, District 7 which contains Columbus (Georgia's 3rd largest city), consistently fared poorly, ranking fourth least favorable with three questions, and fifth least favorable with two questions.

Study Limitations and Suggestions for Further Research

The results of this research support the hypothesis that caregivers of children enrolled in EI programs in the State of Georgia differ in terms of knowledge of rights, access to community resources, and social supports depending on the place in which they reside. Further, this research may lead us to the conclusion that those participants residing in urban areas have a poorer knowledge of their rights, less access to community resources, and fewer social supports than their rural counterparts; however, this conclusion must be taken with caution. Although this study used a nationally recognized form of classification to designate an area as being either rural or urban, it failed to account for other possible classification methods, and certain possible confounding variables, and therefore this

conclusion must be made in a guarded fashion. It is anticipated that this research will prove useful in guiding future research. Future research should expand on these results and attempt to account for variables that were beyond the scope of this project, including socio-economic status of participants, race/ethnicity, and other recognized methods of classifying an area as being either rural or urban.

Socio-economic status must be accounted for in future research in order to develop a clear picture of the relation between these socio-demographic variables and rural or urban residence. Residing in a rural or urban area is not necessarily synonymous with either poverty or high-income, and income level could most certainly have an effect on any one or all of the socio-demographic variables examined. Future studies should explore the income status of participants and the rural or urban classification of residence in order to separate out the effect of or illuminate the relation between these variables and outcomes.

Race/ethnicity must also be taken into account for future research in order to develop a clear picture of the relation between these socio-demographic variables and rural or urban residence. Similar to socio-economic status, race is not necessarily synonymous with residing in either a rural or urban area, and could also have an effect on any one or all of the socio-demographic variables examined. Future studies should explore the race/ethnicity of participants in order to separate out the effect of or illuminate the relation between these variables and outcomes.

Future research interested in clarifying the relation between these variables should develop the classification of areas beyond county designations of either rural or urban. As geographic areas are defined more precisely, more accurate and useful the information regarding differences between populations will become. Rural areas adjacent to urban

areas should be examined to investigate if differences persist even among those rural residents who commute to urban areas. Future research should examine these variables using other classification methods besides the Georgia SORH definition which defines counties simply based on population. For example, the OMB defines geographic areas based on population density, but also includes consideration for outlying areas which are tied economically to core counties. This system results in the categorization of geographic areas into Metropolitan Statistical Areas, Non-metropolitan Statistical Areas, and Micropolitan Statistical Areas, and can also be used to take into account those who commute from rural areas to urban centers for work. The U.S. Census Bureau definition also combines population statistics with population density to categorize geographic areas as either urbanized, an urban cluster, or rural. Examination by alternate geographic classifications would allow the examination of differences beyond the boundaries of county lines.

The rest of this chapter will offer some recommendations for improving outreach and education to urban areas in Georgia, with the hopes of narrowing the gap between socio-demographic outcomes for the two groups.

Recommendations for Early Intervention Programs in Georgia

Community Resources

The largest gap between groups under a particular heading was noted in the "Access to Community Resources" section. Of the three questions under this heading (questions 13, 14, and 15), two of the three were found to be significantly different in both statistical tests used, and all three were found to be significantly different by the Samawi-Vogel Overlap Coefficient.

Under this heading, question 13 asked respondents to rank how well their family's medical care meets their child's special needs. This question found significant differences between groups using both the Kruskal-Wallis Statistic ($p<0.0001$) and the Samawi-Vogel Overlap Coefficient which demonstrated the rural and urban populations to be in agreement only 34% of the time.

Question 15 under this heading, which asked respondents to rank how often their child participates in social activities, also demonstrated significant differences with both the Kruskal-Wallis Statistic and Samawi–Vogel Overlap Coefficient demonstrating p-values of less than 0.0001. The Samawi-Vogel Overlap Coeffieient demonstrated the rural and urban populations to be in agreement only a 56% of the time.

Question 14 under the same heading asked respondents to rank how well their family's childcare met their needs. A significant difference was found between the two groups on both tests used, with a p-value of 0.0096 calculated for the Kruskal-Wallis Statistic, and a p-value of 0.0001 from the Samawi–Vogel Overlap Coefficient. The Samawi-Vogel Overlap Coefficient demonstrated the two groups to be in agreement only 40% of the time.

Given the differences between groups in regard to access to community resources, the goal of program administrators in urban areas should be capacity building at the local level. BCW administrators, other local government agencies, community groups and health care workers should be at the center of the capacity building process and need to be trained to understand and respond to the challenges of an increasingly complex urban population. These challenges will continue to mount with increasing urbanization, and the interactions of BCW participants with other sectors (e.g., health care, daycare, and

community centers) need to be better understood and articulated by those responsible for designing, managing and implementing plans targeted towards improving the access to community resources for BCW participants.

In order to address the difference found in question 13, BCW administrators in urban areas should explore the option of implementing twenty four hour medical support for participants in order to provide a medical home to participants with special medical needs. Twenty four hour medical support could be provided in a simple and cost effective manner by implementing a rotating schedule where program representatives are on-call to answer questions to a toll free number. The toll free number can be given to caregivers upon entry into the program, and they can call the number at anytime to receive feedback from professionals regarding any non-emergency question they may have about a child's medical care.

Question 14 demonstrated a difference between rural and urban participants regarding the desire to use and availability of special needs childcare. Urban participants were significantly more likely to desire special needs childcare than rural participants, and significantly less content with the childcare they were receiving. The acquisition of childcare for children with special needs is particularly challenging because of cost. In-home care for medically fragile children is often financially prohibitive. Shared care outside the home may offer a less expensive option; however, it brings other challenges such as transportation issues, and many parents feel their child gets sick more often when sharing space with other immunocompromised children. In order to address this disparity, it is recommended that Georgia develop, adopt, and fund a five year Inclusive Child Care Strategic Planning Project. Based on a similar project in Florida, the mission of this project

will be to draft a five-year strategic plan that will result in the expansion of the quality, affordability, and accessibility of child care services in urban areas for children with special needs. While the Florida project developed four objectives based on key recommendations from a series of work groups (Florida Children's Forum, 2003), Georgia will have to identify its own specific objectives. Examples of these objectives may include:

1. To develop a long range strategic plan for building inclusive childcare for special needs children residing in urban areas.
2. To identify an implementation plan which presents strategies and actions, and identifies the party(ies) responsible for the accomplishment of those actions.
3. To gain the commitment of all involved parties to build inclusive special needs child care programs in Georgia's underserved urban areas.

In order to meet each objective, a series of desired outcomes will be identified, and a series of strategies and activities identified under each desired outcome category. Strategies and activities will be attached to specific timelines for completion, resources will be identified, and the outcome activity will be assigned to a specific party responsible for the accomplishment of the outcome. Examples of outcomes that may be identified include:

1. To increase awareness among community members, legislators and medical professionals of the need, benefits, and requirements of childcare for children with special needs in urban areas.
2. Build and maintain collaborative relationships between EI, special education programs and childcare programs so that they can conduct joint planning and maximize existing resources.

3. Increase the number of accredited special needs childcare centers in urban areas.
4. Utilize multiple funding sources to increase resources available to special needs childcare providers.

A series of strategies and activities will then be identified under each desired outcome category, and will be attached to specific timelines for completion. For example, objective four which seeks to utilize multiple funding sources to increase resources available to special needs childcare providers. Strategies and activities under this outcome category may include:

A. To identify all funding sources and possible special needs childcare providers.
B. To build funding models with leading funders which secure local money to fund childcare providers for serving children with special care needs.
C. To develop a legislative budget request for FY2013 which provides incentives for private, for-profit childcare centers to serve children with special needs.

Question 15 demonstrated differences between rural and urban populations in regard to participation in social activities. Urban participants both more likely to desire that their child participate in social activities, and less satisfied with the social activities available for their children. In order to address this inequity it is recommended that EI program administrators in urban areas partner with the Easter Seals Camping and Recreation Program. As the largest provider of recreation and camping services for people with disabilities in the United States, Easter seals provides people with disabilities with the opportunity to participate in extracurricular activities such as sports and fitness activities, cultural outings to museums, community events, and social gatherings. Easter Seals also

administers residential and day camps for children and adults with disabilities. These day camps are designed to be barrier-free and provide individuals with disabilities the ability to access a variety of recreational activities. A partnership should be created between BCW and Easter Seals to provide funding out of BCW grant-in-aid which will facilitate access the Easter Seals Camping and Recreation Program. This will allow BCW participants to access the program who could not otherwise afford to participate.

Social Supports

The largest gap between groups found in a single question was question 11 under the heading of Social Supports. Question 11 asked respondents to rank how often their family has someone they can rely on for help to provide a ride, run an errand or watch their child for a short period of time. A significant difference was found between the two groups with the Kruskal-Wallis Statistic reporting a p-value of less than 0.0001, and the Samawi–Vogel Overlap Coefficient indicating that the rural and urban populations are only 37% in agreement ($p>0.0001$). This question clearly showed that those participants residing in rural areas were more likely report having someone they could rely on than those residing in urban areas.

Other questions under the heading of Social Supports (questions 10, and 12) also showed significant differences in one of the two statistical tests used. Question 10 asked respondents to rank how often their family has someone they trust to talk with when they need it. The Kruskal-Wallis Statistic reported a p-value of 0.0327, and the Samawi–Vogel Overlap Coefficient demonstrated the two groups to be only 32% in agreement ($p<0.0001$). Question 12 asked respondents to rank how often their family is able to do the things they enjoy. The Kruskal-Wallis Statistic reported a p-value of 0.0029, and the Samawi–Vogel

Overlap Coefficient demonstrated only a 43% agreement between groups which represents a significant difference ($p<0.0001$).

In an effort to reduce the disparity between rural and urban families in regard to having someone who they trust to talk with and rely on for help, it is recommended that urban districts implement family support groups. These family support groups will provide families with special needs children the opportunity to come together to network, and to offer each other support and information. Membership will be comprised of caregivers or family members of children who receive services from BCW. Members will be identified by BCW staff, and by other support group members, and will be recruited from throughout the urban county or district. The purpose of this strategy is to represent families of children from different specialty areas and a diversity of cultures. Each support group will meet monthly. Meetings will be scheduled at a time and place agreed upon by the group, and all members will be notified of meeting times either by mail or telephone of meeting times. Each support group will select a member to serve as the Group Leader over a period of one-to-two years or as decided by the team. Two people may share this role if that is the desire of the group. Duties of the group leader will include creating an agenda and presiding over each meeting, helping to provide direction for group activities and ensuring that minutes are taken and that they are made available to the membership. Programs should be planned for the meetings, such as having an outside speaker on some topic of interest, and sharing a meal together in order to facilitate networking with other members or guests. Also, meetings should include a review of current BCW policies and procedures followed by a discussion to provide families with the opportunity to advise BCW with concerns. This feedback will help to improve services and develop programs

that are responsive to those needs. Any family with a special needs child may attend a group meeting, including families from the community whose child is not enrolled in BCW. These groups will address the needs identified in this study by providing a forum for parents to establish networks of individuals who they can rely upon for social support.

In order to reduce the discrepancy identified in question 12, which asked participants how often they are able to do things they enjoy, those districts located in urban areas should implement a recreational enhancement program. Identified districts will contract with a recreational therapist who will assess each district and create a customized intervention plan for that district with the objective of improving access to social events for participants. The recreational therapist will be contracted under the same terms as other BCW therapists; however the contract will be time limited and include objectives such as the creation of a pamphlet listing accessible activities for program participants, establishing contacts with local businesses, community centers, and recreation areas, and the creation of specific events for children with developmental delays or disabilities.

The recreational therapist will create a pamphlet which should be included in the intake process by the service coordinator who will emphasize the importance of social activities. The pamphlet will be given to the family and questions will be addressed at this time. Aside from illustrating the importance of social activities, the pamphlet will offer ideas to families of activities available for individuals with developmental delays. The pamphlet will include a listing of local places which are accessible to individuals with special needs, and list the activities that are available at that facility. Another objective for the recreational therapist would be to act as a liaison between the program and local businesses, community centers, or recreation areas to negotiate special rates, discount

days and special events for BCW participants. A calendar of these events should be created and posted on the district's website.

This recreational enhancement program will address a need identified in this study by providing urban participants with education about the importance of recreation, and a listing of recreational activities in their area which are specifically suited to children with special medical needs.

Knowledge of Rights

Of the three questions under the heading Knowledge of Rights (questions 4, 5, and 6), two of the three showed a significant difference using both the Kruskal-Wallis, and the Samawi-Vogel Overlap Coefficient. One question did not show a significant difference between groups in either of the two statistical tests.

Question 4 asked respondents to rank how much their family knows about the programs and services that are available. A significant difference was found between the two groups with a Kruskal-Wallis Statistic reporting a p-value of 0.0001, and the Samawi–Vogel Overlap Coefficient demonstrating only 51% agreement between groups ($p<0.0001$). Question 6 asked respondents to rank how familiar they were with their rights, including what to do if they are not satisfied. A significant difference was found by both statistical tests with the Kruskal-Wallis Statistic reporting a p-value of <0.0001, and the Samawi–Vogel Overlap Coefficient demonstrating only 41% agreement between groups ($p<0.0001$). Question five of the FOS asked respondents to rank how comfortable their family was participating in meetings with early intervention professionals to plan services or activities. No significant difference was found between the two groups of participants by either statistical test.

District 3-2 and district 3-5 ranked average was last and second to last on each of the three questions under this heading. Because knowledge of rights is such an important part of the EI process, it is important that the policies and implementation of policies is examined in these two districts. One policy to be examined in particular is whether each district is following EI implementation protocol and providing each caregiver with a copy of the Notice of Infant/Toddler and Family Rights under BCW pamphlet at intake. This twenty six page pamphlet provides a clear description of the child and family's rights as defined by Part C of the IDEA. It should be examined in program representatives are distributing these pamphlets at intake as required by BCW policies and procedures. If not, district leadership should discuss the importance of this information with the services coordinators, and ensure that each family is provided with a pamphlet during intake and that the services coordinator works with the family to review their rights under Part C, and if necessary provides additional materials to help the family understand their rights. Also, research should be conducted in these districts to examine the possibility that there is a reason that the pamphlet is not being read or understood by participants in these lowest ranking districts. If there is a need to translate the pamphlet into a foreign language or lower the reading level to suit an individual district's clients than these changes should be undertaken and new pamphlets implemented.

Conclusion

The importance of EI programs as a tool for ensuring the continued prosperity of our society cannot be understated. Any costs that the public may incur in the course of funding a comprehensive EI system will be more than recouped over time as high risk children are placed on a developmental trajectory which will allow them to grow into

productive members of society. The alternative to a well funded EI system is a society with an increasingly expanding segment of its population unable to contribute to the system as a whole, and ultimately more individuals dependent upon social programs for their wellbeing. While many people would consider the provision of care to special needs children a necessary undertaking for an advanced society, it can also be viewed in fiscal terms as a smart investment.

Overall, the findings of this study were highly positive. Average responses from both groups indicate that caregivers of children enrolled in BCW are content when it comes to their knowledge of available services, comfortable with the level of social supports they have, and are able to access community resources. Despite the positive nature of these findings, the EI system in Georgia is unarguably in need of repair. Georgia's track record with EI clearly indicates vast room for improvement. The findings from this study have highlighted a difference between participants based on the rural or urban classification of place of residence. Perhaps these findings will serve to identify areas where programmatic policies and procedures should be examined and provide a focal point for interventions.

Despite our mandate as researchers not to predict the direction of our research, upon the inception of this study certain assumptions were made regarding what would be found. Many of those involved, myself included, presumed not only that this study would find differences between groups, but that the rural participants would be the group which responded less favorably. Perhaps as a result of preconceptions regarding residents of rural areas, it was assumed that the urban residents would have a better understanding of their rights, more social supports, and certainly greater access to community resources. Ultimately those predictions proved inaccurate. In every case where a difference was

found, it was the rural residents who responded more favorably to the questions asked. While reinforcing the lesson that a researcher should not presume to predict the results of his or her research, these finding have brought with them a reason to feel optimistic.

A degree of optimism may be warranted in this case, because of the nature of urban areas themselves. By definition, these areas have a higher population density, and therein may already contain many of the resources needed to implement interventions designed to remedy the socio-demographic discrepancies found in this study. Large numbers of families living geographically close to each other, community centers available to host meetings, and community partners to donate resources are perfect examples of requirements for the implementation of a successful family support group program. Wheel chair accessible public transportation and a variety of entertainment venues and cultural centers which are accessible to individuals with special needs are exactly the type of resources required to implement a successful recreational enhancement program. In short, the recommended interventions outlined in this chapter are going to be easier to implement in these areas, where the urban populations will find the resources necessary to elevate themselves to the level of their rural counterparts.

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APPENDICES

A. IRB APPROVAL LETTERS

IRB Approval Letter: Georgia Southern University

Georgia Southern University
Office of Research Services & Sponsored Programs

Institutional Review Board (IRB)

Phone: 912-478-0843
Fax: 912-478-0719
IRB@GeorgiaSouthern.edu
Veazey Hall 2021
P.O. Box 8005
Statesboro, GA 30460

To: Mathew W. Walker
2493 Highway 24
Statesboro, GA 30461

James Stephens
P.O. Box 8015

Robert L. Vogel
P.O. Box 8148

cc: Charles E. Patterson
Associate Vice President for Research

From: Office of Research Services and Sponsored Programs
Administrative Support Office for Research Oversight Committees
(IACUC/IBC/IRB)

Date: March 16, 2010

Subject: Status of Application for Approval to Utilize Human Subjects in Research

After a review of your proposed research project numbered: **H10268**, and titled **"Differences in Self-Perceived Needs Among Caregivers of Children with Special Needs in Rural vs. Urban Counties of Georgia"**, it appears that your research involves activities that do not require approval by the Institutional Review Board according to federal guidelines.

According to the Code of Federal Regulations Title 45 Part 46, your research protocol is determined to be exempt under the following exemption category(s):

☐ Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

Therefore, as authorized in the Federal Policy for the Protection of Human Subjects, I am pleased to notify you that your research is exempt from IRB approval. **You may proceed with the proposed research.**

Sincerely,

Eleanor Haynes

Eleanor Haynes
Compliance Officer

IRB Approval Letter: Department of Community Health

GEORGIA DEPARTMENT OF COMMUNITY HEALTH

Clyde L. Reese, III, Esq., Commissioner *Sonny Perdue, Governor*

Division of Public Health · Two Peachtree Street, N.W. · Suite 15-490 · Atlanta, Georgia 30303-3159 · (404) 657-2700

July 26, 2010

Matthew W. Walker, MPH, DrPHc
Program Director
Children's Special Services
Coastal Health District 9-1
2493 Highway 24
Statesboro, Georgia 30461

Dear Dr. Walker:

PROJECT #100403- Differences in Self Perceived Needs among Caregivers of Children with Special Needs in Georgia Rural and Urban Counties

This study is eligible for approval without detailed review, our procedure # 4.1.1.d. It was reviewed and approved on May 14, 2010. The expiration date for this approval is May 1, 2011. If your involvement with subjects is to continue beyond this date, you must complete the enclosed 'Application for Continuing Approval' and submit the form and attachments to the Board at least 6 weeks prior to the above expiration date. Any involvement with subjects must cease on the above date unless you have received approval from the Board for continuation of the project. It is your responsibility to track the deadline and any notice from the IRB is just a courtesy.

Board review and approval is required before implementing any changes in this project except where necessary to eliminate apparent immediate hazards to human subjects. You are responsible for prompt reporting to the Board any problems involving risks to subjects and others.

Please note that the project has been assigned a number. It would be helpful if you would refer to this number in any future correspondence concerning this project. Note also that approval by the IRB does not constitute approval of any procedures for obtaining of extant confidential information by the investigator. There are other directives that govern authorization for release of confidential information that is held by the Department and other institutions.

If you have any questions, please contact me at 404/657-6390.

Sincerely,

Tamika Z. Matthews

Tamika Z. Matthews, Executive Assistant
DCH Institutional Review Board

C: Anil T. Mangla,

B. FAMILY OUTCOMES SURVEY

Family Outcomes Survey

Part C Version

The Family Outcomes Survey is designed to provide a way for you to describe your family and the ways you support your child's needs.

Instructions:

- This survey should be filled out by the person in your family who has the most interaction with early intervention.
- All of the responses include the word "we" or "our." This refers to your family. Usually this means parents and others who support and care for your child. But every family is different, so think of what "family" means to you when answering.
- On every page, you will be asked to answer questions like the example below:

How much does your family know about dinosaurs?

1	2	3	4	5	6	7
We know a **little** about dinosaurs		We know **some** about dinosaurs		We know a **good amount** about dinosaurs		We know a **great deal** about dinosaurs

- Read each question and circle the number that best describes your family right now.
- If a statement almost describes your family, but not quite, circle the number just to the left or the right. For example if you feel that the statement 5 "We know **a good amount** about dinosaurs" almost describes your family, but not quite—circle the 4.

  If you do not know how to answer a question, or if you are not comfortable answering the question, skip it and go to the next question.

Family Outcomes Survey

UNDERSTANDING YOUR CHILD'S STRENGTHS, ABILITIES, AND SPECIAL NEEDS

1. *Your child is growing and learning. How much does your family understand about your child's development?*

1	2	3	4	5	6	7
We are **just beginning** to understand our child's development		We understand **some** about our child's development		We understand a **good amount** about our child's development		We understand a **great deal** about our child's development

2. *Some children have special health needs, a disability, or are delayed in their development. These are often referred to as "special needs." How familiar is your family with your child's special needs?*

1	2	3	4	5	6	7
We are **just beginning** to understand our child's special needs		We understand **some** about our child's special needs		We understand a **good amount** about our child's special needs		We understand a **great deal** about our child's special needs

3. *Professionals who work with you and your child want to know if the things they do are working. How often is your family able to tell if your child is making progress?*

1	2	3	4	5	6	7
We **seldom** can tell if our child is making progress		We **sometimes** can tell if our child is making progress		We **usually** can tell if our child is making progress		We **almost always** can tell if our child is making progress

KNOWING YOUR RIGHTS AND ADVOCATING FOR YOUR CHILD

4. *A variety of programs and services may be available to help your child and family. How much does your family know about the programs and services that are available?*

1	2	3	4	5	6	7
We are **just beginning** to learn about the programs and services that are available		We know **some** about the programs and services that are available		We know a **good amount** about the programs and services that are available		We know a **great deal** about the programs and services that are available

5. *Families often meet with early intervention professionals to plan services or activities. How comfortable is your family participating in these meetings?*

1	2	3	4	5	6	7
We are **just beginning** to feel comfortable participating in meetings		We are **somewhat** comfortable participating in meetings		We are **generally** comfortable participating in meetings		We are **very** comfortable participating in meetings

6. *Families of children with special needs have rights, including what to do if you are not satisfied. How familiar is your family with your rights?*

1	2	3	4	5	6	7
We are **just beginning** to understand our rights		We understand **some** about our rights		We understand a **good amount** about our rights		We understand a **great deal** about our rights

HELPING YOUR CHILD DEVELOP AND LEARN

7. *Families help their children develop and learn. How much does your family know about how to help your child develop and learn?*

1	2	3	4	5	6	7
We are **just beginning** to know how to help our child develop and learn		We know **some** about how to help our child develop and learn		We know a **good amount** about how to help our child develop and learn		We know a **great deal** about how to help our child develop and learn

8. *Families try to help their children learn to behave the way they would like. How much does your family know about how to help your child learn to behave the way your family would like?*

1	2	3	4	5	6	7
We are **just beginning** to know how to help our child behave the way we want		We know **some** about how to help our child behave the way we want		We know a **good amount** about how to help our child behave the way we want		We know a **great deal** about how to help our child behave the way we want

9. *Families work with professionals to help their children learn and practice new skills at home or in their communities. How often does your family help your child learn and practice these new skills?*

1	2	3	4	5	6	7
We are **just beginning** to help our child learn and practice these skills		We **sometimes** help our child learn and practice these skills		We **usually** help our child learn and practice these skills		We **routinely** help our child learn and practice these skills

HAVING SUPPORT SYSTEMS

10. Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?

1	2	3	4	5	6	7
We **seldom** have someone to talk with about things when we need it		We **sometimes** have someone to talk with about things when we need it		We **usually** have someone to talk with about things when we need it		We **almost always** have someone to talk with about things when we need it

11. Families sometimes must rely on other people for help when they need it, for example to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when your family needs it?

1	2	3	4	5	6	7
We **seldom** have someone we can rely on for help when we need it		We **sometimes** have someone we can rely on for help when we need it		We **usually** have someone we can rely on for help when we need it		We **almost always** have someone we can rely on for help when we need it

12. Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?

1	2	3	4	5	6	7
We **seldom** are able to do the things we enjoy		We **sometimes** are able to do the things we enjoy		We **usually** are able to do the things we enjoy		We **almost always** are able to do the things we enjoy

ACCESSING YOUR COMMUNITY

13. All children need medical care. How well does your family's medical care meet your child's special needs?

1	2	3	4	5	6	7
Our medical care meets **few** of our child's needs		Our medical care meets **some** of our child's needs		Our medical care meets **many** of our child's needs		Our medical care meets **almost all** of our child's needs

14. Many families have a need for quality childcare. By this, we do not mean occasional babysitting, but regular childcare, either part-day or full-day. How well does your family's childcare meet your child's needs?

☐ CHECK HERE IF YOUR FAMILY HAS NOT WANTED CHILD CARE, AND GO TO QUESTION 15.

☐ CHECK HERE IF YOUR FAMILY HAS WANTED CHILD CARE BUT IT IS NOT CURRENTLY AVAILABLE, AND GO TO QUESTION 15.

1	2	3	4	5	6	7
Our childcare meets **few** of our child's needs		Our childcare meets **some** of our child's needs		Our childcare meets **many** of our child's needs		Our childcare meets **almost all** of our child's needs

15. Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?

☐ CHECK HERE IF YOUR FAMILY HAS NOT WANTED YOUR CHILD TO PARTICIPATE IN SUCH ACTIVITIES AND GO TO QUESTION 16.

1	2	3	4	5	6	7
Our child **seldom** participates in the activities we want		Our child **sometimes** participates in the activities we want		Our child **usually** participates in the activities we want		Our child **almost always** participates in the activities we want

THE HELPFULNESS OF EARLY INTERVENTION

The next questions ask how well early intervention has helped your family. When answering, think about the early intervention services you have received.

16. To what extent has early intervention helped your family know and understand your rights?

1	2	3	4	5	6	7
Early intervention has done a **poor** job of helping us know our rights		Early intervention has done a **fair** job of helping us know our rights		Early intervention has done a **good** job of helping us know our rights		Early intervention has done an **excellent** job of helping us know our rights

17. To what extent has early intervention helped your family effectively communicate your child's needs?

1	2	3	4	5	6	7
Early intervention has done a **poor** job of helping us communicate our child's needs		Early intervention has done a **fair** job of helping us communicate our child's needs		Early intervention has done a **good** job of helping us communicate our child's needs		Early intervention has done an **excellent** job of helping us communicate our child's needs

18. To what extent has early intervention helped your family be able to help your child develop and learn?

1	2	3	4	5	6	7
Early intervention has done a **poor** job of helping us help our child develop and learn		Early intervention has done a **fair** job of helping us help our child develop and learn		Early intervention has done a **good** job of helping us help our child develop and learn		Early intervention has done an **excellent** job of helping us help our child develop and learn

Thank you for completing this survey!

C. GEORGIA PUBLIC HEALTH DISTRICTS