Distribution Agreement

Andrea Renée Simon April 7, 2015

Exploring Access and Barriers to Intervention Services for Children with Autism in the State of Georgia

by

Andrea Simon

Dr. Charles Aiden Downey
Honors Adviser

Department of Educational Studies

Dr. Celine Saulnier
Honors Adviser

Dr. Robert Jensen
Committee Member

Dr. Patricia Brennan
Committee Member

2015

Exploring Access and Barriers to Intervention Services for Children with Autism in the State of Georgia

By

Andrea Simon

Dr. C. Aiden Downey
Honors Advisoe

Dr. Celine Saulnier
Honors Adviser

An abstract of
A thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts with Honors

Department of Educational Studies

2015

Abstract

Exploring Access to Intervention Services for Children with Autism

By Andrea Renee Simon

Research has shown that racial and socioeconomic disparities may exist in terms of age at diagnosis, access to and usage of services, and quality of long-term outcome for children with Autism Spectrum Disorder. The present investigation aimed to assess whether these types of disparities were present in a sample of 52 Georgia school-age children with autism. An additional goal was to determine what types of barriers families encounter when seeking services and what resources they have found to be most helpful in overcoming these barriers. The results of the study revealed that few children in Georgia were getting sufficient or appropriate care according to best-practice models. Furthermore, African Americans in the sample showed no significant differences compared to Caucasians neither in access to and usage of services nor symptom severity. However, more severe cognitive and adaptive functioning deficits were found in African Americans than in Caucasians. In regards to socioeconomic status, children of low socioeconomic status did not show any disparities in access to and usage of services, cognitive or adaptive functioning, nor symptom severity when compared with those of high socioeconomic status. However, within the low socioeconomic status participants, racial disparities in cognitive and adaptive functioning persisted that did not present in the high socioeconomic group. Finally, availability and quality seem to be the most frequent barriers that families encounter when seeking services. The results suggest that children with ASD in Georgia may already be at risk for insufficient and inappropriate care, regardless of race or socioeconomic status. Furthermore, being African American could be a risk factor for more severe cognitive and adaptive deficits that affect quality of long-term outcome, but these greater deficits did not seem to be accounted for in their treatment programming. Finally, high socioeconomic status may have acted as a protective factor from the more severe cognitive deficits in the sample's African Americans. Community and legislative leaders as well as professionals across the fields of Autism and Education must come together to create more community viable solutions that provide equal access across all races, ethnicities, and socioeconomic groups in the state of Georgia.

Exploring Access and Barriers to Intervention Services for Children with Autism in the State of Georgia

by

Andrea Simon

Dr. C. Aiden Downey
Honors Adviser

Dr. Celine Saulnier
Honors Adviser

A thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
of the requirements of the degree of
Bachelor of Arts with Honors

Department of Educational Studies

2015

Acknowledgmements

After a full year of hard work, I am so proud of this accomplishment, but I am also humbled by the knowledge that none of this would have been possible without the following people.

I would first like to thank my incredible advisers Dr. Celine Saulnier, whose guidance on this project was invaluable, and Dr. Aiden Downey, whose moral and emotional support counseled me through the ups and downs (of which there were many). I would also like to acknowledge the support of all my friends who dealt with the panic attacks, mood swings, and frequent extended absences during periods of self-imposed solitary confinement—your snapchats made these times bearable. I must also acknowledge the many hugs, tears, and meals shared with my twin sister whose support carried me through the final weeks of this project. Finally, to the person who has been there from long before this project started and who I know will continue to be a remarkable part of my life for many more years to come, thank you for lending me your love and strength when I felt weak, your shoulder when I felt despair, and your hand to hold when I needed guidance—and also for sending me pictures of my cat. You know who you are.

Table of Contents

Table of Figures

Introduction

Man is by nature a social animal - Aristotle

Social interactions and interpersonal relationships shape us as humans, playing a significant role in the overall outcome, functionality, and quality of our lives. As social beings, we naturally seek human connection for comfort and support, but this part of our nature also serves a far more fundamental purpose. Our ability to recognize, interact and communicate with other people plays a crucial role in how we develop and learn to participate in society. During our early and highly formative years, we learn by observing, mimicking, and directing our caregivers, teachers, and friends. This type of learning requires a specific set of socialization skills such as joint-attention[1], gaze following, imitation, and gesture use that facilitate our learning from others. Children lacking these skills are at a disadvantage in terms of their social, emotional and cognitive development.

Clinically identified in 1943 by Leo Kanner, Autism Spectrum Disorder (ASD) has become one of the most prevalent neurodevelopmental disorders of our time. The Diagnostic and Statistical Manual, Fifth Edition (DSM-5) (American Psychiatric Association, 2013) defines ASD as impairments in social language and communication skills as well as the presence of restricted or repetitive behaviors and interests[2]. The most recent Center for Disease Control (CDC) prevalence report estimates that ASD affects 1 in 68 children (2014). Symptoms are not usually noticed until the second, third year, or even fourth year of life (Valicenti-McDermott,

---

[1] Joint-Attention- the shared focus of two individuals on an object. It is achieved when one individual directs the attention of another by means of eye gazing, pointing, or other verbal or non-verbal indications.

[2] See Appendix B for full DSM-5 diagnostic criteria.

Hottinger, Seijo, & Shulman, 2012), however parents report developmental concerns even before 1 year of age(Kozlowski, Matson, Horovitz, Worley, & Neal, 2011). During the first year of life, children at risk for ASD (who will go on to develop the disorder) can have significant problems developing nonverbal communication skills, such as eye contact, facial expressions, and body posture. After the child's first birthday, delays in speech, language, and communication become more apparent. Their language can stereotyped and repetitive, with odd prosody[3] and scripted or echoed speech[4]. As social communication demands increase, children can struggle with understanding perspective taking (i.e., theory of mind) and tend to interpret speech literally, often missing implied meanings. In addition to social communication impairments, children with ASD present with stereotypies[5], such as hand flapping or body rocking, or have unusual sensory experiences. Light can be experienced as painful, a slight touch unbearable, but deep pressure may be calming and pleasant. Finally, children with ASD have a tendency to become so preoccupied with certain topics, such as trains or numbers, and develop an insistence on a routine with such intensity that it interferes with their day-to-day functioning (CDC). Children more severely affected by ASD can present with associated disabilities such as Intellectual Disability (ID), seizures, and self-injurious or aggressive behavior. Those more mildly affected can appear awkward and quirky, motivated to engage with others but lacking the social competency to successfully navigate these interactions.

---

[3] Odd Prosody- peculiar voice characteristics; odd intonation, tone/pitch, or rhythm

[4] Echolalia/Scripting- repetition of words, phrases, intonation, or sounds of the speech of others, sometimes taken from movies, but also sometimes taken from other sources such as favorite books or something someone else has said. Echolalia/scripting was once thought to be non-functional, but is now understood to often serve a communicative or regulatory purpose for the child (Eikeseth, Smith, Jahr, & Eldevik, 2002; P. T. Shattuck & Grosse, 2007)

[5] Stereotypies- stereotyped or repetitive movements or posturing of the hands and body, such as hand-flapping, finger twisting or flicking, rocking, pacing, and odd posturing (Autism Speaks)

Although symptoms may change and even improve over time and with proper and timely intervention (Levy & Perry, 2011), autism is indisputably a lifelong condition. Many children with autism will still require supports as they move into adolescence and adulthood. Some may rely entirely on a caregiver, while others can live semi-independent lives (CDC, Signs and Symptoms). Lockyer and Rutter (1969) developed the first criteria to describe quality of outcome in individuals with autism and found that only about 25% were able to achieve even partial independence, leaving about 75% still requiring substantial supports. However, as supports and services have improved over the years, so too have outcome prospects for those with ASD. In 2004, new estimates were released approximating that that about 41% of adults with autism were able to achieve at least partial independence, nearly double the estimates from before 1990 (Howlin, Goode, Hutton, & Rutter, 2004).

With such a high need for supports throughout the lifespan, the lifetime costs of care for an individual with autism are staggering. A recent study funded by Autism Speaks (Buescher, Cidav, Knapp, & Mandell, 2014) analyzed the best data on ASD to estimate the financial cost of care for ASD in the United States. Data on prevalence, level of functioning, and place of residence were combined with mean annual costs of services and support, opportunity costs, and productivity losses of individuals with ASDs with or without intellectual disability. According to their research, the national economic cost for autism in the United States is $175 billion per year. Given that the study used estimates from the CDC's 2009 prevalence figure of 1 in 110 (which is now outdated), the present economic burden is likely much higher.

Individually, the lifetime cost of supporting one person with ASD ranged from 1.4 to 2.4 million, depending on whether comorbid ID. Broken down into annual expense per individual, Buescher et al. (2014) estimated mean costs of $55,272 per year (ASD, no ID) and $93,859 per year (ASD, comorbid ID). For perspective, even for an individual with no ID, this would be equivalent to paying the full Emory University tuition for every year of that person's life. Special education services and parental productivity loss accounted for much of the cost, as often one parent must quit working in order to provide full-time care to the affected child. Adults with autism incur large expenses from residential care or supportive living accommodations as well as individual productivity loss (i.e. underemployment and unemployment). In an Autism Speaks news release about the study, Dr. Mandell remarked, "We are paying for the costs of inaction and the costs of 'inappropriate action'… increasing the burden not only on these individuals and their families, but on society as a whole." ("Autism's Costs to the Nation Reach $137 Billion a Year," 2012).

Autism experts agree that the key to addressing autism and decreasing its social, personal and financial burden is early intervention. As noted earlier, intervention services for Autism are expensive. The National Research Council's (NRC) guidelines for best practice in treating autism suggest that a child with ASD receive 25 hours of intensive intervention per week (National Research Council, 2001). Furthermore, it is best for the child that their services come with the least intrusion to their regular schedule. This makes public in-school services the most appealing and affordable option for families. Thus, across the country schools are acting as the backbone of treatment for many children with autism, meaning that most parents rely substantially, if not entirely, on in-school services for their child's progress (K. Thomas, Morrissey, & McLaurin, 2007).

While current legislation in general and special education mandates that all educators implement evidence-based educational programs (Individuals with Disabilities Education Improvement Act (IDEA), 2004; No Child Left Behind, 2001), concerning evidence has to come light recently that draws into question whether Georgia Public Schools (GPS) are meeting this requirement. Hess, Morrier, Heflin, and Ivey (2008) found that fewer than 10% of the strategies used with ASD students in GPS were based upon empirically supported practices as identified by Simpson et al. (2005). Furthermore, Hess et al. showed that of the top five most common strategies being used in GPS in 2008, none were considered to be evidence-based. This suggests that there may be a serious disconnect in Georgia between clinically accepted best practice models and current reported classroom practice.

If schools do not provide effective services to these students, families' only option is private providers. However, the cost of these programs makes them prohibitive to many families, which makes school-based treatment the only viable option for them. This paper takes up the question of whether socioeconomic status (SES) (i.e. maternal education and family income) and race influence access to services for children with autism in the state of Georgia. In the sections that follow, I will first present research regarding general trends in prevalence, diagnosis, and treatment courses. I will also address the role of current legislation such as the Individuals with Disabilities Education Act (IDEA) and outline where certain disparities have become evident in the literature, first addressing race and ethnicity, and then socioeconomic status (SES). Second, I will present my own findings on access to care specifically in the state of Georgia, considering both disparities in and barriers to intervention services. Finally, I will draw attention to the implications of these findings in the field of Education, aiming to inform educational institutions on areas of concern in order to generate ideas for more equitable and community viable treatment programs for all children with ASD.

Research Questions and Goals

Questions:

1. Are children with ASD in Georgia receiving appropriate and sufficient special education services based on what the literature states as best practice?

2. Are there racial or SES disparities in the number, type, or hours of services children with ASD in Georgia are receiving?

3. What barriers do families of children with ASD face when seeking services?

Goals:

- To identify and address disparities in access to care for children with ASD
- To inform educational systems of these disparities
- To generate ideas for community viable intervention programs for all children with ASD

Review of the Literature

Prevalence and Diagnosis

The number of children being diagnosed with Autism Spectrum Disorders has been rising at an astonishing rate. Between 1997 and 2008, the number of children being diagnosed with Autism annually increased by 289.5% (CDC). In their most recent report, the CDC estimated the prevalence of children born with autism at 1 in 68 children (2014), making it the 4th most commonly diagnosed developmental disability today (preceded only by (1) Learning Disability, (2) Attention Deficit Hyperactivity Disorder, and (3) Developmental Delay). These staggering numbers have made ASD a national concern. Studies investigating the rise in prevalence suggest that changes in diagnostic patterns could be part of the explanation. A child who might have been diagnosed as having a learning disability or simply "mental retardation" a number of years ago may now receive an autism diagnosis due to broader diagnostic criteria and better assessment methods (Paul T Shattuck, 2006)**.**

In terms of who is at risk for Autism, boys are nearly five times more likely than girls to be diagnosed, however when girls do present with the disorder, they are more likely to have intellectual disability (CDC, 2014)**.** The sibling of a child with autism has just under a 1 in 5 (18.7%) chance of also developing autism and another 20% chance of presenting with shadow symptoms[6] or some other language or social deficit (Ozonoff et al., 2011). Additionally, although ASD can be reliably recognized by age two years (Lord et al., 2006) and parents often express their first concerns around 1 year of age (Frith, Soares, & Wing, 1993; Kozlowski et al., 2011; Sivberg, 2003), the mean age of diagnosis is still almost 4.5 years old (Valicenti-

---

[6] Shadow symptoms- behaviors and symptoms reflective of ASD symptomatology but below diagnostic thresholds.

McDermott et al., 2012). This delay in diagnosis means that many children are not getting early intervention[7].

Intervention and Outcome

Treatment for ASD varies considerably. Among the most empirically supported treatments are behavioral interventions, which involve targeting very specific behaviors and using rewards and consequences to increase good behaviors while reducing problem behaviors. Using a very structured process, desired tasks and behaviors are broken down into smaller pieces and taught as discreet tasks. Each step must be mastered before the child can begin learning the next step. Also popular are developmental interventions, which use the child's own interests and actions to address core deficits rather than specific external behaviors. Other common supports include Speech Therapy for enhancing speech, language, and communication skills, Occupational and/or Physical therapy for fine and gross motor impairments, respectively, Social Skills Therapy (e.g., social skills groups, lunch bunch, facilitated peer groups, etc.) to provide opportunities to practice social engagement, and other Special Education Services such as teacher aides and/or classroom supports. Though the CDC does not specifically endorse any particular program, the National Research Council (2001) recommends that it be intensive (at least 25 hours/week), that it take place in the child's natural environment, and that it begin as early as possible.

These recommendations for intervention are supported in the literature (Boyd, Odom, Humphreys, & Sam, 2010; Dawson, 2008; Eldevik, Hastings, Jahr, & Hughes, 2012; Harris & Handleman, 2000; Perry, Blacklock, & Dunn Geier, 2013). In 2000, Harris & Handleman looked

---

[7] Early Intervention is classified by IDEA as any special needs services administered between 0-3 years old.

at 27 children with ASD (according to DSM-III-R criteria) between the ages of 2 and 5 who had IQs between 35 and 109 according to the Stanford-Binet Intelligence Scale[8]. The children were treated at the Douglass Developmental Disabilities Center with Applied Behavior Analysis and followed up 4-6 years after they left the preschool program to see how many students were in regular education classrooms. The results showed that two factors were significantly predictive of students being in regular classrooms: IQ at intake and age at intake. Specifically, results were better for children with higher IQs (*M*=78) and for those who entered treatment before age four (*M*=42). The study by Harris and Handleman, as well as the others listed above, speak to the importance of early and effective treatment well before age five for improving long-term outcome and thus, quality of life.

Besides germane intervention, there are other factors at play in how children with autism are ultimately able to function as adults. First, just as an individuals IQ is predictive of response to intervention, IQ has consistently been shown to be predictive of long-term outcome (Levy & Perry, 2011). Howlin et al. (2004) found that the crucial cut-off point in IQ appeared to be around 70, with very few individuals scoring below this level as children achieving any real degree of independence as adults. Similarly, both language ability and socialization skills have also been shown to be influential in long-term outcome. Farley et al. (2009) had two significant findings pertinent to the current investigation. First, poorer adaptive function was significantly associated with poorer social functioning in adulthood. Second, this poorer social functioning in adulthood was correlated with a greater need for high levels of support from caregivers and social service agencies.

---

[8] The Stanford-Binet Intelligence Scale is a cognitive ability and intelligence test that is used to diagnose developmental or intellectual deficiencies in young children.

The Individuals with Disabilities Education Act (IDEA)

As the prevalence of ASD has continued to rise, so to has the number of children needing special services in public school classrooms. Between 1976 and 2011, the number of children qualifying for special education supports nearly doubled, rising from about 3,694,000 to 6,419,000. During this same time period, the number of children being served under specifically an autism diagnosis quadrupled, surging from 94,000 to 455,349 (U.S. Department of Education, 2013). This has created a greater demand for legislation and policies that dictate how schools approach education with these individuals. The Individuals with Disabilities Education Act (IDEA), first enacted in 1975 and last revised in 2004, requires schools to serve the educational needs of students with disabilities appropriately under penalty of law. Before IDEA, more than 5 million children with special needs did not have access to an appropriate public education, and in some cases were denied access to public schools entirely (Katsiyannis, Yell, & Bradley, 2001). Today IDEA serves as the federal governing doctrine on how to provide special education and related services to 6.5 million children with disabilities (U.S. Department of Education, 2013).

To qualify for services under IDEA, the child must meet the eligibility criteria in one of thirteen qualifying disabilities *and* require special education services because of the disability. In other words, to be fully eligible for services, a student must have a disability that adversely affects her or his educational performance and must also need special education in order to receive an appropriate education. IDEA provides very specific requirements to guarantee a Free and Appropriate Public Education (FAPE) for students with disabilities in the Least Restrictive Environment (LRE). In order to be in compliance with FAPE, states' education programs for students with disabilities must meet the disabled students needs to the same extent and as adequately as the needs of nondisabled students. Furthermore, LRE dictates that students with disabilities and students without disabilities must, to the maximum extent possible, be placed in the same setting while maintaining appropriate support of the educational needs of each student. Additional stipulations are that all teachers be “highly qualified” (as defined in IDEA) and that teachers use evidence–based programs and activities.

Individualized Education Plan (IEP)

Once a student has been formally evaluated by the school or a professional and found to be eligible for special education services, the school’s plan to meet the requirements set forth in IDEA must be explicitly outlined in what is called an Individualized Education Program (IEP). The IEP is a highly individualized plan for the child’s educational objectives created by a team invested in the child’s educational success. This team consists of the parent(s) as well as the following:

1. A school administrator to manage the meeting and ensure IDEA requirements are met
2. A special education teacher to provide guidance on appropriate instruction
3. A regular education teacher to provide insight on the school's general education requirements and how the child's needs will be met
4. A school psychologist or other evaluation professional to discuss appropriate evaluations and to explain results
5. Any related service providers such as a speech pathologist, occupational therapist, mental health professional, or physical therapist, if the child’s IEP may require such services
6. A guidance counselor to assist with curriculum as it pertains to any counseling issues that may be present

The IEP describes how the student learns, how they demonstrate that learning, and what teachers and other service providers will do to help the student learn more effectively. This must include current school performance, guidelines about expected level of achievement and measurable goals, the plan for how the student will meet these educational goals over the following year, as well as how the student will be participating in the general education curriculum (i.e. their accommodations). An IEP must be developed before a student can begin receiving special education services. IDEA mandates that IEPs be reviewed and updated a minimum of every year for as long as the student remains eligible for special education services.

The guidelines set forth by IDEA provide children with legally protected rights in all 50 states. If a parent feels that the school is failing to comply with these regulations in any regard, they also have the right under IDEA to challenge the school legally. Since its implementation in 1976, IDEA has continued to gain influence and now serves almost twice as many children as when it was first enacted. However, there is still much progress to be made. Parents of children with ASD are 3.4 times more likely to experience difficulty in obtaining services than parents of other children with special needs, and 2.65 times more likely to be dissatisfied with services received (Montes, Halterman, & Magyar, 2009). In order to make successful strides towards improving access to and quality of services for children with Autism, all disparities in access to these services must first be thoroughly investigated and understood.

Disparities

Autism affects all races, ethnicities, and social classes of the world. However, evidence has emerged indicating that racial, ethnic, and socioeconomic disparities exist in terms of diagnosis, access to and use of services, and quality of outcome for children with ASD.

Racial and Ethnic Disparities

Race and ethnicity have been correlated with later diagnosis, misdiagnosis, and diminished usage of services for ASD. Valicenti-McDermott et al. (2012) found that children of Hispanic and African American origin, foreign-born children, and children born to foreign mothers were more likely than Caucasians to be diagnosed after the age of 4. These findings persisted even after the researchers adjusted for other demographic factors such as maternal education, bilingualism, maternal country of origin, medical insurance, clinical characteristics, and family history. David S. Mandell, Listerud, Levy, and Pinto-Martin (2002) found that African-American children with autism were diagnosed an average of 1.4 years later than Caucasian children and spent and average of eight more months with mental health professionals before receiving a diagnosis. Furthermore, in a follow up study, David S. Mandell, Ittenbach, Levy, and Pinto-Martin (2007) found that minority children were 2.6 times more likely to be initially misdiagnosed than Caucasian children. Findings also show that cultural and racial differences influence the quality and quantity of services (Liptak et al., 2008; David S. Mandell & Novak, 2005; Montes et al., 2009; K. C. Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Furthermore, these race and ethnic differences tended to be most salient in lower socioeconomic brackets (Liptak et al., 2008).

Socioeconomic Disparities

Socioeconomic status (SES) contributes to disparities in access to services for individuals with Autism. Typically defined by parental education and family household income, there is evidence of socioeconomic disparities in age of diagnosis, access to and use of services, and quality of long-term outcome. Durkin et al. (2010) and King and Bearman (2011) found higher rates of diagnosis of ASD in higher SES groups and argued that this finding suggests that lower

SES populations have poorer access to diagnostic services. This conclusion is supported by related literature investigating the effect of child and family factors such as parental education, race, income, etc. on the age of diagnosis and satisfaction with the diagnostic process (Fountain, King, & Bearman, 2011; Goin-Kochel, Mackintosh, & Myers, 2006; D. S. Mandell, Novak, & Zubritsky, 2005; P. Thomas et al., 2012). Higher SES levels were associated with earlier detection and higher satisfaction levels. Researchers have also investigated access to and usage of intervention services and found SES differences in both which services are used and how many hours of services children receive (Irvin, McBee, Boyd, Hume, & Odom, 2012; K. Thomas et al., 2007; K. C. Thomas et al., 2007). Finally, SES appears to influence treatment outcomes. For instance, Ben Itzchak and Zachor (2011) found that higher maternal education was predictive of larger cognitive gains both with and without intervention.

Methodology

Purpose

Of particular interest in the present study are the relationships between race and SES in access to intervention services in Georgia. Specifically, the current investigation used a cross-sectional design with a convenient sample of participants and assessed the number, hours, and types of services that children with ASD utilized. Also of interest were any racial and/or SES (e.g., maternal education; family household income) differences among all measures (see below). The hypothesis is that those children of minority race and/or Lower SES will receive fewer services and thus be at a greater risk for poorer long-term outcome. An additional aim of this study on a subset of participants will be to ascertain what types of barriers families may have experienced in pursuing services for their children both when initially seeking services after diagnosis and during the last year. Both special education services offered through the school and private services outside of school were assessed. Barriers included were anything from simple things like transportation to more complex factors such as insurance problems.

Participants

The study sample consisted of 52 Georgia school-age children ages 4-18. Subjects were identified from previous Marcus studies based upon whether the child had an official diagnosis of Autism Spectrum Disorder and was of school-age at the time of assessment The sample consisted of 32 males and 20 females (*mean age* = 111.65 months, *min* = 52.83, *max* = 208.22, *sd* = 40.10). Thirty-four of the participants were African-American (65.4%) and 16 were Caucasian (30.8%). Two participants (3.8%) self-identified themselves as more than one race.

The high concentration of African-Americans is likely a result of one of the school-age studies from which participants were identified having been strictly for African-American subjects.

An additional 10 participants whose parents had consented to be re-contacted by the Marcus Autism Center about future research were interviewed. The mean age of this subset of participants was 118.35 months (*min* = 51, *max* = 210, *sd* = 64.651), 8 were male (80%) and 2 were female (20%), all were African American, and none were Hispanic or Latino.

Measures

The following measures were used to assess access to services, cognitive functioning, and barriers encountered by families.

Parent/Caregiver Questionnaire

(PCQ; developed by investigators at the Marcus Autism Center)

Selected items from Parent/Caregiver Questioner were analyzed. Variables of interest were:

1. Number of services currently being received (i.e. how many types of services are being received; range 0-8)
2. Type of services currently being received (which services are being received, i.e. Speech Therapy, Occupational Therapy, Physcial Therapy, Play Skills Therapy, Social Skills Therapy, Adaptive skills Therapy, Special Education, Other)
3. Time spent in these services (hours/week)
4. Age at first concerns (months)
5. When the child was first identified having special needs (months)

Family Demographics Questionnaire

(developed by investigators at the Marcus Autism Center)

Maternal Education and Household Income were extracted from the Family Demographics Questionnaire. Maternal education was re-coded as “Some college or less”, “Completed college” and “More than college” on a scale of 0-2. (Income was coded on a scale of 1-7, with 1 being equal to $20000 or less and 7 being equal to $150001-200000. To compute a measure of overall SES, the scaled values for Maternal Education and Income were summated for a final value between 0 and 9. This composite score was then dichotomized into Low SES (0-4) and High SES (5-9).

Differential Ability Scales, Second Edition

(DAS-II; Elliott, 2007)

The DAS-II is a measure of cognitive functioning that has an Early Years Battery for preschool-aged children and a School Age battery for children ages 5 to 18. It yields standard scores for verbal (VIQ), nonverbal NVIQ), and spatial cognition and an overall General Conceptual Ability score (GCA) that have a mean score of 100 and a standard deviation of 15. For this study, following standard scores for VIQ, NVIQ, and GCA were analyzed on all participants who received the PCQ measure.

Autism Diagnostic Observation Schedule, Second Edition - Calibrated Severity Score

(ADOS CSS; Gotham, Pickles, & Lord, 2009; Lord et al., 2012)

The Autism Diagnostic Observation Schedule, Second Edition, is a semi-structured assessment for evaluating autism spectrum disorders that captures social interaction, communication, and play or imagination/creativity as well as repetitive behaviors and restricted interests. Researchers administered one of four different modules depending on the age and language abilities of the individual with ASD. Two domain scores are returned: social affect and restrictive and repetitive behavior, and a total score. Research-trained and reliable administrators administered ADOS assessments. For this study, a recently developed algorithm that allows for the comparison of scores across different modules administered was used called the Calibrated Severity Score (CSS). Values for the ADOS CSS range from 0-10, with higher scores signifying more severe autism symptomatology (Gotham et al., 2009).

Vineland Adaptive Behavior Scales, Second Edition, Survey Form

(Sparrow, Cicchetti, & Balla, 2005)

The Vineland-II is a widely used measure of adaptive functioning commonly used in autism diagnostic evaluations due to significant impairments in adaptive functioning observed in the disorder (Mean=100; SD=15). The Vineland standard scores in this study reflect three areas of adaptive functioning: Communication (adaptive receptive, expressive, and written communication skills), Daily Living Skills (domestic, personal, and community skills), and Socialization (adaptive interpersonal, play/leisure, and coping skills).

Interview on Barriers to Services

An additional aim of this study involved interviewing a small subset of participants to explore what types of barriers families have faced in gaining access to services in-school and privately. With approval from the Emory Internal Review Board to contact families who had previously given consent to be re-contacted by Marcus for future research studies, 13 families were interviewed (see Appendix C). After verbal consent was granted over the telephone, participants completed a 30 minute phone interview that used questions modeled after the Event History Calendar Interview (EHCI; developed by Washington University, St. Louis, and used in a grant investigating human diversity in autism). Of interest were barriers that parents may have experienced while seeking services both a) during the last year (i.e. 2014) and b) when the child was first diagnosed with ASD. Specific barriers addressed during the interview were: Wait time to get an appointment, Cost of services, Availability of services in your area, Poor quality of services, Scheduling conflicts, Transportation, Insurance problems, Finding time to attend appointments, Language Barriers, Misunderstandings that may have resulted from cultural differences between you and the clinician, and a comments section for any other problems that had not already been specifically mentioned. Parents were also asked to comment on what resources they found to be most helpful. Responses were recorded and assessed qualitatively.

Statistical Analyses

The following analyses were completed using the IBM developed Statistical Package for the Social Sciences (SPSS) version 22 for Macintosh.

Sample Composition, Descriptive Statistics, and Correlations

The first stage of analysis will involve describing the sample composition and generating descriptive statistics for variables pertaining to cognitive and adaptive functioning and severity of autism symptomatology. Additionally, a series of correlation tests were run to identify noteworthy correlations between variables ($\alpha = .05$).

General Access to Care

Analyses assessing general access to care within the sample as a whole were performed. Descriptive statistics pertaining to total number, total cumulative hours, and type of services received will be computed. To determine if participants received sufficient services, a one sample T-Test was used to compare total cumulative hours to the NRC's recommendations of 25 hours per week (α = .05). In addition, frequencies for total number of services were generated. To assess whether services received were appropriate, frequencies were generated for each specific therapy type reported. Also of interest in assessing general access to care was the child's age at parents' first concerns and the child's age when they were first identified as having special needs.

Disparities

Three sets of analyses were used determine if racial or socioeconomic disparities existed in usage of services, severity of autism symptomatology, and cognitive and adaptive functioning. The first set of analyses used One-way ANOVA's to assess effects within the full sample of race alone and then SES alone (α = .05). The second set of analyses involved first splitting the data set by SES (low vs. high). Then a one-way ANOVA was used to look at the effect of race within each of these SES groups separately (α = .05). The third set of analyses split the data set by race (African American vs. Caucasian) and used a One-Way ANOVA to look at the effects of SES within each racial group separately (α = .05).

Barriers to Services

Descriptive statistics were used to look at what types of barriers are most often encountered by families in their pursuit of services. Parents' comments on what resources were helpful were assessed qualitatively.

Results

Descriptive Statistics and Important Correlations

As mentioned, the overall sample of 52 participants with ASD ranged from age from 52.83 to 208.22 months (*M* = 111.65, *sd* = 40.10), and was composed of 32 males (61.54%) and 20 females (38.46%): Participant breakdown by race was as follows: 30.77% were Caucasian; 65.38% African American; 3.85% Mixed Race. Mean Verbal IQ was 81.95 (*sd* = 32.48); Mean Nonverbal IQ was 88.15 (*sd* = 26.63); and Mean General Conceptual Ability Score was 87.06 (*sd* = 28.21). Mean Vineland-II Standard Scores were as follows: Communication, *M* = 71.96, *sd* = 15.26; Socialization, *M* = 65.90, *sd* = 11.51); and Daily Living Skills, *M* = 73.66, *sd* = 13.51. Mean ADOS CSS score was 7.61 (*sd* = 2.01) with scores ranging from 3 to 10. Maternal Education was divided into three categories, some college or less, completed college, and more than college (0-2). Total Household Income consisted of 8 categories ranging from $20,000 or less to $150,000-200,000 (0-7). After using a dichotomized composite of these variables to determine SES level, 67.6% of my sample fell into the low SES category and 32.4% fell into the High SES category. Of note, a cross-tabulations analysis found a significant relationship between SES Level and Race such that 80.8% of African Americans fell into the Low SES group, *p* = .018, FET.

Because lower VIQ is indicative of a greater need for speech and language therapy, a correlation test was run to determine if VIQ and number of speech and language hours were correlated. Results were significant, *r* (34) = -.376, *p* = .024, two-tails.

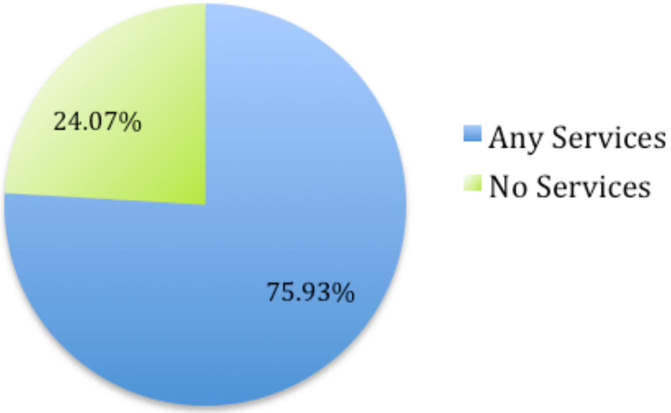
Total number of services (*M* = 1.58, *sd* = 1.27) was correlated with severity of autism symptomatology (*r* (46) = .318, *p* = .032, two-tails) and with Vineland Communication scores, *r* (50) = -.301, *p* = .034, two-tails.

General Access to Care

Number of Services

Most children were receiving one service (*f* = 16), followed by two (*f* = 14). Eleven out of the 52 participants were not receiving any services at all (see Figure 1).

Figure 1: Percentage of Participants Getting Services



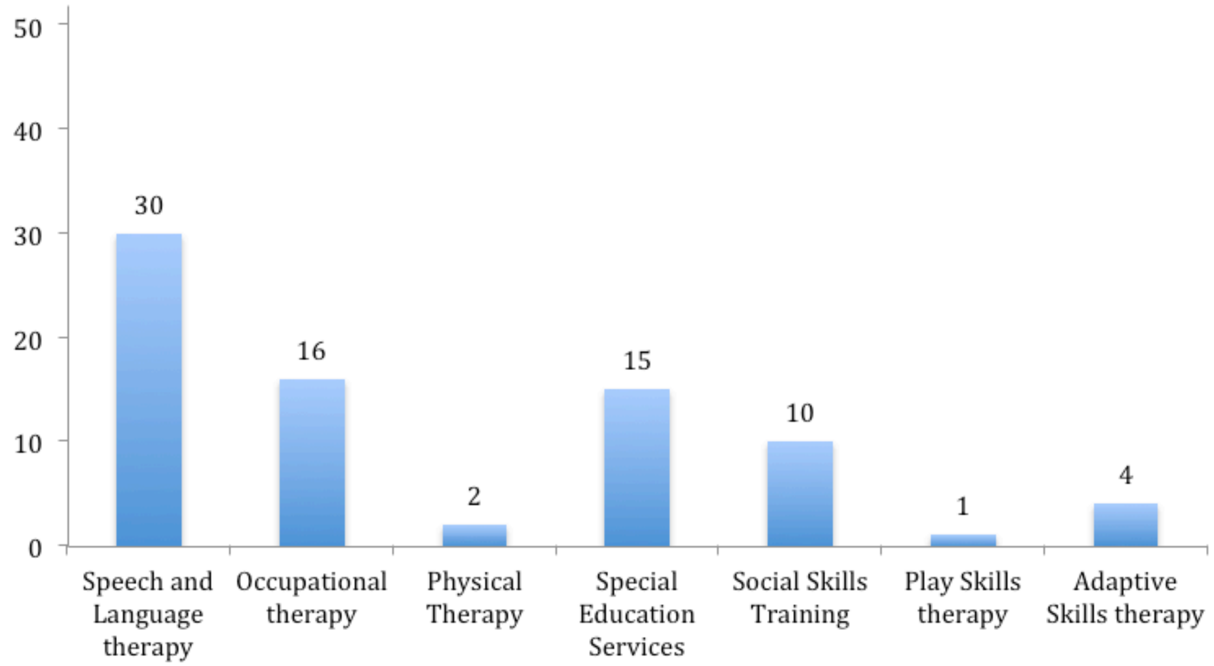
Total Cumulative Hours

A one-sample T-test comparing total cumulative hours of services per week ($M = 7.83$, $sd = 14.62$) with the NRC's (2001) recommendation of 25 hours per week revealed a significant difference between the expected (i.e. recommended) and actual observed mean, $t(52) = -8.473$, $p < .001$. Sixty-six percent of the sample was receiving 5 hours of services or less.

Type of Services

Frequencies were generated for type of services (see Figure 2). The most commonly received services were speech therapy, followed by occupational therapy, and then general special education services.

Figure 2: Frequency of Service Use by Type



Further Investigations of Access to Care

Further descriptive statistics revealed that the average age of first concerns was 24.62 months (*sd* = 18.77) and the average age of identification of any special needs was 46.18 months , *sd* = 27.58. Furthermore, children on average went almost 2 full years between when their parents were first concerned and when they were identified as having any special needs, *M* = 24.214, *sd* = 3.98 (see Table 1).

Disparities

Full Sample

When using an ANOVA to look at differences between African American and Caucasian participants across the sample as a whole, race was found to have significant main effect on DAS

Verbal IQ (*F*(1, 33) = 5.085, *p* = .031), Vineland Communication (*F*(1, 45) = 5.912, *p* = .019), and Vineland Socialization (*F*(1, 45) = 6.125, *p* = .017), with African American children scoring lower on all measures compared to Caucasian children (See Table 1). A trend was found in speech and language total hours, with African American children receiving more speech therapy than Caucasians children, *F*(1, 44) = 3.496, *p* = .069. Because Verbal IQ was correlated with speech and language hours in this sample, an ANCOVA was run to control for the effect of Verbal IQ, and the trend between race and speech and language hours disappeared, *F*(1,31) = .545, *p* = .466.

Table 1: Race Disparities Across the Full Sample

Variable	Race	*n*	Mean	*sd*	*p-value*
DAS Verbal IQ	Caucasian	15	97.27	31.363	**.031**
	African-American	20	73.8	29.788	
	Total	35	83.86	32.245	
DAS Non-Verbal IQ	Caucasian	15	97	29.238	.184
	African-American	29	85.62	25.039	
	Total	44	89.5	26.765	
Autism Symptomatology	Caucasian	13	7.23	2.488	.500
	African-American	30	7.7	1.878	
	Total	43	7.56	2.062	
Vineland Communication	Caucasian	14	80.29	21.309	**.019**
	African-American	33	68.73	11.309	
	Total	47	72.17	15.679	
Vineland Daily Living Skills	Caucasian	14	76.57	18.046	.415
	African-American	33	72.94	11.694	

	Total	47	74.02	13.783	
Vineland Socialization	Caucasian	14	72.21	14.37	**.017**
	African-American	33	63.42	9.513	
	Total	47	66.04	11.74	
Speech & Language Total Hours per Week	Caucasian	15	0.4	0.507	**.069***
	African-American	31	0.9	0.978	
	Total	46	0.74	0.88	
Total Number of Services	Caucasian	16	1.63	1.628	.902
	African-American	33	1.58	1.119	
	Total	49	1.59	1.29	
Total Cumulative Hours	Caucasian	16	4.63	11.366	.245
	African-American	33	9.97	16.301	
	Total	49	8.22	14.964	

Note: Significant values are indicated in red (α=.05)
* Indicates a trend

To determine if SES alone impacted measures of functioning or access to care in the full sample, another one-way ANOVA was used. Analyses revealed no significant differences between SES groups on measures of cognitive and adaptive functioning, ASD symptom severity, or usage of services.

Finally, ANOVA's looking at the individual effects of race and of SES on age of first concerns and age of identification as having special needs yielded no significant findings (see Tables 1 and 2).

Table 2: Age Variables by Race

	Total Sample			African American			Caucasian			
	N	Mean	*sd*	*n*	Mean	*sd*	*N*	Mean	*sd*	*p*
Age	52	111.65	40.10	33	116.23	39.04	16	103.98	42.24	.321
Age of First Concerns (in months	50	24.62	18.77	31	25.94	22.12	16	21.94	12.41	.508
Age at Identification of Spec. Needs	44	46.18	27.58	29	48.28	29.02	13	42.15	26.89	.522
Time Between	42	24.21	3.98	27	26.296	28.78	13	21.15	21.02	.570

Notes: Ages are in months

Table 3: Age Variables by SES Group

	Total Sample			Low SES			High SES			
	N	Mean	*sd*	*n*	Mean	*sd*	*n*	Mean	*sd*	*p*
Age	37	111.32	38.83	24	111.45	35.03	12	111.04	47.52	.977
Age of First Concerns (in months	36	23.58	18.01	24	26.21	20.75	12	18.33	9.31	.221
Age of Identification of Spec. Needs	33	19.12	30.14	23	50.96	34.59	10	44.90	16.62	.604
Time Between	32	27.188	28.44	22	27.41	32.52	10	26.70	17.81	.949

Notes: Ages are in months

Within Groups

In order to examine the impact of race within specific SES groups on levels of functioning and access to services, the sample was split by SES level (low vs. high) and then an ANOVA was used to observe racial differences within each SES group separately (See Table 3). For analyses at this level, the two individuals who had self identified as “more than one race” were removed from the data set due to there being so few cases. Within the Low SES group, significant differences in race were found for DAS Verbal IQ (*F*(1, 13) = 5.527, *p* = .035) and Vineland communication scores (*F*(1, 23) = 5.494, *p* = .028) with African American children having significantly lower VIQ and Vineland Communication scores. No significant racial differences were observed for autism symptomatology. The significant findings between races in the Low SES group were not observed in the High SES group.

Table 4: Participant Characteristics by SES Group then Race

	Low SES (n=25)					High SES (n=12)				
		n	Mean	*sd*	*p*		*n*	Mean	*sd*	*p*
DAS Verbal IQ	White	4	107.75	4.856	.035	White	7	93.14	31.672	.253
	Black	11	76.00	26.237		Black	4	68.25	34.131	
DAS Non-Verbal IQ	White	4	102.00	17.378	.248	White	7	87.14	29.328	.642
	Black	18	87.17	23.345		Black	5	79.40	24.765	
Vineland Communication	White	4	83.25	7.762	.028	White	5	80.40	16.832	.414
	Black	21	67.95	12.472		Black	5	72.60	11.238	
Vineland Socialization	White	4	72.50	6.245	.125	White	5	67.60	5.177	.707
	Black	21	64.19	9.968		Black	5	66.20	6.140	
Vineland Daily Living Skills	White	4	76.75	5.315	.800	White	5	73.40	9.127	. 277
	Black	21	75.10	12.550		Black	5	67.20	7.629	
ADOS-CSS (Autism Symptomatology	White	4	8.50	2.380	.576	White	5	8.00	2.345	.274
	Black	19	7.89	1.853		Black	5	6.40	1.949	
Speech and Language Total Hours per Week	White	4	.50	.577	.447	White	6	.33	.516	.880
	Black	19	.84	.834		Black	5	.40	.849	
Total Cumulative Hours per Week	White	4	.25	.500	.321	White	7	4.71	11.176	.740
	Black	21	9.67	18.230		Black	5	6.80	9.203	

Total Number of Services	White	4	1.50	1.291	.907	White	7	1.71	2.059	.624
	Black	21	1.57	1.076		Black	5	1.20	1.095	

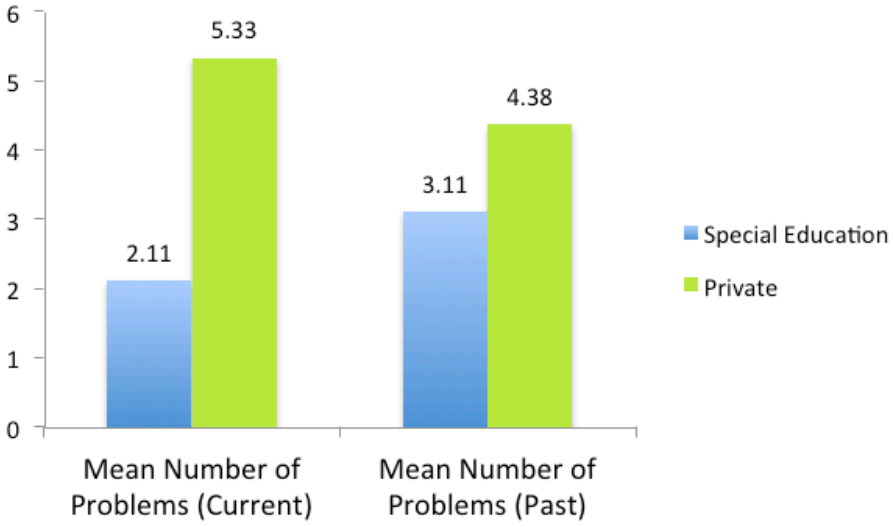
Note: Significant values are indicated in red (α=.05)

In order to examine the data in a slightly differently way, the sample was instead split by race (i.e., African American vs. Caucasian children), and then an ANOVA was used to examine the impact of SES level within each race separately. No significant differences were found when data were analyzed in this way.

Barriers to Services

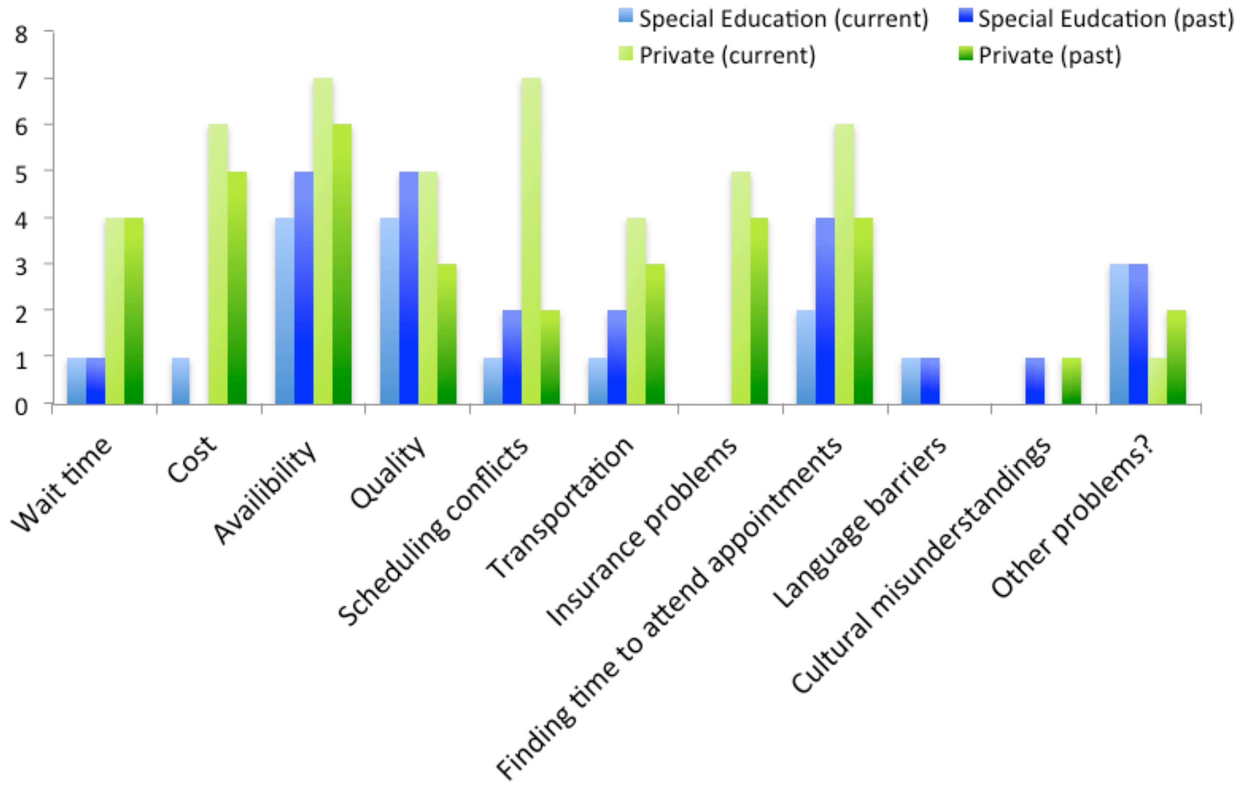
The data gathered from the phone interviews revealed that all 10 participants experienced some difficulty accessing services both in the past and in the last year. On average, during the last year participants encountered *M* = 2.11 (*sd* = 1.69) difficulties with special education services, but twice that number of difficulties with private providers, *M* = 5.333, *sd* = 2.96. When asked about their experiences after their child's initial diagnosis, parents reported *M* = 3.11 (*sd* = 2.32) difficulties with special education providers and *M* = 4.375 (*sd* = 2.20) difficulties with private providers (see Figure 3).

Figure 3: Mean Number of Total Problems Experienced By Provider



Parents reported more problems in accessing private services than special education services for 7 out of the 11 categories of barriers (see Figure 4).

Figure 4: Frequency of Participants Experiencing Difficulties by Provider and Problem Type



Regardless of time period (i.e. Current or past), the two most frequently reported problems specifically for special education services differed slightly from the two most frequently reported problems specifically for private providers (see Table 5). The two most frequently reported problems for private and special education services together, both for the past and during the last year, were availability of services in the area and quality of services offered (See Table 5). As for resources, parents reported the following to be most helpful: other parents, support groups, and the Internet. One parent specifically referred to a list of services and providers that was given to her by the Marcus Autism Center.

Table 5: Total Frequencies of Problems by Time Period and Provider

Total Frequencies	Wait time	Cost	Availability	Quality	Scheduling Conflicts	Transportation	Insurance Problems	Finding Time to Attend Appointments	Language Barriers	Cultural Misunderstandings	Other Problems?
Special Ed and Private (Current)	9	10	**15**	**13**	12	8	8	12	1	0	6
Special Ed and Private (Past)	8	7	**13**	**10**	6	7	6	9	1	2	7
Special Ed (Current and Past)	3	1	**11**	**11**	4	3	0	7	2	1	9
Private (Current and Past)	14	**16**	**17**	12	14	12	14	14	0	1	4

Note: Red bolded values represent the two highest frequencies for the row variable

Discussion

Results of this study reveal that in a sample of school-aged children with ASD who were participating in research at the Marcus Autism Center in Atlanta, Georgia, significant differences were observed in verbal language and communication levels of African American children of low socioeconomic status compared to Caucasian children. Furthermore, African American children had more cognitive and adaptive deficits, though they also received more speech therapy services. These racial differences were not observed in children of higher socio-economic status. Of note, no differences in nonverbal cognition or autism symptomatology were observed between groups by race or SES.

Research Question #1: General Access to Care

Examination of general access to care revealed that most children were only receiving either one or two different services; 24% of the sample received no services at all. Furthermore, with the average number of service hours settling at about 8 per week, and the majority receiving less than 5 per week, the children in this sample were receiving significantly fewer hours than the NRC's recommended 25 hours per week (2001). This finding could be a result of sample bias primarily because it consisted of school-aged children ranging from 4 to 18 years old, and given the push in recent years for early intensive intervention, it is possible that participants had received more services when they were younger.

Finally, while many children were receiving speech therapy or occupational therapy, there was a general lack of participants using autism specific services such as social skills therapy ($f = 10$) and adaptive skills therapy ($f = 4$). These findings are consistent with the literature (White, Scahill, Klin, Koenig, & Volkmar, 2007). There are a couple explanations for why this pattern appeared in the data. Parents could have been less familiar with some of the more informal school-based interventions, such as lunch-bunch groups for social skills. However, it also possible the schools simply did not have the resources or training to deliver these types of autism-specific intervention. Therefore, this may be an area of unmet need in the present sample. Furthermore, the much higher frequency of speech therapy compared to other services suggests that while cognitive-specific services that are commonly used by children across many different disabilities may be fairly accessible, parents struggled to access Autism-specific services. Moreover, this could also indicate that educators weigh cognitive deficits more heavily than deficits in other areas of functioning (e.g. social and adaptive) when determining programming and accommodations.

On average, children in the sample were not identified as having special needs until they were nearly 4 years old, which is after the window of opportunity for most effective early intervention. Yet, the parents' first concerns emerged at 24 months, a full two years earlier, when professionals are increasingly able to reliably and accurately diagnose ASD. The gap between parent's first concerns and diagnosis is consistent with the literature (Sivberg, 2003; Valicenti-McDermott et al., 2012). It is important to note here that while the variables of age of first concerns and age at identification of having special needs are not a direct measure of when the child was specifically diagnosed with autism, they still speak towards the gap between first concerns and ASD diagnosis. Research has demonstrated that once a child (who is later diagnosed with ASD) has been identified as having special needs, they are typically given the ASD diagnosis shortly thereafter (Chawarska et al., 2007). This finding indicates that the early recognition and prompt diagnosis are areas still in need of improvement to provide quality care for children with ASD in Georgia.

Research Question #2: Racial and Socioeconomic Disparities

This particular sample did not show racial or SES disparities in terms of access to care. However, other fundamental differences between racial subgroups indicate that this lack of a finding may yet be indicative of a disparity in access to care. Within the sample as a whole, being African-American presented as a risk factor for more severe cognitive and adaptive deficits. The trend showing that African Americans received more speech and language therapy hours than Caucasians suggests that the extra cognitive deficits in verbal IQ may be at least partially met in their treatment packages. However, this trend did not persist into any other service categories. Thus, beyond Verbal IQ, significantly more severe deficits within this group may yet remain unaccounted for in their programming. One explanation is that schools simply lack the resources to meet the extra need in general, regardless of race, but that other underlying differences have made more severe cognitive and adaptive deficits more prevalent in the African American population. Alternatively, this could be indicative of a true racial disparity in access to services. In other words, the question becomes whether the extra need is unmet due to a lack of resources or due to an actual racial disparity in access to care.

On another note, as has already been discussed, certain childhood factors can have implications for the quality of life led in adulthood (Farley et al., 2009; Howlin et al., 2004; Levy & Perry, 2011; Paul & Cohen, 1984). Thus, the extra cognitive and adaptive deficits in the African American population translate into a greater risk for poorer long-term outcomes. Though the mean overall IQ for African Americans in the sample fell above 70, their mean VIQ was 73.80, falling just above crucial “turning point” for independence in adulthood (Howlin et al., 2004). Furthermore, deficits in childhood adaptive functioning have also been shown to be predictive of poorer long-term outcomes (Farley et al., 2009; Paul & Cohen, 1984). However, on a more positive note, the effect of race did not persist across measures of autism symptomatology. Nevertheless, because this population may be at higher risk for dependency and poorer quality of life as adults, their families and society as a whole may also be at higher risk of significant financial burdens. With these findings in mind, service providers should place an extra emphasis on fostering both cognitive and adaptive development during early and school-age years within the African American population.

Low SES by itself did not present as a significant risk factor for lower cognitive functioning, higher autism symptomatology, or disparate usage of services. However, within the Low SES group, race was again associated with significant differences. Specifically, being African American was associated with higher verbal cognitive and adaptive deficits (*viz.* lower verbal IQ and communication scores). These deficits persisted despite a much lower sample size for the within SES group analyses than the full sample race analyses described above. This speaks to there being more pronounced disparities in verbal IQ and communication scores that are above and beyond those of social functioning. However, within low SES groups, the trend in speech and language hours previously described was no longer present. In other words, while the verbal deficits remained in the low SES group, this deficit was not being accommodated with significantly more speech hours. This highlights the need for educators to pay especially close attention to low SES African Americans so that any demonstrated extra needs can be accommodated. On another note, that none of the previously described racial disparities persisted into the higher SES group could mean that higher SES acted as a protective factor against them. However, with 80% of the African Americans in this sample falling into the low SES group, it is difficult to discern whether it is the higher SES or the lower number of African Americans that truly wash-out effects in the high SES subset. To investigate this question further, SES effects were assessed within racial groups. However, no significant within-race SES relationships were observed, once more pointing to the presence of stronger racial rather than SES disparities in the sample.

Research Question #3: Barriers to Services

The phone interviews should be interpreted in the context of what barriers the at-risk African American population described in the previous section is facing in order to more efficiently determine how health care professionals and educators should move forward in their attempts to extinguish disparities in treatment. The parents that were interviewed reported that while state special education programs were prompt and relatively accommodating, the availability of quality programs in their area presented as their biggest obstacle. Several parents reported having relocated several times in search of satisfactory programs, sometimes moving across the country. In discussing whether they had pursued private providers, parents reported lengthy wait lists for appointments, high out-of-pocket costs, poor availability in their area, and questionable quality and legitimacy of services. Because private providers were so difficult to access, most parents in the sample relied entirely on school services, which is consistent with what has been reported in the literature. Taking these responses into consideration, it appears that at least within this Georgia sample, even families of high SES who were able to afford private services were dissatisfied with them.

When asked which resource had been most valuable to them when searching quality care, parents reported that they found other parents, support groups, and the Internet to be the most helpful. It is interesting that only one parent specifically referred to a list of services and providers that was given to her by the Marcus Autism Center. This indicates that after diagnosis, there may be a dramatic drop-off in communication between parents and health care professionals. This drop in communication could be having a two-sided effect. First, without professional guidance, parents may have more difficulty finding quality services for their children and may be more likely to fall prey to pseudo-science programming. This is especially pertinent in the unmonitored and less regulated private sector. Second, without feedback from the parents about their experiences with specific schools and private providers, professionals may not have up-to-date information with which to direct future families seeking help. Furthermore, if professionals are not aware of the specific challenges parents face, they cannot help the family overcome them.

Implications for Education and Concluding Thoughts

Many public schools in America are in a state of crisis as they are unable to meet national standards for student achievement in the regular classroom (Stevenson, 1994), never mind those in special education classrooms. With the rising number of school-age children presenting in public education settings with ASD diagnoses, schools resources are running dry and they are increasingly unable to meet these students' needs. In effect, state special education programs are becoming the junction of these two crises.

Protecting and serving the students caught at this intersection will require an interdisciplinary effort with a multifaceted plan of action. Health care professionals, community leaders, parents, and educators alike must come together to address the urgent need for advocacy and resources for children with autism, especially in populations at risk for disparate access to care or more severe deficits. Investing today in adequate services for children with autism, thus improving the long-term outcome and costs of care of tomorrow, must become a priority among health care professionals and in the educational institutions that are acting as the primary source of support for these children. Specifically, programs are needed that raise awareness, facilitate earlier referral and diagnosis, and prompt initiation of appropriate autism-specific interventions.

While the research shows that families need to have access to services *before* their child enters public school classrooms, due to the intensity, cost, and poor availability and quality of services, this can be very difficult. Moreover, the results of this study align with the literature cite that indicates many children are not diagnosed until after age 4, which again is past the age for maximum benefits from early intervention. In Georgia, the fact that a child must be 5 years old (60 months) by August 31st to enter a public school kindergarten program creates a significant gap between when children are being identified and when intervention is accessible. However, while it is generally agreed upon among professionals that early intervention is most effective, proper intensive intervention can still have positive results even after age five (Eikeseth et al., 2002). This highlights the need for quality autism-specific programs for children who missed the window for early intervention. In addition, there should be system-wide training in the schools, with a focus on programming specifically for social development and functional independence (i.e. adaptive skills).

Meanwhile, programs and campaigns, such as the “Learn the Signs” campaign launched by the CDC that raise awareness and inform professionals of the importance of ASD screening, will continue to play a vital role in facilitating earlier recognition of symptoms and prompt diagnosis. Families must be informed of risks and signs and pediatric healthcare professionals must be more receptive and attuned to parents’ earliest concerns. Begeer, El Bouk, Boussaid, Terwogt, and Koot (2009) found that only 8% of general pediatricians screened for ASD on a regular basis. Therefore, particular focus should be aimed at encouraging pediatric healthcare providers to screen regularly. At the same time, researchers must hone diagnostic instruments and improve the accuracy of diagnosis in very young children (i.e. 2 years old and younger) to reduce the risk of misdiagnosis.

Currently, the quality and accessibility of state-regulated early intervention programs vary widely. Some parts of the country that claim superior resources and care have become national hotspots for families who can afford to relocate. For most families though, relocation is not an option, which means that states must set high and more uniform standards in order to bring services to these families. The Marcus Autism Center, for example, has gained national recognition for its intensive and state-of-the-art approaches addressing issues that few other institutions have the resources to treat. This has brought many families from all over Georgia and the surrounding states to Atlanta in search of help. However, as a result, the waitlist has grown overwhelmingly long. In response, the Marcus Autism Center has begun pursuing "telemedicine" as a viable community option to bring diagnostic services and training to more people. If this initiative is successful, the Marcus Autism Center will be able to bring quality services to children who might otherwise never have received proper care. Nevertheless, there is still a need for more statewide and national community-viable options.

Additionally, federal legislation regulating special education programs across the country must recognize that the growing number of students presenting in classrooms with ASD will only continue to exhaust current resources more quickly, exacerbate racial and socioeconomic disparities, and allow children to fall further and further behind. White et al. (2007) demonstrated that children in special education programs with certain types of disabilities were able to transition into regular classroom settings with progressively larger numbers as they got older. However, the opposite trend was found for children with ASD. As children with autism moved through school, they fell further behind and moved further out of regular classrooms settings and into special education settings. In other words, the special education programs worked for children with disabilities other than autism. Reversing this trend requires educational policies dealing expressly with autism that mandate evidence-based, autism-specific interventions and monitor the equity of these services across racial and socioeconomic groups.

However, it must also be recognized that there is a limit of what can be expected from state special education programs that must cater to a growing number of children with a great variety of disabilities and deficits with very limited resources. Thus, it is important that access to quality private providers, who are able to compensate where state services fall short, is improved. Progress is already being made on this front. Across the United States, 40 states have already passed laws requiring insurance companies to cover autism-specific services such as diagnostic evaluations and behavioral intervention. On March 29th, 2015, Georgia took the next step to becoming the 41st state with insurance coverage for autism-specific services when the Senate passed Senate Bill 1, otherwise known as “Ava’s Law”. If signed into law, Ava’s law will require insurance providers in Georgia to cover up to $35,000 per year of costs related to autism evaluations, diagnosis, and intervention.

Finally, action also must be taken to address the barriers reported by the parents in this study. Of particular concern are those of availability and quality, as they were the most prevalent barriers reported. First and foremost, educators and other service providers need to work towards re-establishing the dialogue between parents and healthcare professionals who are knowledgeable of resources and how to access them. One way to do this would be to utilize opportunities presented by the resources already being used by caregivers (e.g. other parents, support groups, and the Internet) as a way to disseminate helpful information about services and providers. Furthermore, school administrators should establish annual workshops and programs in collaboration with credible service providers and healthcare professionals to keep their own special education faculty and staff up to date on available resources in the area and best-practice models. Finally, leaders in the fields of education and autism should work with leaders in the community to facilitate community campaigns and events that both raise awareness and provide a safe, comfortable space where educators, professionals, and parents alike can come together to share information and generate ideas.

Limitations

Research Questions #1 and #2

There are several limitations to this study. First, the sample itself was not a true reflection of the population as a whole. For example, while the literature indicates that boys are 5 times more likely than girls to have autism, the study sample only had 1.6 times the number of boys as girls. Furthermore, the racial composition of the sample also indicates that the sample may not be representative of the population.

In addition, the small sample size (*N=52)* created difficulty in the robustness of analyses assessing trends within subsets of the sample (e.g. race trends within low vs. high SES groups), since dividing the sample so many times often left only a handful of participants in some categories.

There are also some limitations within specific measures used in this first part of the study (RQ 1 and 2). The first measurement limitation comes in that the PCQ, developed by the Marcus Autism Center and used as the measure of service use, relied on parent report, which can be unreliable. Additionally, the way the question referring to services was formatted was not very clear, so some parents may have left the section blank or mostly empty simple out of confusion. Finally, while the PCQ measure was twice-entered and validated during data entry, because it is not a measure that was intended to be analyzed, the original researchers who administered the PCQ to families at the Marcus Autism Center may not have been conscientious of how well parents understood the question or how accurately/thoroughly the section was filled out. This was an unforeseen limitation that was beyond the control of the researchers in this particular study, but must be considered in weighing the validity of results in this study.

Second, the SES composite variable (which was ultimately dichotomized to form the two categories Low SES vs. High SES) used the sum of the scaled maternal education variable (0-2) and the scaled household income variable (0-7). Retrospectively, this created an inherent flaw in the variable that may have significantly impacted the results of this study. Specifically, because the scale used for maternal education (0-2) was smaller than the scale used for income (0-7), the SES composite variable did not evenly weighted (i.e. the influences of maternal education and household income were not equally represented). Therefore, in the SES analyses, any actual effects of maternal education may have been washed-out by a lack of effect in the household income variable, causing no significant findings to be returned. To understand the scope of this SES composite error, an attempt was made by the researchers in order to investigate the effect of just maternal education. However, extremely small sample sizes prohibited any interpretation results, thus were kept out of this report. Furthermore, by dichotomizing the SES composite variable via a mid-way split in order to maintain sufficient sample size in each subgroup, what was classified in this sample as "Low SES" may not be reflective of what would truly be considered such. For example, a composite score of 0-4 was classified as Low SES in this sample. Therefore, a participant receiving a scale of 4 could technically have been composed of a 0 maternal education score (less than college) but a 4 income score ($800001-$100000 per year household income). This limits what conclusions can truly be drawn about SES effects in the sample.

Research Question #3

Pertaining to the interviews that investigated barriers to services, one must keep in mind that the sample size was only $N = 10$, which makes it difficult to generalize these results to the overall population. Additionally, the sample was completely homogenous in respect to race, so no inferences can be made about barriers across different races.

In respect to the measures used, there is a limit to the conclusions one can draw about how barriers to services have changed over time. This is because while “current” barriers consistently referred to the year 2014, the year referred to in reference to “past” barriers varied between participants as it was considered a measure of barriers encountered when first seeking services after initial diagnosis.

Finally, it must be kept in mind that no comparative statistical analyses were run on the sample. The data was only interpreted qualitatively in terms of frequencies and means in order to get a general idea of what issues should be investigated further.

Future Research

Future research could take few different directions. First, there should be a focus on diagnosis and investigation into what is happening between the time of first concerns and when a diagnosis is given. One way to approach this would be to investigate the specific barriers and complications parents face when seeking diagnosis.

Additionally, in order to address the limitations of this study that were introduced with the dichotomized SES composite variable, future research should do two things. First, more specific information on household income and maternal education should be gathered. Second, any composite score that is computed should be sure equally weigh these variables. Third, it would be more accurate to use a continuous variable for total household income. Also of interest would be to investigate how trends change as you move across multiple SES levels. Specifically, it would be beneficial to determine at what point SES gains or loses predictive ability in terms of access to care. Researchers could then focus reforms to first eliminate any disparities present within populations most at risk. In addition to investigating disparities across multiple levels of SES, it will be important to investigate disparities in access to services across multiple levels of development—from early screening and detection, through diagnosis and intervention, and on into adult life.

Finally, researchers should further investigate the research questions posed in this study by collecting similar measures of access to services and barriers experienced, but with larger sample sizes that are more representative of the general population. Also of interest would be a wider range of therapies as well as a measure for the approach used (i.e. Applied Behavioral Analysis, Pivotal Response Training, etc.).

Appendices

Appendix A: Diagnostic Criteria for Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

  1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

  1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple

motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

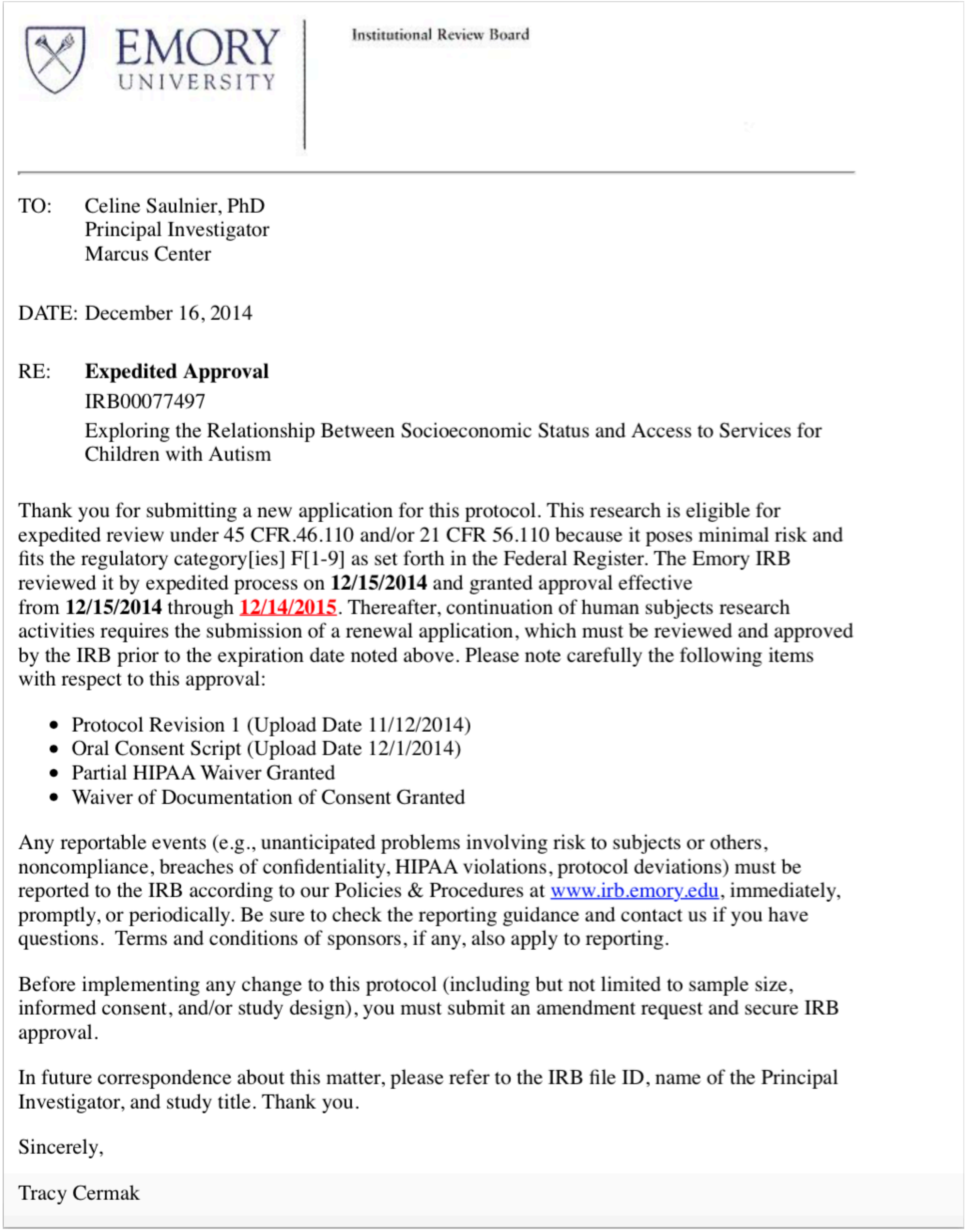
Specify if:

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
- (Coding note: Use additional code to identify the associated medical or genetic condition.)
- Associated with another neurodevelopmental, mental, or behavioral disorder
- (Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)
- With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table: Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support”	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support”	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

Appendix B: Emory Internal Review Board Approval



EMORY
UNIVERSITY

Institutional Review Board

TO: Celine Saulnier, PhD
Principal Investigator
Marcus Center

DATE: December 16, 2014

RE: **Expedited Approval**
IRB00077497
Exploring the Relationship Between Socioeconomic Status and Access to Services for Children with Autism

Thank you for submitting a new application for this protocol. This research is eligible for expedited review under 45 CFR.46.110 and/or 21 CFR 56.110 because it poses minimal risk and fits the regulatory category[ies] F[1-9] as set forth in the Federal Register. The Emory IRB reviewed it by expedited process on **12/15/2014** and granted approval effective from **12/15/2014** through **12/14/2015**. Thereafter, continuation of human subjects research activities requires the submission of a renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this approval:

- Protocol Revision 1 (Upload Date 11/12/2014)
- Oral Consent Script (Upload Date 12/1/2014)
- Partial HIPAA Waiver Granted
- Waiver of Documentation of Consent Granted

Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emory.edu, immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, and/or study design), you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you.

Sincerely,

Tracy Cermak

References

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, (DSM-5®)*: American Psychiatric Pub.

Autism Speaks. Glossary of Terms. Retrieved March 21, 2015, from https://www.autismspeaks.org/what-autism/video-glossary/glossary-terms

Autism's Costs to the Nation Reach $137 Billion a Year. (2012, April 02, 2012). Retrieved November 15, 2014, from Final_SimonA_4-13-15.docx

Begeer, S., El Bouk, S., Boussaid, W., Terwogt, M. M., & Koot, H. M. (2009). Underdiagnosis and Referral Bias of Autism in Ethnic Minorities. *Journal of Autism and Developmental Disorders, 39*(1), 142-148. doi: 10.1007/s10803-008-0611-5

Ben Itzchak, E., & Zachor, D. A. (2011). Who Benefits From Early Intervention in Autism Spectrum Disorders? *Research in Autism Spectrum Disorders, 5*(1), 345-350. doi: 10.1016/j.rasd.2010.04.018

Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and Toddlers With Autism Spectrum Disorder: Early Identification and Early Intervention. *Journal of Early Intervention, 32*(2), 75-98. doi: 10.1177/1053815110362690

Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA pediatrics, 168*(8), 721-728. doi: 10.1001/jamapediatrics.2014.210

CDC. "Signs and Symptoms". from http://www.cdc.gov/ncbddd/autism/signs.html

CDC. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010: Centers for Diesease Control and Prevention.

Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L. E., & Volkmar, F. (2007). Parental Recognition of Developmental Problems in Toddlers with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 37*(1), 62-72. doi: 10.1007/s10803-006-0330-8

Dawson, G. (2008). Early Behavioral Intervention, Brain Plasticity, and the Prevention of Autism Spectrum Disorder. *Development and psychopathology, 20*(03), 775-803. doi: 10.1017/S0954579408000370

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., . . . Schieve, L. A. (2010). Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study. *PLoS One, 5*(7), e11551. doi: 10.1371/journal.pone.0011551

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive Behavioral Treatment at School for 4-to 7-Year-Old Children with Autism a 1-Year Comparison Controlled Study. *Behavior modification, 26*(1), 49-68. doi: 10.1177/0145445502026001004

Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, J. C. (2012). Outcomes of Behavioral Intervention for Children with Autism in Mainstream Pre-school Settings. *J Autism Dev Disord, 42*(2), 210-220. doi: 10.1007/s10803-011-1234-9

Elliott, C. D. (2007). Differential Ability Scales®-l|(DAS-ll).

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., . . . Ritvo, R. A. (2009). Twenty‐year Outcome for Individuals With Autism and Average or Near‐Average Cognitive Abilities. *Autism Research, 2*(2), 109-118. doi: 10.1002/aur.69

Fountain, C., King, M. D., & Bearman, P. S. (2011). Age of Diagnosis for Autism: Individual and Community Factors Across 10 Birth Cohorts. *Journal of epidemiology and community health, 65*(6), 503-510. doi: 10.1136/jech.2009.104588

Frith, U., Soares, I., & Wing, L. (1993). Research into Earliest Detectable Signs of Autism: What Parents Say: Communication.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How Many Doctors Does it Take to Make an Autism Spectrum Diagnosis? *autism, 10*(5), 439-451.

Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS Scores for a Measure of Severity in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 39*(5), 693-705.

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at Intake as Predictors of Placement for Young Children with Autism: A Four- to Six-Year Follow-Up. *Journal of Autism and Developmental Disorders, 30*(2), 137-142. doi: 10.1023/A:1005459606120

Hess, K. L., Morrier, M. J., Heflin, L. J., & Ivey, M. L. (2008). Autism treatment survey: services received by children with autism spectrum disorders in public school classrooms. *Journal of Autism and Developmental Disorders, 38*(5), 961-971. doi: 10.1007/s10803-007-0470-5

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult Outcome for Children with Autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212-229.

Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and Family Factors Associated With the Use of Services for Preschoolers with Autism Spectrum Disorder. *Research in Autism Spectrum Disorders, 6*(1), 565-572. doi: 10.1016/J.Rasd.2011.07.018

Katsiyannis, A., Yell, M. L., & Bradley, R. (2001). Reflections on the 25th Anniversary of the Individuals with Disabilities Education Act. *Remedial and Special Education, 22*(6), 324-334. doi: 10.1177/074193250102200602

King, M. D., & Bearman, P. S. (2011). Socioeconomic Status and the Increased Prevalence of Autism in California. *Am Sociol Rev, 76*(2), 320-346. doi: 10.1177/0003122411399389

Kozlowski, A. M., Matson, J. L., Horovitz, M., Worley, J. A., & Neal, D. (2011). Parents' First Concerns of their Child's Development in Toddlers with Autism Spectrum Disorders. *Developmental neurorehabilitation, 14*(2), 72-78. doi: 10.3109/17518423.2010.539193

Levy, A., & Perry, A. (2011). Outcomes in Adolescents and Adults with Autism: A review of the literature. *Research in Autism Spectrum Disorders, 5*(4), 1271-1282. doi: 10.1016/J.Rasd.2011.01.023

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in Diagnosis and Access to Health Services for Children with Autism: Data From the National Survey of Children's Health. *Journal of Developmental and Behavioral Pediatrics, 29*(3), 152-160. doi: 10.1097/DBP.0b013e318165c7a0

Lockyer, L., & Rutter, M. (1969). A Five- to Fifteen-year Follow-up Study of Infantile Psychosis. *Br J Psychiatry, 115*(525), 865-882.

Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 Years of Age. *Arch Gen Psychiatry, 63*(6), 694-701. doi: 10.1001/archpsyc.63.6.694

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. (2012). Autism Diagnostic Observation Schedule, second edition. Torrance, CA: Western Psychological Services.

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in Diagnoses Received Prior to a Diagnosis of Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1795-1802. doi: 10.1007/s10803-006-0314-8

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children With Autism. *Journal of the American Academy of Child & Adolescent Psychiatry, 41*(12), 1447-1453. doi: 10.1097/00004583-200212000-00016

Mandell, D. S., & Novak, M. (2005). The Role of Culture in Families' Treatment Decisions for Children with Autism Spectrum Disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 11*(2), 110-115. doi: 10.1002/mrdd.20061

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors Associated with Age of Diagnosis Among Children with Autism Spectrum Disorders. *Pediatrics, 116*(6), 1480-1486. doi: 10.1542/Peds.2005-0185

Montes, G., Halterman, J. S., & Magyar, C. I. (2009). Access to and Satisfaction with School and Community Health Services for US children with ASD. *Pediatrics, 124*(Supplement 4), S407-S413. doi: 10.1542/peds.2009-1255L

National Research Council. (2001). *Educating Children with Autism.* . Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Ozonoff, S., Young, G. S., Carter, A., Messinger, D., Yirmiya, N., Zwaigenbaum, L., . . . Stone, W. L. (2011). Recurrence Risk for Autism Spectrum Disorders: a Baby Siblings Research Consortium Study. *Pediatrics, 128*(3), e488-e495. doi: 10.1542/peds.2010-2825

Paul, R., & Cohen, D. J. (1984). Outcomes of Severe Disorders of Language Acquisition. *Journal of Autism and Developmental Disorders, 14*(4), 405-421.

Perry, A., Blacklock, K., & Dunn Geier, J. (2013). The Relative Importance of Age and IQ as Predictors of Outcomes in Intensive Behavioral Intervention. *Research in Autism Spectrum Disorders, 7*(9), 1142-1150. doi: 10.1016/J.Rasd.2013.06.004

Shattuck, P. T. (2006). The Contribution of Diagnostic Substitution to the Growing Administrative Prevalence of Autism in US Special Education. *Pediatrics, 117*(4), 1028-1037. doi: 10.1542/peds.2005-1516

Shattuck, P. T., & Grosse, S. D. (2007). Issues Related to the Diagnosis and Treatment of Autism Spectrum Disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(2), 129-135. doi: 10.1002/mrdd.20143

Simpson, R., de Boer-Ott, S. R., Griswold, D., Griswold, D. E., Myles, B. S., Byrd, S. E., . . . Otten, K. L. (2005). *Autism Spectrum Disorders: Interventions and Treatments for Children and Youth*: Corwin Press.

Sivberg, B. (2003). Parents' Detection of Early Signs in their Children Having an Autistic Spectrum Disorder. *Journal of pediatric nursing, 18*(6), 433-439.

Sparrow, S. S., Cicchetti, D., & Balla, D. A. (2005). Vineland Adaptive Behavior Scales, Second Edition: Pearson.

Stevenson, H. (1994). *Learning Gap: Why our Schools are Failing and What We Can Learn from Japanese and Chinese Education*: Simon and Schuster.

Thomas, K., Morrissey, J. P., & McLaurin, C. (2007). Use of Autism-Related Services by Families and Children. *Journal of Autism and Developmental Disorders, 37*(5), 818-829. doi: 10.1007/S10803-006-0208-9

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to Care for Autism-Related Services. *Journal of Autism and Developmental Disorders, 37*(10), 1902-1912. doi: 10.1007/s10803-006-0323-7

Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2012). The Association of Autism Diagnosis with Socioeconomic Status. *autism, 16*(2), 201-213. doi: 10.1177/1362361311413397

U.S. Department of Education. (2013). Children 3 to 21 Years Old Served Under Individuals with Disabilities Education Act (IDEA), Part B, by Type of Disability: Selected years, 1976-77 through 2011-12. Digest of Education Statistics, Chapter 2: National Center for Education Statistics.

Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at Diagnosis of Autism Spectrum Disorders. *The Journal of pediatrics, 161*(3), 554-556. doi: 10.1016/J.Jpeds.2012.05.012

White, S. W., Scahill, L., Klin, A., Koenig, K., & Volkmar, F. R. (2007). Educational Placements and Service Use Patterns of Individuals with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 37*(8), 1403-1412. doi: 10.1007/S10803-006-0281-0