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AUTISM SPECTRUM DISORDER: THE ROLE OF RACE AND CULTURE IN PARENT
INTERPRETATION AND SERVICE UTILIZATION

A Dissertation presented in partial fulfillment of requirements for the degree of Doctor of
Philosophy in the Department of Clinical Psychology
The University of Mississippi

By

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September 2014

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ABSTRACT

Prevalence rates for autism spectrum disorder (ASD) suggest rates continue to increase, with recent data indicating 1 in 68 children diagnosed with the disorder. Interventions may prove beneficial for both the core symptoms of the disorder and related deficits, although data indicate that effects are stronger with early intervention (e.g., prior to four years old). Unfortunately, many children are undiagnosed until they are school age. Additionally, a number of findings indicate that in comparison to Caucasian children, African American children receive an ASD diagnosis later and less often. The current study examined the role of race/ethnicity on 119 mothers' knowledge about autism spectrum disorder, interpretation of symptomology consistent with ASD (e.g., labeling the child, level of concern, helpful services), attitudes towards mental health services, and trust in providers. Participants were exposed to a vignette of a child displaying typical developmental behavior, mild ASD symptomology, or moderate-to-severe ASD symptomology. Participants indicated their perception of the child's behaviors either as indicative of normal development, a medical disorder, a developmental disorder, an intellectual disorder, or an emotional disorder. Participants then completed measures of ASD knowledge, help seeking attitudes, and provider stigma. In comparison to Caucasians, African Americans displayed less ASD knowledge, were less able to identify a child with ASD symptoms as having the disorder, and held more biases toward medical clinicians. Inconsistent with previous studies, racial/ethnic differences were not found for attitudes of mental health stigma and help seeking intentions. Implications of findings are discussed.

DEDICATION

This dissertation is dedicated to the plethora of individuals who served as a pillar of support throughout my graduate school years. In particular, my parents and grandparents.

ACKNOWLEDGEMENTS

My deepest appreciation is extended to my family who rendered a great deal of emotional (and financial) support over the years. In addition, I'm so very thankful for my advisor for bearing with me through indecisiveness regarding topic choices and numerous document drafts. Lastly, I acknowledge other faculty members and a handful of close friends that became family and played a large role in my development

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CHAPTER 1: INTRODUCTION

Autistic disorder, a neurological disorder more commonly referenced as autism, was initially identified in 1943 (Kanner, 1943). Thought to be very rare, autistic disorder did not gain much attention from the general public until the 1990s. Due to increased awareness during this decade, children with an autism diagnosis became eligible to receive special education services under the Individuals with Disabilities Education Act (U.S. Department of Education, 2005). Compared to 1979, when it was estimated that 2 in 10,000 children met criteria for what was then categorized as autistic disorder, Asperger's disorder, or pervasive developmental disorder-not otherwise specified (PDD-NOS); in 2002 it was estimated that approximately 1 in 150 children in the United States met criteria for one of the disorders (Center for Disease Control and Prevention, 2007). Most recent estimates from the Center of Disease Control and Prevention (2014) suggest that prevalence rates have continued to increase; approximations of 1 in 68 American children having one of the three disorders indicate a 123% increase in diagnoses from 2002.

Autistic disorder, Asperger's disorder, and PDD-NOS, were previously considered to represent a spectrum because of similar symptom requirements; and were socially referenced as Autism Spectrum Disorders, or ASDs (Wing, 1997). Though the number of and severity of symptoms ranged across disabilities, an ASD diagnosis required social interaction and social communication impairments, and restricted and/or repetitive patterns of behaviors, interests, or activities (American Psychiatric Association, 2000). With the release of the most current Diagnostic and Statistical Manual of Mental Disorders, the DSM-5, the aforementioned disorders

are collapsed into one new diagnosis called autism spectrum disorder (American Psychiatric Association, 2013). Furthermore, the APA (2013) specifies that a diagnosis of autism spectrum disorder be given to those with prior diagnoses of autistic disorder, Asperger's disorder, or PDD-NOS.

Currently, the cause of autism spectrum disorder is unknown, although some evidence suggests that a genetic component is involved; and parental age, low birth weight, and fetal exposure to valproate may prove to be risk factors (APA, 2013; Inglese & Elder, 2009). There is no cure, and medication is not effective for core social, language, or the behavioral deficits characteristic of the disorder (Myers & Johnson, 2007). However, other forms of intervention can lead to long-term effects in cognition, expressive and receptive language, social skills, and behavioral deficits such as self-stimulation and tantrums (Myers & Johnson, 2007). Data suggests long-term outcomes are likely better when individuals with autism spectrum disorder receive interventions earlier in their development (Flanagan, Perry, & Freeman, 2012; Harris & Handleman, 2000).

Increases in skills and appropriate behaviors are also beneficial to the families of those with autism spectrum disorder. Studies indicate that parents of children with autism spectrum disorder have higher stress levels and mood disorder symptoms than parents of children with other disabilities or parents of typically developing children (Dumas, Wolf, Fisman, & Culligan, 1991). Parent distress correlates with both challenging behaviors and autism spectrum disorder symptomology, such that as symptoms and challenging behaviors decrease, parent stress levels decrease (Bromley, Hare, Davison, & Emerson, 2004).

Children as young as 18 months may show symptoms of autism spectrum disorder (Baghdali, Picot, Pascal, Pry, & Aussilloux, 2003; Chawarska et al., 2007; Davidovitch, Glick,

Holtzman, Tirosh, & Safir, 2006; DiGiacamo & Fombonne, 1998; Tolbert, Brown, Fowler, & Parsons, 2001; Werner & Dawson, 2005; Werner, Dawson, Munster, & Osterling, 2005), and it is possible to receive a diagnosis by the age of 3-years (Lord, 1995; Mandell, Novak, Zubritsky, 2005). Unfortunately, many children do not receive services and/or a diagnosis until they are of school age (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Studies suggest that socioeconomic status (SES), parents' education level, living area (urban/rural), and cultural factors may affect if a diagnosis is obtained, age at diagnosis, and/or service utilization (American Psychiatric Association, 2013; Fountain, King, & Bearman, 2011; Mandell, Novak, & Zubritsky, 2005; Mandell et al., 2009; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Even when SES is controlled for, some research indicates that African American children are diagnosed with autism spectrum disorder less often than Caucasian children (Jarquin, Wiggins, Schieve, & Naarden-Braun, 2011). Additionally, even after receiving a diagnosis, African American children are less likely to receive the same kinds of, and number of services (Thomas et al., 2007).

To date, few studies have explored specific reasons for African American children's later diagnosis and utilization of fewer services. Hypothesized explanations include practitioner bias, parents' decreased knowledge about the disorders and interventions, financial barriers, and cultural factors (Fountain et al., 2011; Jarquin et al., 2011; Mandell et al., 2002; Mandell et al., 2009). Utilizing a model of service utilization, the purpose of this work is to examine the role of race/ethnicity and parent knowledge of autism spectrum disorder, interpretation of disability symptoms, beliefs regarding necessary interventions, and trust in providers. Following a discussion of autism spectrum disorder and related symptoms, outcomes for individuals with the disorders, as well as their family members will be presented. Predictors for best outcomes,

barriers to early diagnoses and service utilization will be examined. Cultural differences in parent interpretation, knowledge, and behaviors regarding a child with a disability will also be discussed.

CHAPTER 2: LITERATURE REVIEW

AUTISM SPECTRUM DISORDER

As previously stated, individuals exhibiting social interaction and communication deficits, restricted repetitive and stereotyped patterns of behavior, and onset of symptoms prior to the age of 3 were previously categorized into separate pervasive developmental disorders (APA, 2000). Autistic disorder, Asperger's disorder, and PDD-NOS were considered to represent a spectrum, and were commonly referred to non-clinically as Autism Spectrum Disorders, because they shared several diagnostic symptoms with the number of and severity of criteria ranging across the disabilities (Wing, 1997). To date, some research involved individuals in all of the DSM-IV pervasive developmental disorder categories, while others separated them for research purposes. However, according to the APA (2012), autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDD-NOS were validly and reliably distinguished from other disabilities but inconsistently differentiated from one another. As such, with the release of DSM-5, the new diagnosis of autism spectrum disorder encompasses the symptomology for what were previously four separate diagnoses, with severity specifiers for differentiation purposes. For clarification purposes, autism spectrum disorder (or ASD) will be used throughout this work when reviewed research involved all of the now encompassed diagnoses and/or when the study used the term 'Autism Spectrum Disorders' in its descriptions.

Autism spectrum disorder appears to be affecting an increasing number of families. In 2000, The CDC established the Autism and Developmental Disabilities Monitoring (ADDM) Network to monitor characteristics and prevalence rates of children, 8 to 14 years of age, with

autism spectrum disorder in the United States (CDC, 2007). For the purposes of their research, the CDC (2012) considered ASD as comprising autistic disorder, Asperger's disorder, and PDD-NOS. Estimates from the ADDM Network's most recent data from 2010 indicate 14.7 children out of every 1,000 is affected by an ASD; approximately 1 in 68 children (CDC, 2014).

Social deficits are considered the hallmark feature of autism spectrum disorder. According to the APA (2013), social communication and social interaction deficits include the following: deficits in social-emotional reciprocity (e.g., engaging with others and sharing thoughts and feelings); deficits in nonverbal communicative behaviors used for social interaction (such as eye contact, facial expressions, body orientation, and gestures); and deficits in developing, maintaining, and understanding relationships (e.g., some individuals are unable to make friends and others may be unable to make friends their age). These deficits may also appear in the areas of social imitation, joint attention, face perception, and symbolic play (Blair, Frith, Smith, Abell, & Cipolotti, 2002; Lord, Rutter, & Le Couter, 1994; Werner & Dawson, 2005). A diagnosis of ASD also requires at least two of the following restricted, repetitive patterns of behavior, interests, or activities: stereotyped or repetitive motor movements, use of objects, or speech (such as hand flapping, rocking, lining up toys, echolalia, etc.); insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., inability to handle small changes, rigid greeting rituals, eating the same foods all the time, etc.); highly restricted, fixated interests that are abnormal in intensity or focus (e.g., attachment to unusual objects, increased knowledge and awareness of certain topics, etc.); and hyper-reactivity or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., adverse reactions to specific smells, textures, or sounds; excessive touching, smelling, tasting, or peering at certain objects, etc.), (APA, 2013).

When making a diagnosis, clinicians are to specify if intellectual or language impairments are present since autism spectrum disorder can occur without them. The severity of language deficits varies, with some individuals having vocal language with impaired reciprocal social communication and others never developing vocal language (APA, 2013; CDC, 2012). Many with autism spectrum disorder have motor skills deficits, including odd gait, clumsiness, and other abnormal motor behaviors such as toe walking (APA, 2013; Jansiewicz et al., 2006). Other adaptive skills deficits often occur, even when there is no intellectual impairment (APA, 2013). Attention deficits, hyperactivity, maladaptive or oppositional/defiant behaviors (including self-injurious behaviors), eating and sleeping disturbances, receptive and expressive language problems, seizure disorders, tics similar to or indicative of Tourette's Disorder, affective symptoms (including anxiety and depression) and Obsessive Compulsive Disorder (OCD) symptoms are common in individuals with autism spectrum disorder (APA, 2013; Bakken et al., 2012; Billstedt, Gillberg, & Gillberg, 2005; Jordan, 2005; Robertson, Chamberlain, & Kasari, 2003; Werner et al., 2005). Behavioral deficits tend to be more pronounced in individuals with comorbid cognitive impairment ($IQ < 70$), (Bishop, Luyster, Richler, & Lord, 2008).

In comparison to females, autism spectrum disorder continues to occur at higher rates for males: approximately 1 in 42 boys and 1 in 189 girls are affected (CDC, 2013). However, females with the disorders are typically more impaired with a higher rate of Intellectual Disability (CDC, 2012). Contrary to past research indicating majority of people with ASD have concurrent Intellectual Disability, the CDC (2012; 2013) indicate that, nationwide, around 30-40% of individuals with ASD have significant cognitive impairment (IQ scores less than or equal to 70). Recent studies have similarly concluded that approximately 40-50% of individuals with

ASD have Intellectual Disability (CDC, 2007; Croen, Grether, Hoogstrate, & Selvin, 2002; Edelson, 2006).

The APA (2000) previously specified that symptoms of ASD must be present before the age of 3. Current diagnostic specifications do not indicate an age requirement, but state that the symptoms need be present during the early developmental period (APA, 2013). De Giacomo and Fombonne (1998) examined parents' initial concerns regarding their child diagnosed with autism, Asperger's, or PDD-NOS. Results indicated that parents initially became aware of problems with speech and language. Parents then noticed social skills deficits, developmental milestone delays or medical problems, challenging behaviors, and more specific ASD related behaviors, respectively. On average children were 19.1 months when parents initially became concerned (De Giacomo & Fombonne). Other investigators found somewhat similar results with majority of parents observing ASD symptom onset before twenty-four months, with social and regulatory symptoms (e.g. excessively fussy, overly sensitive, eating problems, etc.) noticed as early as three to four months of age (Baghdali et al., 2003; Chawarska et al., 2007; Davidovitch et al., 2006; Tolbert et al., 2001; Werner & Dawson, 2005; Werner, Dawson, Munster, & Osterling, 2005).

Developmental regressions, occurring typically between the ages of 18 to 24 months, elicit concerns for other parents. Between 20-50% of children with ASD regress in areas of social behaviors (e.g., social skills, play, etc.) and/or language (Davidovitch et al., 2000; Goldberg et al., 2003; Parr et al., 2001; Werner et al, 2005). Some toddlers exhibit ASD symptomology prior to the regression while others develop normally (Goldberg et al., 2003; Werner et al., 2005). To date, studies have not found parental age, pre or perinatal complications,

family SES, or family medical history to correlate with likelihood of a child experiencing a regression (Davidovitch et al., 2000).

ASD symptomology and related characteristics have been examined with hopes of identifying best predictors of favorable outcomes. White, Scahill, Klinn, Koenig, and Volkmar (2007) found that in terms of educational placement, individuals with ASD and higher cognitive ability, better overall communication skills, and less autistic communication impairment (e.g. echolalia) were more likely to be educated alongside typical peers in an inclusion classroom. Similarly, Yianni-Coudurier et al. (2008) concluded that students with ASD and higher adaptive skills, fewer behavior problems, and parents of higher socio-professional status were less likely to be educated in more restrictive settings.

Longitudinal studies have compared childhood characteristics of individuals with ASD to their adult functioning and prognosis. Individuals considered to have ‘good’ outcomes lived independently, were employed, and had friends and/or romantic relationships. Limited to no verbal skills and required assistance for everyday tasks were criteria for ‘poor’ or ‘very poor’ outcomes. Positive outcomes for adults with ASD were more likely when children had higher cognitive abilities, specifically verbal IQ in one study (Eaves & Ho, 2008); useful speech and/or communicative phrases by 5 or 6 years of age; less autistic symptomology, as measured by the Childhood Autism Rating Scale (CARS); and fewer behavior problems (i.e., hyperactivity, aggression, self-injurious behaviors, etc.) (Billstedt et al., 2005; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004).

FAMILY FUNCTIONING

Symptomology and characteristics indicated as influencing educational placement and long-term outcomes for those with ASD might also affect family functioning. Dumas et al.

(1991) investigated levels of stress and depressive symptomology for parents of children with autistic disorder, behavior disorders, Down Syndrome, or typical development. Parents were given instruments that measured depression, perceived stress, and their child's challenging behaviors. Parents of children with autistic disorder and behavior disorders reported higher levels of stress than parents of typically developing children or those with Down Syndrome. Additionally, mothers of children with autism and behavior disorders indicated more symptoms of depression. Even when investigators controlled for depression and child behavior problems, mothers of children with the two disorders had significantly higher levels of stress (Dumas et al.).

Higgins, Bailey, and Pearce (2005) examined parent ratings on a measure of family cohesion and adaptability. Married parents of children with ASD, whom had never separated or sought assistance for their marriage, completed the questionnaire. Results indicated that in comparison to parents of typical children, parents of children with ASD have decreased marital happiness, family cohesion, and family adaptability.

Parental distress and perceived level of necessary assistance has also been studied. Bromley et al. (2004) asked mothers of children with ASD to complete questionnaires regarding their child's level of disability and disruptive behavior, perceived family support, and other autism spectrum disorder specific symptomology. Data indicated that mothers' levels of distress increased as their child's emotional/behavioral challenges and/or withdrawal increased. Additionally, as children exhibited increasing amounts of distress, disruptive behaviors, social impairments, or language deficits, mothers were increasingly likely to indicate unmet needs. Similarly, Siklos and Kerns (2006) found a positive relationship between autistic symptomology and parents' indications of needing help. Results of studies involving children with other kinds

of disabilities yield similar results: behavioral deficits, not the child's developmental level, correlated with family problems (Baker et al., 2003).

INTERVENTION

As suggested above, as children with ASD exhibit fewer challenging behaviors, display less autism spectrum disorder symptomology, acquire more adaptive behaviors (e.g., personal domestic, community use, etc.), and utilize better communication/language skills, they are more likely to be educated with their typical peers, function more independently as well as have friendships as adults, and their parents have fewer depression symptoms and less overall stress. Higher cognitive ability was also related to better adult outcomes. In order for ASD treatments to lead to the best outcomes for individuals with the disorders, as well as their families, it is imperative that the aforementioned symptoms are targeted.

Medications may help ameliorate sleep problems, symptoms of comorbid psychological disorders (e.g. anxiety and mood disorders), and associated medical conditions (e.g. seizures), but are ineffective on the principal social interaction, social communication, and behavioral deficits associated with the disorder (Myers & Johnson, 2007). Some interventions for autism spectrum disorder that are utilized by parents lack empirical support or have been found ineffective (Green et al., 2006; Myers & Johnson, 2007). For example, Green et al. (2006) surveyed parents of young children with ASD to determine services they used most. Ten percent or more of parents reported utilizing services such as facilitated communication, vitamin or other dietary supplements, auditory integration therapy, music therapy, and floor time; treatments that are either not recommended or have been found to have only limited support (Green et al.; Simpson, 2005).

Existing data for some interventions suggest they are promising and may possibly become indicated as efficacious as more research is completed. Teaching procedures such as specifically structured classrooms (e.g. TEACCH- Treatment and Education of Autistic and related Communication- handicapped Children) or teaching children with autism spectrum disorder to self-evaluate and monitor is classified in this manner (Odom et al., 2003; Simpson, 2005). Social stories, Picture Exchange Communication System (PECS) and other visual supports, fluency training, video modeling, Sensory Integration Therapy, and peer interventions have limited, but emerging research support (Odom et al.; Simpson).

Kuttler, Myles, and Carlson (1998) used social stories to prevent precursors to tantrum behaviors and cease tantrums in a 12-year-old male with autism. The participant was taught in a self-contained classroom for individuals with ASD. He typically exhibited tantrums during transitions, occasions when he needed to wait, and during unstructured classroom time. Researchers introduced social stories during the two times of day he was most likely to engage in pre-tantrum behaviors. Utilized social stories illustrated the necessity of waiting and transitioning, as well as reminding the participant that reinforcement would be earned when his behavior was appropriate during those times. Results indicated a significant change in precursors to tantrums: from 15.6 during morning work and 11.6 during lunch to 0 and 1.0, respectively (Kuttler, Myles, & Carlson).

Gordon et al. (2011) investigated the result of Picture Exchange Communication System (PECS) on spontaneous speech. PECS is a specified utilization of picture cards to facilitate language. Specifically, the authors wanted to examine if the use of PECS would increase spontaneous requests for tangible items as well as spontaneous language for socialization. Participants were 4- to 10-year-old children with diagnoses of autism and co-morbid Intellectual

Disability. All children had little to no functional communication or sensory impairments. Children were videotaped for 15-minute intervals during their snack time and an observation checklist was utilized pre and post training. Results indicated increases in spontaneous language; such that measured increases occurred for spontaneous speech, picture communication, and picture and speech used together. Spontaneous communication gains included requests for tangible items and requests for assistance; there were no gains in social speech.

Data suggests interventions are most effective when a behavior analytic emphasis, one-to-one instructional components, consideration of individual differences, integration with typical children, and parental/family involvement are included (Levy, Kim, & Olive, 2006; Stahmer, Collings, & Palinkas, 2005). Discrete Trial Teaching (DTT), other Applied Behavior Analysis (ABA) based practices such as functional communication training and pivotal response training, and similar behavior modification techniques (e.g. techniques involving adult prompting and differential reinforcement of positive behavior) have considerable empirical support (Odom et al., 2003; Simpson, 2005). Unlike other practices these interventions are effective on core deficits of the disorder: these treatments increase social communication and language skills, improve play behaviors and other social skills, increase daily living skills, advance cognition and academic achievement, and decrease challenging and inappropriate behaviors (Myers & Johnson, 2007).

Lovaas (1987) examined outcomes for children with autism receiving differing amounts of DTT. Participants were randomly assigned to either the intensive therapy group receiving over 40 weekly hours of DTT, or the minimal therapy group receiving 10 hours or less of DTT each week. Children in both groups were assigned therapists who worked with the child for at least two years. Significantly higher educational placements and IQ score gains were found for

children in the intensive treatment group. Forty-seven percent of the children receiving 40 hours or more, in comparison to 2% of the group receiving 10 hours or less, were enrolled in a typical first grade classroom. Post intervention assessment revealed the average IQ for the intensive treatment group was significantly higher (30 points) than the average IQ score for the minimal treatment group. These gains were maintained at follow-up (Lovaas). Sheinkopf and Siegel (1998) similarly reported greater cognitive gains and decreased autism symptom severity when children with ASD received more intervention hours.

Osborne, McHugh, Saunders, and Reed (2008) examined amount of intervention time and outcomes for children with ASD. Participants were children ages 2.6 to 4 years of age who received differing amounts of miscellaneous interventions: treatment included reinforcement-based intervention, structured preschool classroom time, speech and language therapy, and parent training. Participants received 15 to 40 hours of weekly intervention, 15.6 on average. For the purposes of their research, children receiving less than 15.6 hours were considered low time intensive and those receiving greater than 15.6 hours, high time intensive. Results indicated that adaptive functioning, developmental scores, and cognitive abilities increased as intervention time increased. However, when parent stress increased, developmental functioning and adaptive functioning decreased for children in the high time intensive group (Osborne et al.).

Flanagan et al. (2012) examined outcomes based on age at which child received interventions previously indicated as efficacious. Participants were children averaging 3.5 years of age who received 20 to 40 hours of Intensive Behavior Interventions (IBI), discrete trial teaching and natural environment training, per week or were on a wait list for services. In comparison to children on the wait list, decreased symptom severity, increased adaptive functioning, and increased cognitive abilities were found at follow-up for children who received

IBI. However, results indicated better outcomes for children who began receiving services at a younger age. Harris and Handleman (2000) similarly found earlier service obtainment (specifically before 48 months) correlated with better outcomes of IBI.

In summary, academic and long-term outcomes for individuals with ASD are positively correlated with higher cognitive abilities, advanced speech/language and communication skills, better adaptive functioning, less autistic symptomology, and fewer behavioral challenges. Data also indicates parent and family functioning is better when the family member with ASD has less challenging behaviors, less social impairment, more advanced language and communication skills, and less autism symptomology. Therefore, interventions with empirical support (such as IBI; DTT or other ABA based services) and those with increasing support (i.e., PECS, social stories, TEACCH, etc.) that target the aforementioned symptoms and associated difficulties will likely affect educational placement and long-term outcomes for individuals with ASD as well as the functioning of their family members. Data indicates that these interventions are most effective when the individual with autism spectrum disorder receives a large number of intervention hours (ideally between 20-40) at a young age (four years old and under).

DIAGNOSIS AND HELP SEEKING

Developed to understand and examine the decision-making processes in service utilization, models of help seeking have been proposed. While more general models of mental health seeking have been expanded and applied to specific populations such as adolescents or parents of children with attention-deficit/hyperactivity disorder (Cauce et al., 2002; Eiraldi, Mazzuca, Clarke, & Power, 2006) no such models have been specifically revised for parents of children with autism spectrum disorder. However, there are central themes to help seeking models, as well as the understanding that culture, beliefs, and other characteristics (i.e., number

of children, parent education level, knowledge of the disorder, treatment acceptability) influence certain stages of the model (Cauce et al., 2006; Cornally & McCarthy, 2011; Eiraldi et al., 2006; Srebnik, Cauce, & Baydar, 1996).

The first step involved in parental help seeking is problem recognition and identification. Thus, parents must identify a diagnostic or functional impairment in their child, as well as a perceived need of assistance from an outside source (Cauce et al., 2006; Eiraldi et al., 2006; Srebnik, Cauce, & Baydar, 1996). Culture may play a role in an individual's interpretation of a problem as mental health related or caused by something else (Cauce et al., 2002). Next, the parent either voluntarily, or coercively (i.e., an outside source saying get help or else...), makes the decision to obtain help (Cauce et al., 2006; Cornally & McCarthy, 2011; Eiraldi et al., 2006; Srebnik, Cauce, & Baydar, 1996). This step is also more likely when the problem is seen as both undesirable and as unable to ameliorate without assistance (Cauce et al., 2002). Third, after parents decide to obtain help, they must decide from whom they will obtain it. Social networks and context may inhibit or promote certain types of support based on the norms within that group. Cauce et al. (2002) and Srebnik et al. (1996) describe three types of service selection groups: mental health, collateral, and informal/ethnic/traditional supporters. Family, friends and clergy are examples of informal supports. Collateral service providers include physicians, school counselors, or members of the justice system. Formal mental health service providers include psychiatrists, psychologists, and social workers. Cornally and McCarthy (2011) described the first three steps as antecedents to the fourth, which is the process of actually attaining services for the problem. In essence, parents must perceive their child as needing assistance, make the decision to seek out help for their child, determine the type of help they would like to receive,

and utilize the service of their choosing (Cauce et al., 2002; Cornally & McCarthy, 2011; Veroff as cited in Eiraldi et al., 2006; Shyu, Tsai, & Tsai, 2010).

Problem Recognition and Decision to Seek Help

Prevalence studies find higher rates of autism spectrum disorder in Caucasian children than in children of minority ethnic groups (CDC, 2007; CDC 2014). As such studies are based on diagnosed individuals, experts caution interpreting the data as autism spectrum disorder occurs less in African Americans, and instead suggest that cultural or socioeconomic factors play a role in age of recognition and/or diagnosis (CDC, 2014; APA, 2013).

Fountain et al. (2011) examined the influence of demographic factors on age of diagnosis for ASD using a sample of children ages 2 to 8 years of age with diagnosed autism, Asperger's disorder, or PDD-NOS. Participants were enrolled with the California Department of Developmental Services, reportedly, the state's largest information source for individuals with ASDs. Results indicated Caucasian race, higher socio-economic status, increased communication deficits, higher parental education, having parents born in the United States, having older siblings, and living in areas with higher ASD prevalence were associated with earlier diagnosis.

Mandell et al. (2002) similarly indicated ethnic differences in age of diagnosis. Children and adolescents eligible for Medicaid in a Pennsylvania county served as participants. Researchers examined age at diagnosis and demographic information, dates of services received, and number of doctor visits. Results revealed mean age for African American children to first receive a diagnosis of ASD was 7.9 years of age, compared to 6.3 years for Caucasian children. After sex and time eligible for Medicaid were adjusted, African Americans received a diagnosis 1.4 years later than their Caucasian counterparts.

Mandell et al. (2009) examined the role of demographic factors in the diagnosis of ASD. Participants included 8-year-old children from the national sample utilized by the Center of Disease Control and Prevention's ADDM network. As mentioned earlier, the ADDM network identified children diagnosed with autism, PDD-NOS, or Asperger's disorder in varying locations across the country. Analysis revealed that documented ASD diagnoses were higher when children had an unknown or IQ at or below the level of intellectual disability (70), and when mothers received education beyond high school. Additionally, in comparison to Caucasian participants, African American participants were more likely to have documented low IQ (below 70) and less likely to have diagnosed ASD. Despite African Americans' increased likelihood of cognitive impairment and those with lower IQs being more likely to have an identified ASD, for participants with cognitive impairment, documented ASD diagnoses were lower for African Americans.

Jarquín et al. (2011) examined racial differences in ASD identification. Researchers utilized the Atlanta metropolitan component of the Center of Disease Control and Prevention's ADDM network's sample. Similar to the findings of Mandell et al. (2009), analyses indicated that African American children were less likely to be identified as having an ASD. When African Americans were diagnosed with one of the autism spectrum disorders, they were more likely to be diagnosed with the more severe autism spectrum disorder: autism. Conversely, Caucasian children had more variability in their diagnoses and had higher rates of Asperger's disorder and PDD-NOS. Differences in the specific diagnosed disorders remained for race when SES was controlled, despite data indicating that ethnic differences do not appear to exist for autism spectrum disorder severity or the core symptomology (Horovitz et al., 2011; Liptak et al., 2008; Mayes & Calhoun, 2011).

Further review of the data involved examining demographic factors for participants diagnosed only with autism, diagnosed with autism and another ASD, diagnosed only with Asperger's disorder, and diagnosed with Asperger's disorder and PDD-NOS (Jarquin et al., 2011). Relative to Caucasian children, African American participants were more likely to have a diagnosis of autism and no other ASD and less likely to have Asperger's disorder alone or Asperger's disorder and PDD-NOS. Like Mandell et al.'s (2009) results, analyses also indicated that African American participants were more likely to be diagnosed with a co-occurring intellectual disability, while Caucasian participants were more likely to have comorbid attention-deficit/hyperactivity disorder (ADHD) or learning disability diagnoses.

The data suggests children with lower IQs and/or lower communication levels are more likely to have a documented ASD (Fountain et al. 2003; Mandell et al., 2009). However, even when their symptoms concurrently met eligibility criteria for an ASD, African American children are more likely to be diagnosed with ID and less likely to receive an ASD diagnosis (Mandell et al., 2009). Additionally, in comparison to Caucasian children who are identified with an ASD early even when their symptomology is less severe, African American children are diagnosed later even when their ASD symptomology is severe (Jarquin et al., 2011; Mandell et al., 2009). Receiving a diagnosis at an early age, or getting a diagnosis at all, appears to be affected by variables such as maternal education level, SES, symptom severity, birth order, IQ, living in non-metropolitan area, and living in areas where ASDs are more prevalent (Fountain et al., 2003; Liptak et al., 2008; Mandell, Novak, & Zubritsky, 2005). However, some research suggests that ethnic disparities continue to exist when the above-mentioned variables are held constant (Jarquin et al., 2011).

Ethnic differences in diagnosis and decisions to obtain services have also been found for children with ADHD, another disorder that affects children's social skills and behavior. Bussing, Zima, Gary, and Garvan (2003) examined barriers for diagnosis and treatment of attention deficit-hyperactivity disorder (ADHD). Variables of interest included problem recognition, pursuit of evaluations, diagnosis attainment, and decision to seek treatment. Data indicated that African American and Caucasian parents were equally able to identify when their child had a problem and indicated similar levels of barriers to care. However, African American parents were less likely to have their child evaluated, diagnosed, or treated for ADHD. Additionally, African American parents were more likely to have negative expectations of formal treatment for their child's disorder.

Bussing, Schoenberg, and Perwien (1998) examined parent knowledge and exposure to ADHD in a sample of parents whose child was considered high-risk for the disorder. African American parents were less likely to indicate recent exposure to ADHD information; had less perceived knowledge about this disorder; were less likely to have heard of ADHD or indicate knowing someone with the disorder; and less likely to understand the etiology of ADHD and attribute it to factors such as sugar intake. Even when SES, gender of the child, and child's ADHD treatment status were controlled, the aforementioned ethnic/racial differences persisted for African Americans.

As noted, the initial antecedents for parents seeking services for their child are problem recognition and the decision to obtain services. Additionally, knowledge and beliefs about a disorder have been previously indicated as facilitating their recognition (Jorm et al., 1997). Studies reviewed above regarding ADHD suggest disparities in diagnoses and service utilization between Caucasian and African Americans may be due to African Americans lack of knowledge

and awareness concerning ADHD (Bussing et al., 1998). Researchers hypothesized that cultural differences were affecting parent conceptualization of the disorder in terms of not perceiving the behaviors as a problem, attributing alternative explanations for their child's behavior (such as believing that the child will grow out of the symptomology) or believing that nothing can lead to improvement; thus decreasing their likelihood of seeking professional services (Bussing et al., 1998; Bussing et al., 2003). Additionally, African Americans parents may be less likely than Caucasian parents to encounter children/families with ADHD and/or engage in fewer discussions about ADHD among their cultural group, limiting their awareness/education concerning the disorder (Bussing et al., 1998).

Though there aren't specific studies regarding knowledge and awareness of autism spectrum disorder, several authors have hypothesized similar reasons for ethnic disparities in ASD diagnoses and relatively low levels of service utilization (Fountain et al., 2011; Jarquin et al., 2011; Mandell et al., 2002; Mandell et al., 2009; Thomas et al. 2007). For example, Mandell and Novak (2005) suggest that culture may influence how parents view symptoms or behaviors that are otherwise considered indicative of ASD. Also, culture may lead to interpretations and explanatory beliefs for ASD symptomology that are inconsistent with the literature and thus affect utilization of services (Hebert & Koulouglioti, 2010; Mandell & Novak, 2005). Jarquin et al. (2011) suggested that African Americans might be unaware of the milder versions of ASDs or unable to identify milder symptoms.

Service Selection and Use

Mandell et al. (2002) suggests that some of the disparity in African American service utilization for ASD services is due to differences in actual treatment by professionals. Mandell et al. found that for children with a diagnosed autism spectrum disorder, African American

participants required more visits to a mental health professional before receiving a diagnosis. If just looking at the first mental health visit, 72% of Caucasians with ASD were diagnosed at their first mental health visit compared to 57% of African Americans.

Thomas et al. (2007) examined patterns in service utilization for individuals with ASD. Families with a child diagnosed as having autism, Asperger's disorder, or PDD-NOS, age 11 or younger served as participants. Participants were interviewed and completed a self-administered questionnaire regarding service use. Analyses indicated that families utilized a variety of services including those with support, such as TEACCH and ABA. Additionally, most families reported utilizing multiple types of services. Race, parent education level, and SES were found to affect service use. African American children, children of lower SES, and children whose parents received less formal education received fewer services. Similarly, studies on service utilization when children meet criteria for Developmental Delay found African Americans received less early intervention than their Caucasian counterparts (Feinberg, Silverstein, Donahue, & Bliss, 2011).

Other studies unspecific to developmental disorders indicate ethnic disparities in help seeking. Research indicates that African Americans are less likely than Caucasians to seek help from mental health professionals (Snowden, 2001). Even when African Americans utilize mental health services, they are more likely than Caucasians to drop out of treatment (Snowden & Yamada, 2005; Sue & Sue, 2007). Decreased help seeking for African Americans may be related to personal barriers like financial hardships, lack of service providers, stigma, and prior negative experiences. However, data from a study performed by Owens et al. (2002) indicated that for individuals indicating barriers to help seeking, attitudes and perceptions of mental health problems were more likely than structural barriers. In line with those findings, Dobalian and

Rivers (2008) found that even after controlling for SES and insurance status, African Americans adults were less likely to obtain mental health services or have visited a mental health practitioner. Similarly, Ringel and Sturm (2001) found that African American children had a higher rate of unmet mental health needs than Caucasian parents, but, African American parents were less likely than their Caucasian counterparts to seek mental health services, even after controlling for insurance status.

Parent attitudes toward mental health and mental health service may influence their help seeking behaviors for their children (Stiffman, Pesosolio, & Cabass, 2004). From their aforementioned findings, Owens et al. (2002) suggested that the largest barrier for African American parents obtaining treatment for their children is stigma and a negative perception of mental health services. Fear of being stigmatized affects the attainment of mental health services in individuals as young as middle-school-age children (Chandra & Mink, 2006). African Americans may face double stigma when it comes to mental health services: concern about stigma because of race (i.e., stereotypes, prejudice, etc.) and negative beliefs regarding the mental health system (i.e., misdiagnosis, distrust, etc.), (Gary, 2005).

Even when the problem is perceived as something other than a mental health concern, data suggest that stigma exists regarding treatment from medical professionals as well. African American participants with higher rates of medical mistrust are less likely to have visited a doctor in the last year, have a personal physician, obtain warranted medical treatment, keep follow up appointments, take medical advice, and fill prescriptions (LeVeist, Isaac, & Williams, 2009; Shelton et al., 2010; Thompson, Valdimarsdottir, Winkel, Jandorf, & Redd, 2004).

Data suggests African American children with autism spectrum disorder are less likely to receive services than Caucasian children (Thomas, et al., 2007). Thomas, Morrissey, and

McLauren (2007) suggested that though not many studies have examined ethnic disparities in service utilization for ASD, it may be the case that utilization patterns are different for African Americans as a result of economic disadvantages, cultural differences, and stigma. This is consistent with found barriers for African American service utilization for other mental health concerns and medical problems (Bailey & Owens, 2005; LeVeist et al., 2009; Richman, Kohn-Wood, & Williams, 2007; Shelton et al., 2010; Snowden, 2001; Thompson et al., 2004).

Increasing numbers of families are being affected by autism spectrum disorder as prevalence rates for the disorder continues to rise. Research indicates that symptomology can often be identified before 2 years of age. Unfortunately, in comparison to Caucasian children, African American children remain undiagnosed or receive diagnoses later (one study suggested a mean age of diagnosis at 7.9 years of age). When they are diagnosed African American children are likely to have more severe autism spectrum disorder symptomology and preliminary evidence suggests rates of service utilization are lower in this population.

The purpose of the present investigation was to examine the role of race and culture at the three antecedent stages of service utilization as proposed by multiple models, in addition to some of the characteristics indicated as affecting the stages. Specifically, examining race and parents' interpretation of autism spectrum disorder symptomology, belief that the child needs services, pattern of help seeking if the child exhibited ASD symptoms, knowledge of autism spectrum disorder, and mental health stigma. Parents were asked to read a vignette describing a child displaying varying behavioral concerns. Vignettes included a description of a young child with typical behaviors, a child with behaviors indicative of less severe autism spectrum disorder symptomology (such as meeting criteria for the former diagnoses of Asperger's Disorder or PDD-NOS), or a child with more severe autism spectrum disorder symptomology (such as

meeting criteria for the former diagnosis of autistic disorder). Participants were asked to complete measures reflecting problem identification and need for intervention, as well as measures of knowledge of autism spectrum disorder, and attitudes towards mental health services. It was expected that relative to Caucasian participants, African American participants would have a different conceptualization regarding the child displaying autism spectrum disorder symptomology. Additionally, African American participants would have less autism knowledge than Caucasian participants. Lastly, African American participants would indicate more stigma towards mental health services, more biases towards clinicians, and would be less likely to seek formal mental health services.

CHAPTER 3: METHODS

PARTICIPANTS

A total of 143 parents, with at least one child between toddler age and ten years old, residing in northern Mississippi were recruited to participate in the current study. Demographic information for each participant was collected (Demographic Questionnaire, Appendix A). Participants primarily identified as African American/Black (48.3%), followed by Caucasian/White (40.6%), other race/ethnicity (6.3%), Hispanic/Latino (3.5%), and Asian (1.4%). The majority of participants were female (95.8%). No individuals were denied participation, however, only the data from female African American and Caucasian participants were utilized in the current study. The reason for this specificity was a concise comparison between this minority and majority group without the additional confound of parent sex. Thus, analyses included a sample of 119 participants: 51.3% African American and 48.7% Caucasian. Demographic information varied for race (Table 1, Appendix G) and is further discussed in the results section.

STIMULUS MATERIAL

Vignettes

Three vignettes (Appendix B) depicting a 4-year-old child with typical development, with mild autism spectrum disorder symptomology (similar to criteria for a former diagnosis of Asperger's disorder), and with more severe autism spectrum disorder symptomology (similar to criteria for a former diagnosis of autistic disorder) served as stimulus materials in the present study. Based on vignettes developed by Johnson (2011), behaviors were modified to reflect (e.g.

DSM-5 criteria) the above listed children. That is, each vignette was similar in format with the child exhibiting varying levels of social-communication concerns and challenging behaviors in the school setting. For example, the typical child met developmental milestones on time, played with peers, and sometimes had tantrums when things did not go his way; while the child with autism spectrum disorder met some developmental milestones late, preferred to be alone, and had tantrums when things did not go his way or when changes occurred in his daily routine.

MEASURES

Interpretation of Symptoms

Literature suggests that parent perceptions of severity, lack of awareness regarding mild ASD symptomology, and misinterpretations of behavior may effect their utilization of services (Bussing, Schoenberg, & Perwien, 1998; Bussing et al., 2003; Fountain, 2011; Hebert, 2010; Jarquin, 2011; Mandell et al. 2003). However, researchers have not created a standardized measure assessing these constructs. As such, 7 items (e.g. *John's behaviors are: no different from (the same as) other children his age, mildly different from other children his age, moderately different from other children his age, significantly different from other children his age.*) were designed to explore parent beliefs, interpretations of ASD symptomology, and type of help perceived as most helpful and would utilize (Appendix C).

Parental Attitudes Toward Psychological Services Inventory

The Parental Attitudes Toward Psychological Services Inventory (PATPSI, Appendix D) is a multidimensional instrument designed to assess parents' overall attitudes towards help seeking (Turner, 2012). Initial development included a vignette describing a child and participants were asked to imagine they were the child's parent. Participants were then asked to rate their level of agreement with each statement regarding the utilization of services on a 6-point

scale ranging from ‘*strongly disagree*’ to ‘*strongly agree*.’ Twenty-six items were originally developed, but 21 items were retained in the final version of the scale.

Factor analyses of the PATPSI indicated a three-factor structure: Help-Seeking Intentions, Stigmatization, and Help-Seeking Attitudes (Turner, 2012). Though, 26 items were originally developed, the 21 items that loaded strongly onto only one of each of the factors and correlated with the total score were retained in the final version. Domain scores, as well as the total score can be obtained by summing responses. Negatively phrased items are reversed scored so that higher scores indicate more positive attitudes. Internal consistency using Cronbach’s alpha was found to be .86 for the Total Score, .73 for Help-Seeking Attitudes, .72 for Help-Seeking Intentions, and .84 for Stigmatization. On follow up administration, Cronbach’s alphas were in a similar .70 to .90 range. Test-retest reliability using Pearson correlation coefficients were moderate to high with .82 for Total Score, .77 for Help-Seeking Attitudes, .66 for Help-Seeking Intentions, and .84 for Stigmatization (Turner). An additional study indicated similar results with another population, internal consistencies ranged from .70 to .90 regardless of participant race (Turner). For the purposes of this study the vignette portion of the survey was dropped and participants were instructed to answer the questions with their own child or children in mind. In the current study, Cronbach’s alpha coefficients were .83 for the Total Score, .67 for Help-Seeking Attitudes, .76 for Help-Seeking Intentions, and .76 for Stigmatization.

Group Based Medical Mistrust Scale

The Group Based Medical Mistrust Scale (GBMMS, Appendix E) is an instrument designed to assess an individual’s beliefs regarding the ability of mainstream healthcare systems and medical professionals to provide treatment to people in their ethnic/racial group (Thompson et al., 2004). Initial development included five items from other measures (e.g., the Cultural

Mistrust Inventory; Terrell & Terrell, 1981) and seven items based on the literature regarding medical mistrust (Thompson). The 12 items were each ranked on a 5-point scale; strongly disagree to strongly agree. Positively phrased items were reverse scored, with higher sums indicating less trust. Factor analyses of the Group Based Medical Mistrust Scale indicated a three-factor structure: Suspicion, Group Disparities in Health Care, and Lack of Support from Health Care Providers. Internal consistency was found with Cronbach's alpha of .83 for the Total score, .80 for Suspicion, .76 for Group Disparities in Health care, and .55 for Lack of Support from Health Care Providers (Thompson et al., 2004).

In the original study, the GBMMS was administered to a sample of Latino and African American women interviewed as part of an ongoing program designed to increase cancer screenings. Thus, participants also completed measures regarding previous medical follow-up, perceived benefits of cancers screenings, and racial acculturation. Convergent validity was supported by data indicating that women with higher scores on the GBMMS were less likely to receive follow-up medical screenings than women with lower scores. Additionally, scores on the GBMMS were negatively related to perceived benefits of cancer screenings and acculturation, and positively related to perceived disadvantages of cancer screenings (Thompson et al., 2004).

In a study further investigating the psychometric properties of the GBMMS, data continued to support a three-factor structure and scores were significantly related to racial identity, having a physician, visiting a physician in the last year, satisfaction with medical procedures, and attitude about screenings (Shelton et al. 2010). Shelton et al. (2010) found Cronbach's alpha coefficients of .87 for the Total Score. Cronbach's alpha coefficients for the current study were .88 for Suspicion and .85 for the Total Score.

Autism Spectrum Disorder Knowledge

To date there is no scale to measure parents' knowledge about autism spectrum disorder. Stone's (1987) Autism Knowledge Survey was designed to compare professionals' (e.g. psychologists, medical doctors, speech/language therapists, etc.) knowledge of symptoms, myths, etiology, and treatment of autism. The first portion of the survey consisted of a 21-item questionnaire, rated on a six-point Likert type scale ranging from 'fully agree' to 'fully disagree.' However, questions such as "autism is an emotional disorder," would not be relevant for parents. Other items like, "most autistic children are Mentally Retarded," now have evidence to the contrary.

In order to assess parents' ASD knowledge, a fourteen item, true/false questionnaire was established for use in the current study (Appendix, F). Five items from the original Autism Knowledge Survey (Stone, 1987) were modified and nine additional items were created based on ASD literature and modifications utilized by other researchers (Stuart, Swiezy, & Ashby, 2008). Total scores were obtained by summing responses. Negatively phrased items were reversed scored so that higher scores indicated more greater autism knowledge. Following the deletion of two items, internal consistency continued to be poor (Cronbach alpha coefficient of .53). In an attempt to examine construct validity, an independent-samples t-test was conducted to compare autism knowledge scale total scores for people who correctly and incorrectly identified the hypothetical child in this study with moderate-to-severe autism spectrum symptomology as having ASD. There was no significant difference in scores for those who incorrectly ($M = 10.33$, $SD = 1.73$) and correctly identified the child as having ASD ($M = 11.25$, $SD = .15$; $t(43) = 1.93$, $p = .60$, two-tailed).

PROCEDURE

Participants were recruited through the use of notes and direct invitation. Notes were sent to the parents of children attending day care, preschool, or elementary schools located in the Southeastern United States. Notes briefly described the study, allowed parents to choose their preferred method of participation (i.e., email link to the survey, interview over the phone, or in person interview at their home or child's school) should they choose to participate, described the incentive, and included a permission slip for them to return to the school. Informed consent was attached to the note. Parents were also asked to invite other parents of young children to participate. Returned permission slips were obtained from each participating school, and participants were contacted per their identified method.

Trained research assistants served as interviewers to ensure data were secured and procedures for confidentiality were followed. Via research assistant or typed directions, participants were reminded about confidentiality, consent, and their ability to discontinue at any time. Participants first completed a demographic questionnaire. Research assistants or typed directions then informed them to imagine that a hypothetical child was theirs, and they read, or had read to them, one of the three vignette and follow up questions designed for the study. Participants were informed that questions were no longer about the hypothetical child and they were to answer questions based on their level of agreement. PATPSI, GBMMS, and the autism knowledge questionnaire were administered in a counterbalanced order.

Following their participation, parents had the opportunity to enter their information into a drawing for twenty dollars. Participants interviewed over the phone verbally gave their preferred contact information to the researcher/research assistant, while participants who completed the survey via Internet emailed an address created specifically for the study. Fourteen individuals, ten percent of participants, received twenty dollars.

CHAPTER 4: RESULTS

Data Cleaning and Preliminary Analysis

As previously stated, prior to conducting statistical analyses, male participants and participants having specified their race as Hispanic/Latino, Asian, or other race/ethnicity were removed from the data set. Data were examined with respect to missing values. Participants having only completed demographic information were removed from the study. The dataset was examined for presence of multivariate outliers using Mahalanobis distance. Multivariate outliers were removed from the dataset ($N = 2$). Measures not filled out completely were excluded only if the missing data were required for the specific analysis being performed. Descriptive statistics were calculated (Tables 1-3, Appendix G).

Demographic Variables

A correlation matrix was generated to explore bivariate relationships among the continuous demographic variables (see Table 4). Participant's age was positively correlated with education ($r = .339, p < .01$) and income ($r = .373, p < .01$). Education was positively correlated with income ($r = .579, p < .01$) and number of hours worked each week ($r = .242, p < .01$). A significant positive relationship was identified between the number of weekly hours worked and income ($r = .208, p < .05$).

According to Mann-Whitney U Tests, African American and Caucasian participants did not differ significantly on number of children ($p = .56$) or number of hours worked outside of the home ($p = .21$). A Mann-Whitney *U* Test revealed a significant difference in the income levels of

African Americans ($Md = \$10,000-19,999$, $n = 61$) and Caucasians ($Md = \$75,000-84,999$, $n = 58$), $U = 512.50$, $z = -6.73$, $p < .001$, $r = .6$.

Relationships between categorical demographic variables were analyzed via chi square tests for independence. Yates' Correction for Continuity was utilized when 2x2 tables were analyzed to compensate for the overestimate of the chi-square value (Pallant, 2010). A Chi-square test for independence (with Yates Continuity Correction) indicated no significant association between race and employment $X^2 (1, n = 119) = .86$, $p = .36$, $phi = -.11$. A significant association was found between race and education, $X^2 (1, n = 119) = 10.05$, $p < .01$, $Cramer's V = .29$. Race was also associated with insurance type (i.e., Medicaid versus private insurance), with 83.6% of Caucasian's having private insurance compared to 16.4% of African Americans as indicated by a Chi-square test for independence (with Yates Continuity Correction), $X^2 (1, n = 116) = 49.71$, $p < .001$, $phi = -.67$. Another Chi-square test for independence (with Yates Continuity Correction) indicated Caucasians (87.9%) were more likely to be married than African Americans (31.1%), $X^2 (1, n = 119) = 37.27$, $p < .001$, $phi = -.58$.

Relationships between race and familiarity with children receiving different types of services were also analyzed via Chi-square tests for independence with Yates Continuity Correction. Chi-square tests for independence indicated no significant associations between race and familiarity with children receiving special education assistance, $X^2 (1, n = 119) = .09$, $p = .76$, $phi = .63$; familiarity with a child obtaining assistance from a mental health practitioners, $X^2 (1, n = 119) = 1.05$, $p = .31$, $phi = .11$; or familiarity with a child taking medication to assist with their behaviors, $X^2 (1, n = 119) = 3.43$, $p = .06$, $phi = .19$. However, Caucasian participants (81.0%) were more likely than African American participants (45.9%) to be familiar with a child receiving services from a speech/language practitioner (SLP), $X^2 (1, n = 119) = 14.28$, $p < .001$,

$\phi = .37$. Caucasian participants (60.3%) were also more likely than African American participants (27.9%) to be familiar with a child receiving services from an occupational therapist (OT) or physical therapist (PT), $X^2(1, n = 119) = 11.46, p = .001, \phi = .33$.

Race and Interpretation of Hypothetical Child John

In order to examine the relationship between race and perception of hypothetical child John with varying levels of ASD symptoms, Chi-square tests for independence were performed. However, one of the assumptions of chi-square was violated as a number of cells contained a frequency below five. Statistical analysis (Fisher's exact test) indicated that for participants assigned to the hypothetical child with moderate-to-severe ASD symptoms, Caucasians (88.9%) were more likely than African Americans (50.0%) to correctly identify the hypothetical child as having a developmental disorder like ASD versus identifying him as something else ($p < 0.01$, Fisher's exact test). However, when analyses were performed regarding the identification of the child as not developing typically, Caucasians (91.7%) and African Americans (75%) did not significantly differ in the identification of the child having something affecting his development ($p = .16$, Fisher's exact test).

There were no significant differences between African Americans (56.0%) and Caucasians (44.4%) for identifying the hypothetical child with mild ASD symptoms as having a developmental disorder ($p = 0.70$, Fisher's exact test) or in identifying the typically developing child as a normal active boy (Caucasian, 100.0%, African American, 77.0%; $p = 0.143$).

Autism Knowledge, Stigma, and Mistrust

Preliminary assumption testing was conducted to check for linearity, univariate, and multivariate outliers, homogeneity of variance-covariance matrices, and multi-collinearity, with no serious violations noted for the PATPSI or the GBMMS. The autism knowledge questionnaire

violated the assumption of homogeneity of variances. As such, reflect and logarithm transformation was performed on the scale. Normality violations were found for the PATPSI, however, previous studies have found F to be robust to non-normality when violations are not a result of outliers and the sample size is large enough (Tabachnick & Fidell, 2013).

In order to examine the impact of race on parental help seeking intentions, parental help seeking stigma, medical suspicion, the perception of group disparities in health care, and autism knowledge a one-way multivariate analysis of variance (MANOVA) was performed with race as the independent variable and the PATPSI Help Seeking Intentions subscale score, PATPSI Stigmatization subscale score, autism knowledge questionnaire total score, Medical Suspicion subscale of the GBMMS, and Group Disparities subscale of the GBMMS as the dependent variables. The overall F was significant, $F(5, 106) = 9.29, p < .001$, Wilks' $\Lambda = .70$; partial eta squared = .31. Box's Test of Equality of Covariance Matrices significant value was .60; therefore the assumption of homogeneity of variance-covariance was not violated. When the results for dependent variables were considered separately, three differences reached statistical significance, using a Bonferroni adjusted alpha level of .01: Medical Suspicion, $F(1, 110) = 7.49, p = .007$, partial eta squared = .06; Group Disparities in Medical Treatment, $F(1, 110) = 13.24, p < .001$, partial eta squared = .11; and the autism knowledge survey, $F(1, 110) = 27.36, p < .001$, partial eta squared = .20.

An inspection for the mean scores indicated that African Americans reported higher levels of medical suspicion ($M = 13.39, SD = 5.84$) than Caucasians ($M = 10.41, SD = 4.98$). Similarly, African Americans reported higher levels of the belief that group disparities exist in medical treatment ($M = 9.14, SD = 3.66$) than Caucasians ($M = 6.78, SD = 2.98$). Mean scores on

the autism knowledge scale indicate that Caucasians had higher levels of autism knowledge ($M = 11.31$, $SD = 0.80$) than African Americans ($M = 9.98$, $SD = 1.70$).

Statistical analyses were performed to examine the role of race on specific scale items that were of interest to the study. Regarding the perception that an individual was personally treated poorly or unfairly by doctors or healthcare workers because of their race, a Mann-Whitney U Test revealed a significant difference between African American participants ($Md = 2$, $n = 59$) and Caucasian participants ($Md = 1$, $n = 54$), $U = 891.50$, $z = -4.28$, $p < .001$, $r = .4$. Overall, African Americans (25.4%) were more likely than Caucasians (7.4%) to agree to some level that they had been treated unfairly, as indicated by a Chi-square test for independence (with Yates Continuity Correction), $X^2 (1, n = 113) = 5.32$, $p < .05$, $phi = .24$

Statistical analysis (Fisher's exact test) indicated no difference between Caucasians (96.3%) and African Americans (94.8%) in agreement early intervention can lead to large gains in social and communication skills for children with ASD ($P = 1.00$); number 1 on the autism knowledge scale. However, results of Fisher's exact test indicated that Caucasians (98.1%) were more likely than African Americans (84.5%) to agree that behavioral interventions can lead to higher IQs and higher everyday functioning for Children with ASD ($P < 0.05$); number 15 on the autism knowledge scale.

Help Seeking Preferences

A Chi-square test for independence indicated no significant association between race and type of services (mental health therapist, collateral services, informal services, no services) participants were most likely to seek for the hypothetical child, $X^2 (1, n = 115) = .39$, $p = .942$, $phi = .06$. In order of services they would most likely obtain, 58.3% of participants indicated collateral support, 20.9% informal support, 12.2% mental health therapist of some kind, and

8.7% no one. When analyses observed type of support that was chosen last, only 5.3% of individuals chose to seek help from a mental health therapist, with no significant differences between European Americans (3.6%) and African Americans (6.9%), ($p = 0.68$, Fisher's exact test).

Chi square tests for independence were attempted to examine the associations between race and type of service indicated as most helpful for each condition of John. However, the assumption of at least 80 percent of cells with frequencies of 5 or more was violated and the tests could not be performed. Similarly, analyses could not be performed examining the association between condition and type of services for the same reason. Frequency data are reported in figures 1-5.

Level of concern

An independent-samples t-test was conducted to compare the sum of scores on items regarding concern and impact of the hypothetical child for the different race levels. For participants in the typical child group, there was no significant difference in scores for Caucasians ($M = 7.55$, $SD = 2.07$) and African Americans ($M = 9.36$, $SD = 2.89$; $t(31) = -1.86$, $p = .07$, two-tailed).

For participants in the mild ASD group, there was a significant difference in levels of concern, with Caucasians ($M = 9.56$, $SD = 3.50$) showed lower levels of concern than African Americans ($M = 12.04$, $SD = 2.86$; $t(32) = -2.10$, $p = .04$, two-tailed). The magnitude of the difference in the means (mean difference = -2.48 , 95% *CI*: -4.89 to $-.08$) was large (eta squared = $.12$).

For participants in the severe ASD group, there was no significant difference in levels of concern for Caucasians ($M = 13.58$, $SD = 2.22$) and African Americans ($M = 13.08$, $SD = 1.67$; t

(46) = .71, $p = .48$ two-tailed). The magnitude of the difference in the means (mean difference = .5, 95% *CI*: -.91 to 1.91) was small (eta squared = .01).

CHAPTER 5: DISCUSSION

As expected, in comparison to African American parents, Caucasian parents were better able to identify a child with moderate-to-severe ASD symptomology as having autism spectrum disorder. While both racial/ethnic groups demonstrated some knowledge of ASD, Caucasian parents demonstrated fewer misconceptions and greater knowledge of ASD symptomology and treatment. Previous studies suggest that knowledge of a disorder aids in its recognition (Jorm et al., 1997). Thus, it is not surprising that Caucasians more accurately identified the child with ASD symptomology as having the disorder. Studies examining racial differences in ADHD knowledge and recognition report similar findings. That is, African American parents demonstrated less knowledge about ADHD and were less likely than Caucasian parents to recognize ADHD symptomology as indicative of the disorder (Bussing et al., 1998).

African American and Caucasian parents were equally able to identify the active child developing normally as a typical preschooler. Both parent groups failed to recognize a same-aged child meeting developmental milestones within normal limits, but with mild autism spectrum disorder symptomology as having ASD. The child in the mild ASD symptom vignette was described as meeting developmental milestones within normal limits possibly suggesting to parents typical overall abilities. Research suggests that children exhibiting ASD symptoms whom also display greater communication and intellectual skills receive an ASD diagnosis later and less often regardless of race (Fountain et al., 2011; Mandell et al., 2009). These findings suggest parents may be less alarmed by social/communication difficulties and restrictive repetitive behaviors indicative of ASD when unaccompanied by intellectual impairments.

Results also indicated no racial differences regarding parental concern for atypical development indicative of ASD, or parental beliefs that early intervention services were likely beneficial for children with ASD. These data suggest that even in the absence of higher levels of awareness of behavior patterns consistent with identified forms of pathology, African American parents are sensitive to their child's behavioral difficulties. African American children are diagnosed with autism spectrum disorder 1.4 years later than, and less often than Caucasian children (Mandell et al., 2002). Thus, while African American parents recognize and are concerned about their child's display of atypical development, absence of knowledge concerning autism spectrum disorder may be an important factor in delaying service seeking. Further studies should examine racial/ethnic differences in parent knowledge regarding autism spectrum disorder, particularly its role in help seeking.

Although African American parents differed from Caucasian parents in their ability to correctly label the moderate-to-severe ASD symptomology child, they were able to identify that the child exhibited atypical development. This finding is consistent with prior studies regarding racial differences in the identification of ADHD (Bussing et al., 2003). It is not clear why African-American parents are less knowledgeable concerning behavioral indicators of these types of child psychopathology. Studies have shown that racial/ethnic differences occur regarding preventative and curative care, with African American parents seeking medical services later and less often than Caucasian parents (Flores, Bauchner, Feinstein, & Nguyen, 1999; Flores & Tomany-Korman, 2008). It may be that African American parents are less exposed to ASD information (and other forms of childhood psychopathology) because relative to Caucasian parents, delays in seeking behavioral healthcare services results in fewer informal discussions/knowledge sharing concerning ASD within the African American community.

When asked about seeking services for their child's psychological or behavioral problems all parents indicated the importance of seeking treatment, and no racial differences were found for mental health stigma. Overall, parents indicated preference for seeking assistance from collateral supporters (e.g., physician, school, etc.) and not a mental health therapist. However, racial differences were observed in terms of awareness of the benefits of ASD specific treatments, and suspicions and distrust of health service providers. That is, African-Americans were less aware that behavior interventions could lead to higher IQs and higher everyday functioning for children with ASD. African Americans were also more likely to have a general lack of trust towards health care providers and the overall health care system.

These findings may provide some explanation for reported lower rates of early intervention for African American children with developmental delay, and fewer services received by African American children with ASD (Feinberg et al., 2011; Thomas et al., 2007). It may be that even when atypical development is observed, the absence of knowledge of the disorder and ASD treatments, in conjunction with lack of trust of the health care system contributes to delays in seeking assistance.

Past negative health care experiences may also contribute to a lack of help seeking for African American parents. Relative to Caucasians, African Americans were more likely to believe that they received different treatment than members of other races, and that a healthcare worker treated them unfairly because of their race/ethnicity. Literature indicates that even when an individual acknowledges that services are warranted, those with higher rates of medical mistrust are less likely to perceive positive benefits of treatment, have a physician, visit a physician recently, receive follow up services, and be satisfied with treatment procedures (Shelton et al., 2010; Thompson et al., 2004).

Limitations and Future Directions

The current work utilized a rural southern sample limiting the generalizability of findings. Additionally, sample size and limited variability restricted our ability to examine several potentially important demographic variables (e.g., SES). Future work would benefit from a larger and more demographically diverse sample. Additionally, the ASD knowledge scale was adapted for the current study and displayed limited internal consistency. Developing a psychometrically sound measure of parent/caregiver ASD knowledge for future work would be beneficial.

Despite acknowledged limitations of this work, findings suggest the importance of enhancing knowledge of ASD symptomology among African Americans. It is possible that enhancing general knowledge about autism spectrum disorder in African Americans may be an important step toward enhancing rates of early service seeking for children displaying ASD symptoms. Educating parents concerning benefits of

ASD specific interventions (e.g., applied behavior analysis based interventions), as well as general early interventions that target behavioral deficits associated with ASD (e.g., developmental intervention, occupational therapy, speech/language therapy, etc.) may be an important factor in ensuring timely intervention for children with ASD. Moreover, understanding treatment options for their child with autism spectrum disorder may reduce African American distrust of healthcare providers as it may lead to improved communication between parents and service provider.

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LIST OF APPENDICES

APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE

13. Do you know anyone whose child takes (or used to take) medication to assist with his/her behavior?

Yes

Not that I know of

14. Do you know anyone whose child receives (or received in the past) services from a speech/language pathologist?

Yes

Not that I know of

15. Do you know anyone whose child receives (or received in the past) services from a psychologist, therapist, or other kind of mental health professional?

Yes

Not that I know of

16. Do you know anyone whose child receives (or received in the past) services from a physical therapist (PT) or occupational therapist (OT)?

Yes

Not that I know of

APPENDIX B: VIGNETTE

Vignette

Imagine that John is your four-year-old son. As a baby he met most of his developmental milestones (such as walking and talking) on time, with the exception of not being toilet trained until around three years of age. You go to John's school halfway through the year to check on his progress. He's had his hearing and vision tested at school and both were fine. His teacher reports that he sometimes does not follow classroom rules, has a hard time sitting still, and sometimes gets upset easily when he does not understand a task. John sometimes has tantrums when things do not go his way, but they are small tantrums and the teacher is usually able to calm him down easily. John can play well alone, but he usually plays with the other children at school and appears to have many friends. John reportedly has a lot of energy and runs around the playground during recess, playing games and pretending with the other children. John's teacher reports that he does well with answering questions in the classroom and his favorite things to talk about are superheroes and having super powers.

Imagine that John is your four-year-old son. As a baby he met most of his developmental milestones (such as walking and talking) on time, with the exception of not being toilet trained until around three years of age. You go to John's school halfway through the year to check on his progress. He's had his hearing and vision tested at school and both were fine. His teacher reports that he sometimes does not follow classroom rules, has a hard time sitting still, and often gets upset easily when he does not understand a task. John often has mild tantrums and is hard to calm down when things do not go his way or when his schedule or routine are changed. John often plays alone and does not appear to have many friends, but he sometimes plays with the other children at school. John reportedly has a lot of energy and runs around the playground during recess pretending to be a superhero instead of playing with the other children. John's teacher reports that he talks about superheroes and having super powers all the time; even when he's asked about other unrelated things.

Imagine that John is your four-year-old son. As a baby he met many of his developmental milestones (such as walking and talking) later than other children and was not toilet trained until around three and a half years of age. You go to John's school halfway through the year to check on his progress. He's had his hearing and vision tested at school and both were fine. His teacher reports that he usually does not follow classroom rules, has a hard time sitting still, and typically gets upset easily when he does not understand a task. John often has severe tantrums and is hard to calm down when things do not go his way or when his schedule or routine are slightly changed. John doesn't seem to have any friends. He typically stays alone and never seems to play with other children at school. John reportedly has a lot of energy and runs around the playground during recess: flapping his arms and making squealing noises. John's teacher reports that he does not talk much and often makes noises or repeats what other people say when he's asked a question.

APPENDIX C: FOLLOW-UP QUESTIONS

Follow-Up Questions

John is your child. For each of the following questions or statements, choose the best answer from the choices provided below.

1. John's behaviors are

No different from (or are the same as) other children his age	Mildly different from other children his age	Moderately different from other children his age	Significantly different from other children his age
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2. John is... (choose the one that best applies)

An active normal boy	A boy who has a medical disorder (like diabetes)	A boy who has a developmental disorder (like autism spectrum disorder)	A boy who has an intellectual disorder (like mental retardation)	A boy who has an emotional disorder (like depression)
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3. How concerned are you about John?

I'm not at all concerned	I have very few concerns	I have some concerns	I have a lot of concerns
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4. John exhibits some challenging behaviors. How much will they impact you and the other members of your family?

They won't really affect us.	They will affect us a very little bit.	They will affect us some.	They will affect us a lot.
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5. How much will his behaviors affect his school life and learning?

They won't really affect him.	They will affect him a very little bit.	They will affect him some.	They will affect him a lot.
-------------------------------	---	----------------------------	-----------------------------

6. John exhibits some challenging behaviors. Rank the following items in terms of how helpful they would be for John... (Items ranked with a 1 are MOST helpful while items marked with a 4 are LEAST helpful. NOTE: you will only be able to choose each number ONE time.)

- Nothing (he will grow out of this)
- More discipline (e.g., spankings, time outs, etc.)
- Medication
- The help of a specialist

7. John exhibits some challenging behaviors. Rank the following behaviors in terms of what you would do... (Items ranked with a 1 are MOST likely while items marked 7 are LEAST likely. NOTE: you will only be able to choose each number ONE time.)

- I would not talk to anyone
- I would talk to my family members or friends
- I would talk to a religious or church leader
- I would talk to John's pediatrician
- I would read about behaviors like John's in books or on the internet
- I would talk to a psychologist or another kind of therapist
- I would talk to John's school (e.g., principal, teacher, etc.)

The remainder of this questionnaire is no longer about John. For each item, indicate whether you strongly disagree, disagree, somewhat disagree, somewhat agree, agree, or strongly agree. The term "psychological problems" refer to reasons one might visit a professional. Similar terms include mental health concerns, emotional problems, mental troubles, and personal difficulties. The term "professional" refers to individuals who have been trained to deal with mental health problems (e.g., psychologist, psychiatrist, social workers, and physicians).

APPENDIX D: PATPSI

Parental Attitudes Toward Psychological Services Inventory (PATPSI; Turner, 2011)

1. I would not want others (friends, family, teachers, etc.) to know if my child had a psychological or behavior problem

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

2. To avoid thinking about my child's problems, doing other activities is a good solution

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

3. Having mental illness carries with it feelings of shame

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

4. If my child were experiencing a serious psychological or behavior problem at this point in my life, I would be confident that I could find relief in professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

5. If my child were to experience a psychological or behavior problem, I would get professional help if I wanted to

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

6. Important people in my life would think less of my child if they were to find out that (s)he had a psychological or behavior problem

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

7. Psychological problems tend to work out by themselves

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

8. It would be relatively easy for me to take my child to see a professional for help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
-------------------	----------	-------------------	----------------	-------	----------------

9. I would want to get professional help if my child were worried or upset for a long period of time

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

10. I would be uncomfortable seeking professional help for my child because people (friends, family, coworkers, etc.) might find out about it

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

11. I would not want to take my child to a professional because what people might think

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

12. There is something admirable in the attitude of people who are willing to cope with their conflicts and fears without seeking professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

13. If I believed my child were having a mental breakdown, my first decision would be to get professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

14. I would feel uneasy going to a professional because of what some people would think

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

15. Strong willed individuals can handle emotional or behavior problems without needing professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

16. Had my child received treatment for a psychological or behavior problem, I would feel that it ought to be “kept secret”

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

17. I would be embarrassed if my neighbor saw me going into the office of a professional who deals with mental health concerns

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

18. People should work out their own problems instead of getting professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

19. There are things that happen in my family I would not discuss with anyone

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

20. Seeking professional help is a sign of weakness

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

21. Strong willed parents can handle problems without professional help

strongly disagree	disagree	somewhat disagree	somewhat agree	agree	strongly agree
----------------------	----------	----------------------	-------------------	-------	-------------------

APPENDIX E: GBMMS

Group Based Medical Mistrust Scale (GBMMS; Thompson et al., 2004)
(modified to a six point scale similar to PATPSI)

1. Doctors and health care workers sometimes hide information from patients who belong to my ethnic group

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

2. Doctors have the best interests of people of my ethnic group in mind

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

3. People of my ethnic group should not confide in doctors and health care workers because it will be used against them

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

4. People of my ethnic group should be suspicious of information from doctors and health care workers

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

5. People of my ethnic group cannot trust doctors and health care workers

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

6. People of my ethnic group should be suspicious of modern medicine

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

7. Doctors and health care workers treat people of my ethnic group like “guinea pigs”

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

8. People of my ethnic group receive the same medical care from doctors and health care workers as people from other groups

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

9. Doctors and health care workers do not take the medical complaints of people of my ethnic group seriously

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

10. People of my ethnic group are treated the same as people of other groups by doctors and health care workers

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

11. In most hospitals, people of different ethnic groups receive the same kind of care.

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

12. I have personally been treated poorly or unfairly by doctors or health care workers because of my race

strongly disagree disagree somewhat disagree somewhat agree agree strongly agree

APPENDIX F: PARENT AUTISM KNOWLEDGE QUESTIONNAIRE

Parent Autism Knowledge Questionnaire

Please indicate whether or not you agree with each of the following statements.

Note: the term “autism” is synonymous with the recent classification term “autism spectrum disorder”.

1. True False Early intervention can lead to large gains in social and communication skills for children with autism.
2. True False Children with autism do not show attachments, even to parents/caregivers.
3. True False Many children with autism do not have mental retardation and are just as smart as other children.
4. True False Children with autism are purposely uncooperative and non-compliant with requests.
5. True False It is important that children with autism receive some form of special education services at school.
6. True False Autism occurs more frequently in the children of parents with higher income and education levels.
7. True False Poor parenting can cause autism.
8. True False It is possible for children with autism to “outgrow” it.
9. True False Autism tends to run in families.
10. True False Children with autism have facial abnormalities and characteristics that make them distinguishable from children without the disorder.
11. True False We now have treatments that can cure autism.
12. True False Children with autism can grow up to live independently.
13. True False Some medications help children with autism be more social.
14. True False Behavior interventions can lead to higher IQs and higher everyday functioning for children with autism.

APPENDIX G: TABLES AND FIGURES

Table 1

Descriptive Statistics by Race

	Full		Caucasian		African American	
	N	%	N	%	N	%
Age						
18-29	43	(36.1)	18	(31.0)	25	(41.0)
30-39	60	(50.4)	30	(51.7)	30	(49.2)
40-49	8	(7.6)	6	(10.3)	3	(4.9)
50+	7	(5.9)	4	(6.9)	3	(4.9)
Marital Status						
single/never been married	42	(35.3)	2	(3.4)	40	(65.6)
married	70	(58.8)	51	(87.9)	19	(31.1)
separated	0	(0)	0	(0)	0	(0)
divorced	5	(4.2)	4	(6.9)	1	(1.6)
other	2	(1.7)	1	(1.7)	1	(1.6)
Highest level of education						
no H.S. completion	4	(3.4)	0	(0)	4	(6.6)
GED/high school diploma	12	(10.9)	3	(5.2)	10	(16.4)
tech. prog./comm. college	7	(5.9)	2	(3.4)	5	(8.2)
some college	24	(20.2)	12	(20.7)	12	(19.7)
college degree	37	(31.1)	19	(32.8)	18	(29.5)
some graduate school	8	(6.7)	5	(8.6)	3	(4.9)
graduate or professional	26	(21.8)	17	(29.3)	9	(14.8)

Table 2

Descriptive Statistics by Race Continued

	Full		Caucasian		African American	
	N	%	N	%	N	%
Total household income						
≤ \$9,999	19	(16.0)	1	(1.7)	18	(29.5)
\$10,000-\$19,999	18	(15.1)	5	(8.6)	13	(21.3)
\$20,000-\$29,000	14	(11.8)	3	(5.2)	11	(18.0)
\$30,000-\$39,000	11	(9.2)	5	(8.6)	6	(9.8)
\$40,000-\$49,000	5	(4.2)	2	(3.4)	3	(4.9)
\$50,000-\$59,000	6	(5.0)	4	(6.9)	2	(3.3)
\$60,000-\$69,000	7	(5.9)	3	(5.2)	4	(6.6)
\$70,000-\$79,000	7	(5.9)	6	(10.3)	1	(1.6)
\$80,000-\$89,000	8	(6.7)	6	(10.3)	2	(3.3)
\$90,000-\$99,000	6	(5.0)	6	(10.3)	0	(0)
≥ \$100,000	18	(15.1)	17	(29.3)	1	(1.6)
Number of children						
1	31	(26.1)	12	(20.7)	19	(31.1)
2	42	(35.3)	21	(36.2)	21	(34.4)
3	27	(22.7)	20	(34.5)	7	(11.5)
4+	19	(16.0)	5	(8.6)	14	(23.0)
Employment Status						
Unemployed	39	(32.8)	17	(29.3)	22	(36.1)
Employed part-time	17	(14.3)	14	(24.1)	3	(4.9)
Employed full-time	58	(48.7)	27	(46.4)	31	(50.8)
full/part-time student	5	(4.2)	0	(0)	5	(8.2)
Child's health insurance coverage						
no-insurance	3	(2.5)	3	(5.2)	0	(0)
Medicaid	60	(50.4)	9	(15.3)	51	(83.6)
private insurance	56	(47.1)	46	(79.3)	10	(16.4)

Table 3

Means and Standard Deviations Across Measures

Variable	Full Sample	Caucasian	African American
PATPSI Help Seeking Intentions	25.434 (3.795)	25.315 (3.452)	25.542 (3.949)
PATPSI Mental Health Stigma	39.062 (5.813)	38.537 (5.361)	39.542 (6.204)
PATPSI Total Score	101.487 (11.316)	101.333 (10.800)	101.627 (11.860)
GBMMS Medical Suspicion	11.965 (5.624)	10.407 (4.981)	13.390 (5.837)
GBMMS Treatment Disparities	8.009 (3.540)	6.778 (2.982)	9.135 (3.655)
GBMMS Total Score	26.832 (10.742)	22.611 (8.732)	30.695 (11.018)
Autism Knowledge Scale	11.259 (1.587)	11.315 (0.797)	9.983 (1.701)

Note: Means given with standard deviations in parentheses (SD)

Table 4

Correlational Matrix of Demographic Variables

	1	2	3	4	5
1. Age	1	.339**	.373**	.130	-.019
2. Education	.339**	1	.579**	-.115	.242**
3. Income	.373**	.579**	1	.014	.208*
4. Number of Children	.130	-.115	.014	1	-.060
5. Weekly Working Hours	-.019	.242**	.208*	-.060	1

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Figure 1
Help Seeking Preferences

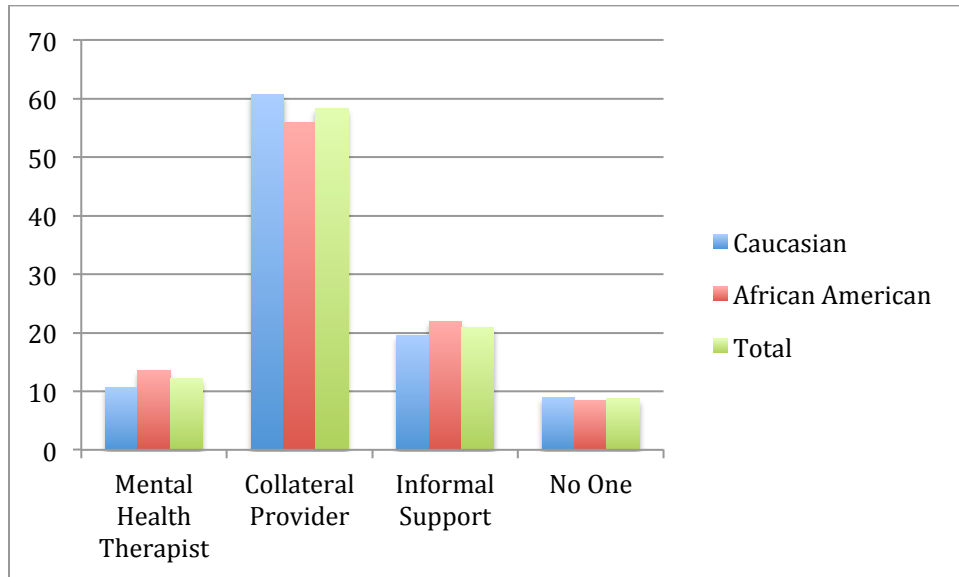


Figure 2

Most Helpful Treatment for Typical Child

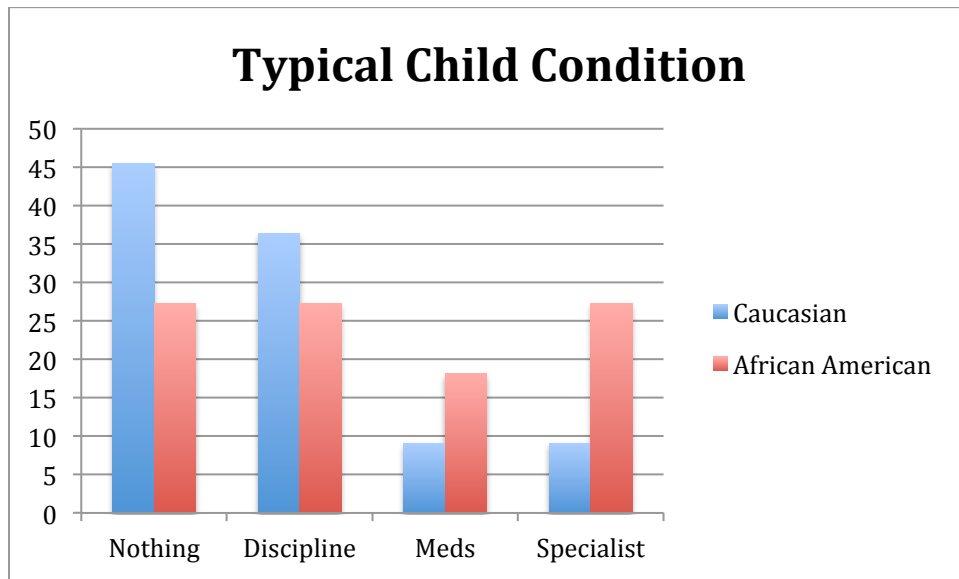


Figure 3

Most Helpful Treatment for Mild ASD

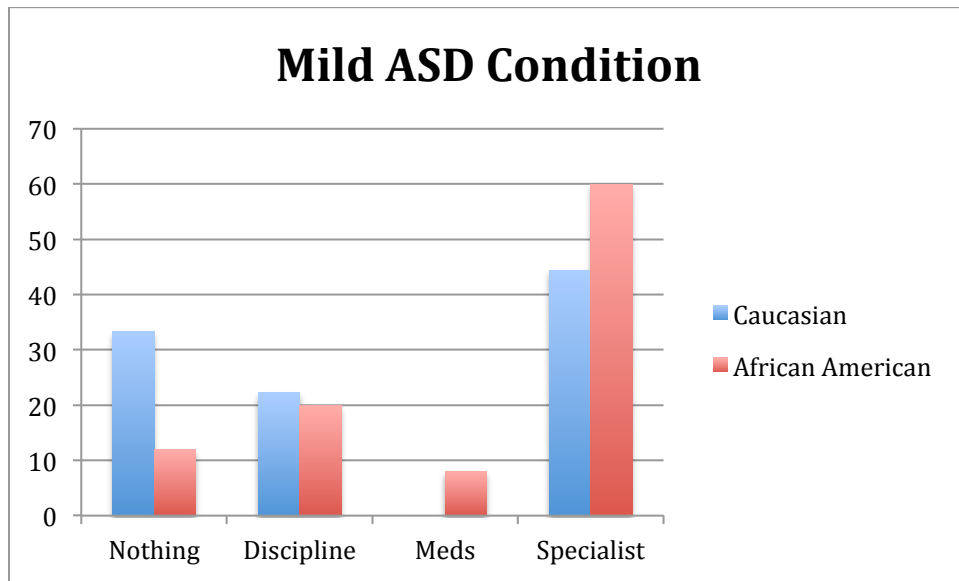


Figure 4

Most Helpful Treatment for Moderate-to-Severe ASD

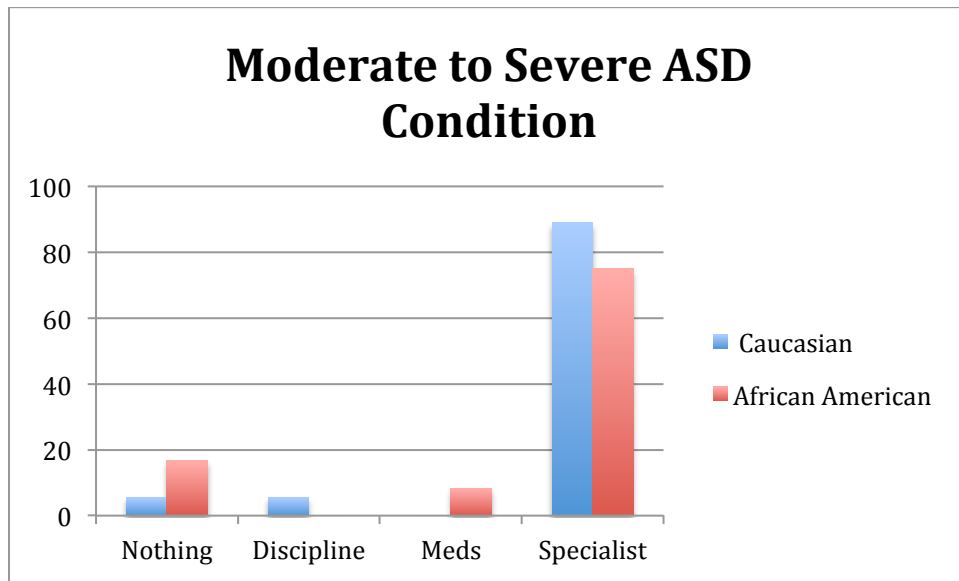
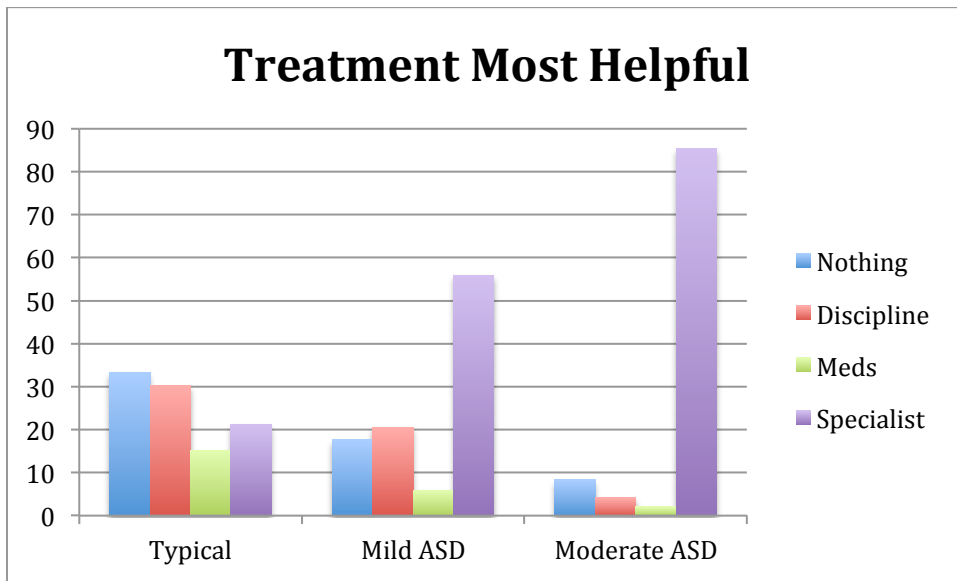


Figure 5

Most Helpful Treatment per Category



VITA

EDUCATION

University of Tennessee Professional Psychology Internship Consortium, University of Tennessee Health Science Center, Memphis, TN
APA-Accredited Pre-doctoral Internship, 2013-2014 (end date: August 8, 2014)

University of Mississippi, University, MS

Ph.D., Clinical Psychology, degree requirements completed September 2014

Dissertation: *“Autism Spectrum Disorder: The role of ethnicity and culture in parent interpretation and service utilization”*

Alan M. Gross, Ph.D. (Chair), Kelly G. Wilson, Ph.D., John N. Young, Ph.D., Debra J. Moore, Ph.D.

M.A., Clinical Psychology, May 2012

Thesis: *“An Examination of the Relationship Between an Autism Label and Teachers’ Attitudes, Expectations, and Behavioral Intentions”*

Alan M. Gross, Ph.D. (Chair), Kelly G. Wilson, Ph.D., John N. Young, Ph.D.

Xavier University of Louisiana, New Orleans, LA

B.A., May 2004

Major: Psychology

Minor: Elementary Education

HONORS AND AWARDS

2004	Kappa Gamma Pi (National Catholic College Graduate Honor Society)
2003-2004	Alpha Kappa Mu (National Honor Society)
2002	Volunteer of the Semester Award, Xavier University of Louisiana
2001-2004	Psi-Chi (National Psychology Honor Society)
2000-2004	Dean’s List, Xavier University of Louisiana
2000-2004	Academic Scholarship, Xavier University of Louisiana

PROFESSIONAL AFFILIATIONS

American Psychological Association, Student Affiliate (APA)
American Association on Intellectual and Developmental Disabilities (AAIDD)
Association for Behavior Analysis International (ABAI)
Association for Contextual Behavioral Science (ACBS)
Mississippi Psychological Association, Student Affiliate (MPA)

SUPERVISION OF CLINICAL EXPERIENCE

5/2013- 6/2013

Co-Supervisor for Graduate Student Group Therapists

Psychological Services Center, The University of Mississippi, MS

On-campus outpatient clinic

Duties: With the assistance of a licensed clinical supervisor, provide in-vivo and group supervision for graduate student therapists facilitating a social skills group for pre-teens with ASD and a simultaneous group for their parents; assist with constructing curriculum.

Supervisor: J. Scott Bethay, Ph.D.

SUPERVISED CLINICAL EXPERIENCE

8/2013- 8/2014

Pre-doctoral Psychology Intern

University of Tennessee Professional Psychology Consortium,

University of Tennessee Health Science Center, Memphis, TN

Rotations:

UT Center of Excellence for Children in State Custody

Part of a statewide network of pediatric referral centers to serve children in state custody and those at risk of entering state custody.

Duties: conduct comprehensive psychological evaluations, record reviews, and clinical interviews for children in state custody and those at risk of entering state custody; participate in multidisciplinary team staffing four mornings per week; staff clients in a multidisciplinary team staffing; prepare a presentation for staff, faculty, and trainees regarding Applied Behavior Analysis as it is used for individuals with ASD and eating/feeding difficulties.

Supervisors: Janet Todd, Ph.D., Kerrie Murphy, Ph.D.

Child and Adolescent Psychiatry

Duties: conduct outpatient therapy with children and adolescents (ages 2-16) with a variety of presenting problems (depression, separation anxiety, history of trauma, disruptive behavior problems, OCD, anger and aggression, parent-child relationship problems) in a community mental health clinic; participate in didactics and trainings with Psychiatry Residents and Fellows.

Supervisor: Melissa Hoffmann, Ph.D.

Parent-Child Interaction Therapy Clinic

Duties: receive training and supervision in Parent Child Interaction Therapy (PCIT) by PCIT In-House Trainers; conduct PCIT with families of children aged 3-6 with disruptive behavior problems; train in Dyadic Parent-Child Interaction Coding System (DPICS; observational parent-child assessment)

Future Duties: complete requirements during training year to become

officially trained PCIT therapist as designated by PCIT International.
Supervisor: Kerrie Murphy, Ph.D.

Boling Center for Developmental Disabilities

University Center of Excellence in Developmental Disabilities (UCEDD) and Leadership and Education in Neurodevelopmental Disabilities (LEND) program as well as a center specializing in developmental disabilities

Duties: participate in Interdisciplinary Leadership training; conduct comprehensive interdisciplinary assessments for children (primary diagnoses: ASD, IDD, ADHD, Disruptive Behavior Disorders); provide Applied Behavior Analysis (ABA) to clients; develop and administer ABA programs, collect data, and present data to families; train parents to administer ABA programs at home.

Supervisors: Amber Hasty-Mills, Psy.D., Colby B. Reed, Ph.D.

CANDLE Project (Conditions Affecting Neurocognitive Development and Learning in Early Childhood)

Duties: conduct cognitive and socio-emotional assessments as part of a large-scale longitudinal study of infant development (children ages 1-4); provide feedback and appropriate referrals to parents based on assessment results.

Supervisor: Laura Murphy, Ed.D.

Exchange Club Family Center

Duties: Conduct individual and family therapy with children and parents referred due to trauma exposure and other mental health conditions; conduct individual therapy with adults with a history of domestic violence or other history of trauma exposure; conduct psychoeducational groups with children and parents

Supervisor: Catherine Collins, Ph.D.

St. Jude Children's Research Hospital

Future Duties: conduct medical record reviews; conduct neurobehavioral screening assessments with children (ages 8 to 12) with sickle cell disease as part of the St. Jude Comprehensive Sickle Cell Program; interpret test results, conceptualize cases based on detailed behavioral observations and data from the assessment, and write reports.

Supervisors: Jane Schreiber, Ph.D., Darcy Raches, Ph.D.

8/2007- 8/2013
(10-20 hours/week)

External Practicum

Education and Research Intern/Research Assistant

Education and Research Dept., The Baddour Center, Senatobia, MS
Private residential facility for adults with mild to moderate intellectual disabilities

Duties: Conduct assessments (intellectual, adaptive behavior,

medication side-effects, dementia, social skills, functional behavior); provide individual and group therapy (grief group, roommates groups, social skills groups, disability support groups) to residents; train staff; develop and implement behavior plans; assist with various research projects.

Supervisor: Shannon L. Hill, Ph.D.

9/2006- 8/2013
(6 hours/week)

Behavioral Consultant

Behavior, Attention, and Developmental Disabilities Consultants, LLC
School districts in northern counties of Mississippi including, Tunica County, Coahoma County, Lafayette County, and Tate County

Duties: Conduct assessments (full battery assessments, functional behavior assessments, risk assessments) and provide written reports; lead IEP and eligibility meetings; provide teacher and classroom consultations, staff in-services, and trainings for teachers and personal aides; monitor ABA/discrete trial programs; social skills training (individual and group); provide classroom supports for children with developmental disabilities.

Supervisors: Emily Thomas-Johnson, Ph.D., BCBA-D and Sheila Williamson, Ph.D., BCBA-D

8/2005- 7/2013
(2-5 hours/week)

In-house Practicum

Graduate Student Therapist

Psychological Services Center, The University of Mississippi, MS
On-campus outpatient clinic

Duties: Conduct screenings and intake interviews; provide individual and group therapy; attend weekly supervision meetings; provide and receive feedback during weekly meetings.

Supervisors: Alan Gross, Ph.D., Kelly Wilson, Ph.D., Thomas Lombardo, Ph.D., John Young, Ph.D., Karen Christoff, Ph.D., Laura Johnson, Ph.D.

9/2012- 5/2013
(4 hours/week)

Behavioral and Mental Health Consultant

Head Start Preschools, Northern MS

Duties: Behavioral programming, teacher support, classroom management consultation, and family services for referred children experiencing challenging behaviors at school.

Supervisor: Alan M. Gross, Ph.D.

9/2010- 5/2011
(10 hours/week)

External Practicum

Behavioral Consultant

Baptist Children's Village, Water Valley, MS
Residential setting for privately placed children and children with state appointed guardians

Duties: Revise the agency's token economy system; direct and participate in group-supervision during team meetings; staff training;

keep records of behaviors in the home.
Supervisor: Randy Cotton, Ph.D.

8/2009- 5/2010
(8 hours/week)

External Practicum

Graduate Student Therapist

Psychological Services Center, The University of Mississippi, MS
Satellite-campus student center

Duties: Conduct screenings and intake interviews; provide individual and group therapy; provide career counseling services; attend - weekly supervision meetings.

Supervisors: Scott Gustafson, Ph.D.

8/2007- 5/2008
(2 hours/week)

In-house Practicum

Clinic Administrative Group Member

Psychological Services Center, The University of Mississippi, MS
On-campus outpatient clinic

Duties: Serve as a liaison with graduate student therapist supervision groups; manage clinic database; financial accounting assistant.

Supervisor: D. Scotty Hargrove, Ph.D.

8/2006- 7/2007
(10 hours/week)

External Practicum

Behavioral Consultant

Desoto County School System, Desoto County, MS

Duties: Facilitate social skills groups (students with Pervasive Developmental Disorders, ADHD, intellectual disabilities); provide teacher and classroom consultations; conduct assessments and provide written reports (functional behavior assessments and full battery assessments).

Supervisor: Sheila Williamson, Ph.D., BCBA-D

7/2006- 7/2007
(6-8 hours/week)

Therapist in Applied Behavior Analysis (Discrete Trial)

Private residence, Oxford, MS

Duties: Provide in-home discrete trial training for a child with autism.

Supervisor: Emily Thomas Johnson, Ph.D., BCBA-D

6/2005- 8/2006
(6 hours/week)

Assistant to Clinical Psychologist

Family Services of North Mississippi (Private Practice), Tupelo, MS

Duties: Conduct comprehensive psychological evaluations with children and adolescents.

Supervisor: Dr. Priscilla Roth-Wall, PhD.

8/2005- 7/2006
(20 hours/week)

External Practicum

Psychology Intern

North Mississippi Regional Center (NMRC), Oxford, MS

ICF/MR for individuals with mild to profound intellectual disabilities

Duties: Provide individual and group counseling services; write and

create behavior plans; conduct assessments (intellectual, adaptive behavior skills, medication side-effects, dementia); attend psychiatric consults regarding the use of psychotropic medications; assist individuals with communication devices; lead group and individual social skills trainings.

Supervisor: Dr. Kimberly Sallis, PhD.

9/2003- 5/2004
(10 hours/week)

Intern

School Related Internship: CASA Jefferson, Harvey, LA

Duties: Assist advocate supervisors with research regarding foster children; type Case Studies for the agency; perform office tasks.

Supervisor: Pat Sylvester, M.S.

SELECT PROFESSIONAL TRAININGS

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). 2014. University of Tennessee Health Science Center (UTHSC), Memphis, TN. Attended 2-day in-house training on the ADOS-2 in addition to currently working towards completion of DVD/video training necessary for certification.

N-CAST Parent-Child Interaction Teaching Scales. 2013. University of Tennessee Health Science Center (UTHSC), Memphis, TN. Attended 2-day training and completed requirements for certification and reliability in administration of this measure.

NONCLINICAL WORK WITH INDIVIDUALS WITH DISABILITIES

2002- 2003
(seasonal)

Direct Support Personnel for Residential Respite

Abraham Lincoln Centre, Chicago, IL

Temporary residential placement for children and adolescents with developmental disabilities.

Duties: Assist and instruct the children with daily living skills; provide recreational therapy; aid with the use of assistive communication devices; conduct play activities; provide educational tutoring.

Supervisor: Wanda Barnes, M.S.

2001- 2003
(seasonal)

Direct Support Personnel for Family CILA

Abraham Lincoln Centre, Chicago, IL

Residential facility for individuals with intellectual and developmental disabilities.

Duties: Assist with and provide parent and daily living skills training for mothers who have intellectual disabilities; medication upkeep and administration; provide educational tutoring; develop and implement a summer camp for children.

Supervisor: Lyntica Seawood, M.S.

TEACHING/TRAINING POSITIONS

- 8/2007- 8/2013 ***Education and Research Intern/Research Assistant***
The Baddour Center, Senatobia, MS
Duties: Conduct in-service trainings for staff members on behavior analysis, specific disabilities, and supporting resident relationships; facilitate teamwork in both the work environment as well as with residents.
Supervisor: Shannon Hill, Ph.D.
- 9/2006- 8/2013 ***Behavioral Consultant***
Behavioral, Attention, and Developmental Disabilities Consultants, LLC
Duties: Conduct in-services regarding dealing with challenging behaviors, Special Education rulings, and specific disabilities; work with teachers on following functional behavior plans; provide individual aides and teachers with training on Applied Behavior Analysis/Discrete Trial Training.
Supervisors: Emily Thomas Johnson, Ph.D., BCBA-D and Sheila Williamson, Ph.D., BCBA-D
- 8/2011- 5/2013 ***Instructor of Record***
Abnormal Psychology (PSY 311)
University of Mississippi, Southaven, MS
Duties: All aspects of instruction including textbook and readings selection, syllabus and exam construction, lecture development and delivery, and assignment of grades for this undergraduate course.
Supervisor: Alan M. Gross, Ph.D.
- Fall 2007 ***Student***
Seminar on College Teaching
University of Mississippi, University, MS
Coursework duties: Create a syllabus for a 15 week course in Abnormal Psychology; prepare and deliver an Abnormal Psychology lecture to a small number of students which incorporated learning objectives, active learning techniques, exam questions, and outcome measures; receive peer review of the lecture; provide peer review for colleagues' lectures; create a teaching portfolio with a statement of Teaching Philosophy; join and contribute to the Society for the Teaching of Psychology Listserv; serve as a guest lecturer for a colleague's Abnormal Psychology class.
Supervisor: Kenneth J. Sufka, Ph.D.
- 8/2005- 7/2006 ***Psychology Intern***
North Mississippi Regional Center, Oxford, MS
Duties: Provide Direct Care Workers with monthly behavior analysis training.
Supervisor: Kimberly Sallis, Ph.D.

RESEARCH POSITIONS

8/2007- 8/2013

Education and Research Intern/Research Assistant

The Baddour Center, Senatobia, MS

Duties: Design and implement research projects; conduct group interventions; collect and analyze data; present findings at conferences.

Research Areas: Video modeling and social skills improvements for individuals with intellectual disabilities; grief interventions for individuals with intellectual disabilities; peer relationships and social skills interventions for individuals with intellectual disabilities; variables affecting residential service selection for families of individuals with intellectual disabilities; staff training in behavior analysis.

Supervisor: Shannon Hill, Ph.D.

8/2004- 7/2013

Research Team Member

The University of Mississippi, University, MS

Duties: Assist in designing research projects; provide feedback for team member research proposals; assist with data collection; design and implement individual projects.

Supervisor: Alan M. Gross

PUBLICATIONS AND PRESENTATIONS

Hamblin, R. J., **Johnson, C. N.**, Luchkiew, T. K., & Young, J. N. (in progress). *Teacher Perceptions of Mental Health in Public Schools*.

Johnson, L. R., Hankton, U. N., Bastien, G., **Johnson, C. N.** (2011, November). *Positive Youth Development and Civic Engagement in an International Context*. Presented at the Caribbean Regional Conference of Psychology. Nassau, Bahamas.

Bastien, G., **Johnson, C. N.**, Martin, R. C., & Hankton, U. N. (2011, August). *Assessment of the Campus Climate for GLBT Students and the Programmatic Response at a Conservative Southern University*. Presented at the APA Conference. Washington, D. C.

Hamblin, R. J., **Johnson, C. N.**, Slater, R. M., & Young, J. (2010, June). Teacher perceptions of appropriate mental health practice. In J. N. Young (Chair), *Behavioral Principles Applied to System Issues: The Role of Good Science in Building Good Relationships*. Symposium conducted at the 36th annual Association for Behavior Analysis International, San Antonio, TX.

Hill, S. L. & **Johnson, C. N.** (2010, June). *Parental reflections on raising a child with intellectual disability: Advocacy variables*. Poster session presented at the annual meeting of the American Association on Intellectual and Developmental Disabilities, Providence, RI.

- Hill, S. L., Gardner, C., & **Johnson, C. N.** (2009). Pilot study of a grief group intervention for people with Intellectual Disabilities: Process and Outcomes. *The NADD Bulletin*, 12, 85-92.
- Williamson, S., Nassar, S. L., & **Johnson, C.** (2009, October). Elementary and Middle School Interventions. In E. T. Johnson (Chair), *Tutorial: Clinical Strategies within the Classroom for Children with Autism*. Symposium presented at the 60th Annual Conference of the Mississippi Psychological Association, Gulfport, MS.
- Hill, S. L. & **Johnson, C. N.** (2009, October). *Advocacy Behaviors of Parents of Adults with Intellectual Disabilities: The Supermom Phenomenon*. Program presented at the 28th annual Mississippi Joint Conference on Mental Health and Mental Retardation, Philadelphia, MS.
- Durkee, A. O., **Johnson, C. N.**, & Hill, S. L. (2008, November). *The effect of a staff training program on perceived competence and job stress*. Poster session presented at the annual meeting of the Association for Behavioral and Cognitive Therapies, Orlando, FL.
- Johnson, C. N.** & Hill, S. L. (2008, November). *Grief group therapy for adults with Intellectual Disabilities: Process and outcomes*. Paper presented at the annual Mental Health/Mental Retardation joint conference, Philadelphia, MS.
- Durkee, A. O. & **Johnson, C. N.** (2008, November). *Supporting residents through supporting staff: A model for a staff support group with behavior analysis training*. Paper presented at the annual Mental Health/Mental Retardation joint conference, Philadelphia, MS.
- Hill, S., Gardner, C., **Johnson, C.**, Surdock, A., & Durkee, A. (2008, May). *Grief group therapy for adults with intellectual disabilities: Process and outcomes*. Poster session presented at the annual meeting of the American Association on Intellectual and Developmental Disabilities, Washington, D.C.

REFERENCES

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