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Perceived Barriers to Autism Spectrum Disorder Services

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PERCEIVED BARRIERS TO AUTISM SPECTRUM DISORDER SERVICES

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
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ABSTRACT

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder with hallmark symptoms that can be severely impairing to both the individual and the overall family dynamic. The path to diagnostic and therapy services is often lengthy and complex. Despite various state and federal efforts to improve service access, disparities remain evident across ethnic, socioeconomic, and geographic lines with caregivers reporting financial, cultural, geographic, and practical (e.g., transportation, scheduling) barriers. For those able to access treatment, several interventions have been proven efficacious in addressing ASD symptoms, problem behaviors, and adaptive skills deficits. Other often-used interventions include those without established merit for ASD. This study found a tendency for income, insurance type, and ethnicity to affect service access. Out of pocket costs remain a significant barrier to evidence-based services. Scheduling difficulties and long wait lists impact diagnostic services, as do perceptions of misguided reassurances from professionals (e.g., healthcare worker stating "he'll grow out of it"). Disparities in service use indicate a need to develop policy, practice, and family-level strategies to address barriers to ASD services.

CHAPTER 1: INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder marked by difficulties in three domains: communication, socialization, and restricted or repetitive behaviors, activities, or interests (e.g., hand flapping, preoccupation with parts of objects, intense interest in narrow subjects; Matson, Dempsey, & Fodstad, 2009). As a neurodevelopmental disorder, ASD is present from birth, is typically evident in early childhood, and is usually diagnosed in the first few years of life. Until the recent publication of the 5th edition of the *Diagnostic and Statistical Manual of Mental Disorders* in May 2013 (*DSM-5*; American Psychiatric Association [APA], 2013), ASD as a *DSM-IV-TR* category included five disorders. As outlined in the previous version of this widely used manual, the *DSM-IV-TR* (APA, 2000), these disorders included Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS); each disorder was marked by varying degrees of deficiencies in communication, social skills, and repetitive / restricted behaviors or interests.

Significant changes in ASD diagnostic criteria in the *DSM-5* (APA, 2013) include removal of Rett's Disorder and the collapse of the remaining diagnoses into one diagnosis: Autism Spectrum Disorder. Socialization and communication deficits have been combined into one domain in which an individual must meet all three symptoms (i.e., deficits in nonverbal communication during social interactions, lack of social reciprocity, and deficits in developing and maintaining developmentally appropriate relationships) in order to receive an ASD diagnosis (APA, 2013). Under the *DSM-5,* individuals must also meet two of the following criteria: stereotyped or repetitive speech, motor movements, or object use; adherence to routines or ritualized patterns of behavior; highly restricted interests which are abnormal in intensity or

focus; or abnormal hypo- or hyper-reactivity to sensory input. The age of onset criterion

includes early childhood, noting that some symptoms may not be fully evident until social

demands exceed the individual's level of functioning. To fully meet criteria for an ASD

diagnosis, symptoms must negatively impact the individual's ability to function in activities of

daily living. Lastly, individuals carrying an ASD diagnosis that was diagnosed using the *DSM-IV-TR* are permitted to retain their ASD diagnosis as the *DSM-5* is adopted. In the future,

however, these changes will undoubtedly impact the prevalence of ASD.

CHAPTER 2: PREVALENCE AND DIAGNOSTIC DISPARITIES

Prevalence of Autism Spectrum Disorder

In the early years of diagnostic conceptualization, ASD was considered to be a very rare disorder. Mid-20th century prevalence estimates indicated fewer than 10 in 10,000 individuals met ASD criteria at that time (Sevin, Knight, & Braud, 2007). Prevalence rates have increased drastically from these early estimates, reaching approximately 30-60 per 10,000 in the early 1990s (Inglese & Elder, 2009). Prevalence estimates released by the Centers for Disease Control and Prevention (CDC) indicated a prevalence of 1 in 150 in 2007 (CDC, 2007). More recent estimates increased to 1 in 88 (CDC, 2012) and then 1 in 68 (CDC, 2014), with a corresponding rise in concern about an autism "epidemic." Throughout the years, the male to female ratio described by Leo Kanner in the 1940s of approximately 4:1 has remained stable (Bertoglio & Hendren, 2009; Dawson, Mottron, & Gernsbacher, 2008; Rice et al., 2010; Inglese & Elder, 2009). In a recent epidemiological study, researchers estimated that there is little regional variation worldwide in ASD prevalence, with an average rate of approximately 1 in 132 (Baxter et al., 2014).

While ASD diagnostic rates have undoubtedly increased over the years, it is impossible to pinpoint a specific reason for the increase. It is likely that a confluence of factors have contributed to increased diagnostic rates. Differing methodology in various estimates affects results (Fombonne, 2009, Matson & Kozlowski, 2011). Furthermore, prevalence rates have been affected by changes to the criteria between *DSM* editions (Fombonne, Quirke, & Hagan, 2009; Matson & Kozlowski, 2011; Shattuck, 2006). Changes to criteria over the years may lead to diagnostic substitution; even minor changes in criteria may shift individuals from meeting criteria in one diagnostic category to another, and thus effect change in apparent prevalence rates

(Fombonne, 2009; Matson & Shoemaker, 2009). For example, changes between *DSM* editions have led to concomitant increases in ASD rates and decreases in intellectual disability (ID) rates in a process called diagnostic substitution (Fombonne, 2009; Leonard et al., 2010), though now it is customary to give both diagnoses where warranted with ASD as a primary diagnosis and ID as a secondary diagnosis (Matson & Shoemaker, 2009). ASD criteria were most recently updated with the release of the *DSM-5* in 2014; it is as yet unclear how much this change will affect prevalence rates. Though only time will tell, some researchers anticipate 30% or more decrease in new diagnoses due to the introduction of more stringent criteria that would likely exclude many who met *DSM-IV-TR* criteria for PDD-NOS, Asperger's Disorder, or ASD without concurrent ID (Frazier et al., 2012; Matson, Belva, et al., 2012; Mattila et al., 2011; McPartland et al., 2012; Worley & Matson, 2012).

Other factors impacting prevalence rate include increased awareness and acceptance of ASD, increased awareness of early symptoms, and increased service availability and screening efforts (Fombonne, 2009; Koenig et al., 2000; Leonard et al., 2010; Matson & Kozlowski, 2011). Increased awareness of ASD can lead to better identification, treatment, and outcome for many affected individuals, but increased awareness also increases the chance for misdiagnosis. ASD diagnosis can be complicated by heterogeneity of symptom expression and symptom overlap with other conditions (e.g., communication disorders; Matson & Kozlowski, 2011); it is likely that inexperienced clinicians may occasionally misdiagnose ASD, and it is possible that ASD diagnosis is being over-used (Leonard et al., 2010; Matson & Kozlowski, 2011). Additionally, it is possible that shifting environmental factors contribute to increased actual cases of ASD. Etiology is yet undetermined, but research indicates a confluence of biological and environmental factors increase the risk for ASD symptoms (Inglese & Elder, 2009). Fortunately,

the survival rate for premature births has increased significantly over the years; however, prematurity is recognized as a risk factor for later ASD diagnosis (Matson & Kozlowski, 2011). Improved medical care likely contributes to increased survival of children with risk factors (e.g., prematurity, genetic conditions) who go on to receive an ASD diagnosis.

Other factors affecting prevalence estimates include geography and cultural factors. Particularly in Asian countries, the concept of ASD is a relatively new one (Leonard et al., 2010; Matson & Kozlowski, 2011). In the United States, recent estimates have found significant differences in prevalence across ethnic groups; for example, the 2007 estimates released by the CDC noted significantly higher rates of ASD in non-Latino white children compared to minority groups (CDC, 2007). Perhaps affected by increased awareness and culturally sensitive diagnostic efforts, a decrease in the ethic gap was noted in the 2012 CDC report, though differences still exist (CDC, 2012), as discussed in the section on Diagnostic Process.

Diagnosis and Diagnostic Disparities

ASD is a neurodevelopmental disorder, so it is unsurprising that symptoms often become evident early on in life. Currently, researchers indicate that ASDs can often be reliably diagnosed as early as 18 months of age, with some researchers positing that the appropriate screening tools and assessment practices can reliably diagnose some children as young as 12 months of age (Council on Children with Disabilities, 2006; Kim & Lord, 2012). Parents often report concerns about their child's development before one year of age, long before other caregivers or healthcare providers notice concerning signs (Kishore & Bashu, 2011). Jónsdóttir and colleagues (2011) found that of children who later received an ASD diagnosis, 76.2% of parents were concerned about their child's development before 3 years of age (Jónsdóttir, Saemundsen, Antonsdóttir, Sigurdardóttir, & Ólason, 2011).

Despite parents' early concerns, many children are not diagnosed with ASD until school age. Shattuck and colleagues (2009) reviewed educational and medical records from 13 sites across the United States, and found that the median age at ASD diagnosis was 5.7 years. In this same study, the researchers noted that 27% of the students had undiagnosed ASD at age 8 years. Under the *DSM-IV-TR* criteria, which divided ASDs into Autistic Disorder, PDD-NOS, and Asperger's Syndrome, the CDC (2012) found the average age of diagnosis ranged from 4 years (Autistic Disorder) to 6 years, 3 months (Asperger's Disorder). In the case of children with Autistic Disorder, the most severe ASD category in the *DSM-IV-TR,* Chakrabarti (2009) found parents became concerned about their child's development when the child was around 23.4 months of age, and sought professional help approximately 4 months later. Despite an average point of first professional contact around 27 months, the mean time from the first evaluation to the diagnosis was 32 months (Chakrabarti, 2009). In total, this indicates a gap of about 2.5 years from point of first concern to a formal ASD diagnosis for the most severely affected category of children in this study—time during which the child and family might have benefitted from early intervention services. Interestingly, maternal age over 35 years has been associated with later recognition of autism symptoms by parents (Chawarska et al., 2006).

Many children receive one or more other psychological and/or developmental diagnoses before finally receiving an ASD diagnosis. To investigate the possibility of misdiagnosis, Yeargin-Allsopp and colleagues (2003) conducted a thorough review of educational and/or medical records to ascertain whether an ASD diagnosis was present in prior records and found 18% of children enrolled in special education services at that time had not been correctly classified as having an ASD. It can take months to receive an accurate ASD diagnosis even when developmental concerns are noted early on. Symptoms are heterogeneous, and may emerge or

change over time, highlighting the necessity of periodic re-evaluation. Individual factors associated with later diagnosis include being female, IQ over 70, moderate to mild ASD symptoms, and absence of developmental regression (Shattuck et al., 2009).

Recent efforts to improve early diagnosis have increased general awareness of early symptoms among parents and health care professionals, and resulted in greater research and development of measures designed for early ASD screening. These efforts have contributed to decreases in the average age of diagnosis (Charman & Baird, 2002). However, evident disparities in the diagnostic process still exist. Race, ethnicity, socioeconomic status (SES), and rural versus urban location remain concerns for professionals seeking to improve diagnostic and treatment services.

CHAPTER 3: INTERVENTIONS

According to the American Psychological Association, evidence-based practice (EBP) is practice that applies empirically supported principles to integrate the best available research with clinical expertise in the provision of psychological interventions (APA, 2002). The APA encourages EBP to "promote effective psychological practice and enhance public health," while acknowledging that an intervention that has not yet been carefully studied may one day prove to be effective (APA, 2002). Establishing treatments as EBP requires multiple carefully conducted research trials, and it takes time to gather enough strong evidence for any new efficacious intervention to become widely recognized as EBP. The need for establishing guidelines to separate EBP and non-EBP is based in the potential dangers of providers delivering non-EBP. Some non-EBPs may eventually be proven efficacious after adequate research, but wide use of non-EBPs exposes treatment-seeking individuals to greater risk of wasting time and resources on ineffective interventions, instead of allocating resources towards those interventions more likely to be efficacious. Greater ill effects of pursuing non-EBPs are also possible. In the treatment of ASD, non-EBPs range from relatively benign (e.g., animal-assisted therapy) to downright dangerous (e.g., chelation therapy), including controversial treatments (shock therapy) and interventions that have been proven effective for other conditions but not for ASD (e.g., gluten-free diet for individuals with celiac disease; National Autism Center, 2015). Navigating the ocean of touted autism interventions can be daunting with information regarding both EBP and non-EBP readily available via social media, support groups, etc. Information on EBP and non-EBP can even be found in the grocery checkout aisle (at least in Austin, Texas), where in 2012 the author picked up issues of *Autism Science Digest* (issues 3 and 4) and *Autism File: Hope and Help for Autism Families* (issue 44). These magazines had headlines such as "Fermentation and

the Gut: The Suppression of Science," "Stem Cell Therapy, Quantitative EEG, & Fecal

Microbiota Transplantation," "Breakthrough Vision Therapy: Transforming Learning and

Behavior" and "Therapeutic Application of Transcranial Magnetic Stimulation in Autism

Spectrum Disorders." When one can so easily pick up scientific-sounding journals with articles

written by MDs including statements such as "Hyperbaric therapy has been shown to be

beneficial in the treatment of autism. . . it is possibly that hyperbaric therapy may be acting

through mitochondrial hormesis to decrease oxidative stress and improve underlying metabolic

abnormalities in autism" (van Dyke, 2012) it is no wonder that parents may have difficulty

sorting out the wheat from the chaff when making treatment choices. (It appears that the *Autism

Science Digest* is now defunct, although its parent organization, Autism One, still hosts popular

annual conferences for parents with topics similar to those found in the former *Digest*.)

The National Autism Center initiated the National Standards Project to provide

guidelines informing professionals, educators, and caregivers about which treatments have been

shown effective in treating individuals with ASD (National Autism Center, 2015). The National

Standards Project categorizes a number of ASD interventions as established interventions,

emerging interventions (supported by some preliminary research results, but studies are not of

number and/or rigor to qualify them as EBP), and unsubstantiated.

Deyro and colleagues (2014) surveyed parents of children with ASD regarding available

ASD treatments and their perceived effectiveness and scientific validity of treatments included in

the National Standards Project. These researchers found that the majority of parents agreed with

the National Standards Report for only 9 out of the 26 treatments included in their survey. The

authors concluded much work remains for professionals who regularly interact with parents of

children with ASD in educating them and guiding them towards treatments most likely to be

efficacious. Complicating this goal, some non-EBPs are frequently recommended by clinicians and advertised on the internet in places likely to be frequented by parents (Deyro, Simon, & Guay, 2014).

<div align="center">**Established Interventions for Autism Spectrum Disorder**</div>

Methods Using Principles of Applied Behavior Analysis (ABA)

According to the National Standards Project, the principal category of established ASD interventions is Behavioral Interventions. This category includes a number of behavioral intervention packages that incorporate antecedent interventions (to modify the situational events typically preceding a target behavior) and consequent interventions (making changes to the environment following an instance of the target behavior; NAC, 2015). The identification of antecedent and consequent interventions is generally based on Applied Behavior Analysis (ABA), a process of systematically applying behavioral principles of human behavior and learning to effect desirable change in social behaviors (e.g., decreasing problem behaviors, teaching functional social skills and alternate behaviors, and increasing desirable behaviors in the appropriate situational context). In the course of the National Standards Project, 298 research articles on behavioral interventions were reviewed in the first phase and 155 articles in the second phase, providing an ample research base supporting the efficacy of behavioral interventions.

Complicating the description of these most effective behavioral treatments, many intervention packages share ABA-based application techniques. Common elements include prompting, shaping, use of natural consequences, naturalistic teaching strategies, contingent reinforcement, differential reinforcement, extinction, chaining, function-based intervention, reinforcement schedules, response interruption and redirection, joint attention intervention,

stimulus fading, modeling (video and/or live), repeated practice, discrete trial training, and other techniques. An in-depth description of these ABA-based elements is beyond the scope of this paper, but the interested reader may consult Matson (2009) and Fisher and Piazza (2013) for greater detail of these and other individual components. Early Intensive Behavioral Intervention (EIBI) is a behaviorally-based intervention; however, as EIBI is often studied as a separate treatment package, and is limited to the first years in life (early childhood), it will be discussed in more depth below.

Early Intensive Behavioral Intervention (EIBI)

Early intensive behavioral intervention (EIBI) is a treatment based on the principles of applied behavior analysis. EIBI is also sometimes referred to as Comprehensive Behavioral Treatment for Young Children (CBTYC; NAC, 2015). This intervention is usually delivered for 2-3 years starting in early childhood at an intensity of 20 to 40 hours per week. Typical interventions include discrete trial teaching, incidental teaching, behavioral momentum, shaping, modeling, errorless learning, and other ABA-based techniques. Instruction may be carried out in multiple settings such as home, community, inclusive classrooms, self-contained classrooms, and small group instruction (NAC, 2015). Each program is highly individualized but nonetheless includes a strong application of ABA-based strategies. The National Standards Project reports of EIBI/CBTYC were based on the review of 21 and 20 studies respectively in phases 1 and 2 of the project. EIBI is one of the most well-studied and research-supported interventions for improving prognosis for young children diagnosed with ASD (for review, see Reichow, Barton, Boyd, & Hume, 2012; and Tonge, Bull, Brereton, & Wilson, 2014).

Within the context of the family, early intervention services for children with ASD can support positive outcomes not only for the individual, but also for the family unit. On an

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individual level, early intervention can improve social skills, communication skills, challenging

behaviors, family functioning, and perhaps even IQ (American Academy of Pediatrics

Committee on Children with Disabilities, 2001; Committee on Educational Interventions for

Children with Autism, 2001; Manning-Courtney et al., 2003; Martinez-Pedraza & Cater, 2009;

Matson, 2007; OCDD, 2012; Symes, Remington, & Brown, 2006), reducing the impact of delays

and potentially decreasing the intensity needed for future supports. Ben-Itzchak and Zachor

(2007) conducted a review of early behaviorally-based intervention studies, and found that

approximately half of participants later exhibited significant improvement in standardized testing

scores, peer to peer interactions, and functioning in mainstream classes. On a family level, early

intervention services may reduce the future costs to meet special education, rehabilitation and

health care needs; reduce feelings of isolation, stress, and frustration by family members and

caregivers; and help children become more productive and financially and socially independent

of primary caregivers in the future (Matson, 2007; OCDD, 2012).

Clinicians and researchers generally agree that an earlier diagnosis and subsequent

treatment based on the principles of applied behavior analysis improves overall prognosis

(Matson, Wilkins, & Gonzalez, 2008), in addition to improving family functioning.

Acknowledging the importance of early intervention services in promoting positive outcomes, in

1986 the United States Congress established Part C (Early Intervention) of the Individuals with

Disabilities Education ACD (IDEA). Legislators recognized the "urgent and substantial need" to

improve the development of infants and toddlers with disabilities, reduce educational costs by

diminishing the later need for special education, curtail the likelihood of institutionalization

while increasing independence, and support the ability of families to meet their child's needs

(Data Accountability Center, 2012). Recognition of the value of early intervention has increased

focus on early detection (Gutierrez et al., 2009; Hayward, Gale, & Eikeseth, 2009), and programs to make early intervention services accessible irrespective of SES.

Cognitive Behavioral Intervention Package (CBIP)

Between publication of National Standards Project phase 1 and phase 2 results, the cognitive behavioral intervention package was moved from the "emerging interventions" category and recategorized as an established intervention (NAC, 2015). Cognitive behavioral therapy (CBT) has been used as an evidence-based intervention for many years in the treatment of anxiety and mood disorders in individuals without ASD. Per National Standards Project review of 13 research studies investigating the use of CBT in individuals with ASD, manualized CBT with a few modifications can be an effective intervention for individuals with ASD. Modifications may include the addition of visual cues, use of role-play, and other elements of individualized structure added to the session. Common CBIP strategies include psychoeducation around identifying and describing emotions and corresponding physiological components. Cognitive restructuring can be used in a manner very similar to the way in which it is used for individuals without ASD to assist in recognizing and modifying cognitive distortions such as all-or-nothing thinking or catastrophizing. Like other manualized CBT interventions for individuals without ASD, use of CBT in the course of ASD includes use of a scale to identify the magnitude of various distressing situations, homework assignments to record behavioral observations and work on identified skills at home and school/community, and parent sessions or inclusion of parents in parts of the intervention sessions (NAC, 2015). Manuals reviewed by the NAC (2015) for use in individuals with ASD include the Coping Cat Program and the Exploring Feelings program.

Language Production Training

Language production training is often, but not always, given in the form of speech therapy sessions. Language production training targets the use of functional, spoken (verbalized) language communication. Intervention begins with assessment and identification of developmentally appropriate targets, followed by use of a variety of strategies to elicit functional verbalizations. Strategies include modeling, prompting (e.g., verbal, visual, or gesture), cue-pause-point procedure, incorporation of music, and reinforcement for production of the targeted verbal response (NAC, 2015).

Parent Training Package

In the first phase of the National Standards Project, elements of the parent training package were reviewed individually; however, in the second phase, elements of parent training which generally occur in tandem were investigated as a whole. Effective parent training can occur in a variety of forms including *in vivo,* group training, support groups with an educational component, and training manuals. Skills commonly taught to the parents include strategies to cultivate imitation skills, commenting on the child's behavior, expectant waiting to elicit communication, increasing joint attention, developing play date activities, and fostering suitable sleeping routines (NAC, 2105).

Peer Training Package

Many individuals with ASD desire and attempt to interact with peers, but do so in counterproductive ways. Similar to the parent training, in peer training skills are taught to those who regularly interact with the individual in order to help foster the individual's social and other adaptive skills. One goal of peer training is to decrease an individual's reliance on adults for prompting and guiding, and to instead train peers how to initiate and respond to social

interactions with an individual with ASD. These programs are used primarily in school and community settings, and have been found effective in increasing communication and interpersonal skills as well as decreasing restricted, repetitive behaviors, interests, or activities in shared social settings. Important factors for consideration include the maturity and skill level of the child with ASD as well his/her peers, activities that incorporate interests of all parties involved to increase motivation, and teaching of specific skills for peers to get attention of the individuals with ASD in order to model appropriate play skills, facilitate sharing, provide help, and organize play activities (NAC, 2015). Interaction should occur in a structured setting around familiar activities with the instructor available to provide prompts and feedback. Training should occur in multiple settings and with a variety of peers. Some of the effective peer training curriculums/strategies in the National Standards Project include Project LEAP, circle of friends, buddy skills packages, facilitated integrated play groups, peer initiation training, and peer-mediated social interaction training.

Pivotal Response Training (PRT)

Like other EBPs discussed above, PRT makes use of ABA-based techniques. Unlike some of the previously discussed treatments, PRT is a package carrying a registered trademark; it was registered by Koegel and Koegel, researchers from Santa Barbara, California. PRT focuses on naturalistic teaching strategies. Rather than focusing on specific target behaviors, PRT targets motivation, responsiveness to cues, self-management, empathy, and self-initiated activities. Child choice, natural and direct reinforcers, and interspersing maintenance tasks, and variation of tasks are used to maintain motivation. Of note, these strategies are not unique to PRT and are often incorporated in other ABA-based approaches as well. Delivery of PRT relies on parent involvement and implementation in the natural environment such as home, community, and

school setting. National Standards Project's review of PRT yielded a total of 16 research studies focusing on PRT; reviewers concluded these studies were of sufficient rigor to qualify the PRT package as an established intervention for ASD (NAC, 2015).

Schedules

Individuals with ASD often respond better to visual than to auditory cues, and many have difficulty with transitions. Individuals with ASD are able to better navigate transitions when they know what is coming next. Schedules make use of visual information (via picture or text) to help the individual know what is coming next, understand first/then concepts, and incorporate choice into the daily schedule of required activities. Use of schedules varies widely depending on the individuals' abilities and needs. Schedules may be as simple as placing the corresponding picture/text in a designated place to signal the beginning and/or end of an activity, pointing to provide cues for what comes next, removing the cue when the task is completed, or placing the picture in a "done" pile (NAC, 2015). Schedules are often incorporated into other interventions.

Scripting

Scripting involves developing a scenario (often written) to assist an individual in verbally responding to certain social situations. Scripts target specific skills or situations (e.g., asking for help or for a break) that is practiced repeatedly before the skill is used in an *in vivo*, real-life situation. These methods are generally used in tandem with other behavioral interventions. In order to use scripting, the individual must have prerequisite reading and/or imitation skills. The end goal is to eventually fade scripting and increase the variety and spontaneity of responses (NAC, 2015).

Self-Management

The goal of self-management is to increase independence in a given situation, particularly in tasks where adult supervision is not usually needed or expected. Self-management involves teaching the individual to be aware of, evaluate, and record their own performance while engaging in an activity, and can be used to help monitor social and disruptive behaviors. The process should include concrete criteria defining success, systematic methods for recording performance (e.g., counters, checklists), adults who can provide feedback regarding accuracy of recording and provide prompts during learning stages, and teaching the ability to independently access reinforcers after meeting pre-established criteria. Self-management has primarily been studied in adolescents and young adults (NAC, 2015).

Social Skills Package

Social skills encompass a large number of skills such as eye contact, joint attention, use of nonverbal communication/gestures, reciprocal conversation or engagement in a social exchange, and both initiating and ending an interaction. A number of similar social skills packages exist; the goal of each is to increase the ability of an individual to participate in various social settings by teaching necessary social skills. Packages typically include elements of modeling, reinforcement and prompting, regardless of if sessions are one-on-one, in a peer dyad, small group, or other social situation (NAC, 2015).

Story-Based Interventions

Story-based interventions target a specific behavior by using a written description of the situations in which a specific response is expected. For example, stories may target perspective-taking skills to teach an individual not to laugh when a peer gets injured or is crying. Individualized stories are typically written from an "I" or "some people" point of view. Stories

identify target behavior, situations in which behavior is expected, and likely outcome of

engaging in the target behavior (which often includes information about others' expected

interpretations or reactions; NAC, 2015).

Emerging Interventions for Autism Spectrum Disorder

An emerging intervention is an intervention for which results of at least one study indicate

potential favorable outcome, but overall the intervention lacks a base of high-quality research

studies showing that the intervention is consistently effective in multiple independent trials.

Based on the available evidence, emerging interventions cannot yet be designated as reliably

effective or ineffective. Because more well established interventions are available, established

interventions should be the treatments of choice, and parents should generally be dissuaded from

relying too heavily on emerging interventions. Many emerging interventions exist, including but

not limited to: augmentative and alternative communication devices, developmental relationship-

based treatment, exercise, structured teaching, imitation-based intervention, initiation training,

massage therapy, music therapy, picture exchange communication system (PECS), reductive

package, sign instruction, social communication intervention, structured teaching, theory of mind

training, and technology-based intervention. Interventions from this list are often used in

conjunction with other strategies, such as using PECS for the individual to indicate a need or

choice. Assessment of their efficacy may be complicated by their inclusion in a treatment

program using established practices (NAC, 2015). However, at this point treatments in the

"emerging interventions" category are not independently considered to be evidence-based

practices.

Unestablished Interventions for Autism Spectrum Disorder

Unestablished interventions have little to no evidence to support them in the scientific

literature, and thus no firm conclusions can be drawn regarding effectiveness. For some

interventions, multiple studies consistently disconfirm efficacy, and yet the treatments continue

to be used by caregivers and even popularized by medical professionals. Many of the

unestablished ASD interventions are relatively benign other the hassle involved (e.g., gluten-free

diets) and possible high cost (e.g., auditory integration), but some unestablished interventions are

potentially harmful. Unestablished interventions are bountiful, including but not limited to:

animal assisted therapy, auditory integration training, concept mapping, floor time, facilitated

communication, gluten-free/casein-free diet, movement-based intervention, theater intervention,

sensory integration/sensory intervention package, shock therapy, social behavioral learning

strategy, social cognition intervention, dietary supplements, acupuncture, homeopathy, and more.

Some of these practices, such as gluten- and casein-free diets, are widely held to be efficacious

by parents (Winburn et al., 2014) although the two large randomized clinical trials that tested

their efficacy failed to show any positive effect (Elder et al., 2006; Knivsbert, Reichelt, HØien,

& NØdland, 2002). Reports of using dietary supplements (e.g., omega 3 fatty acids) are

becoming more frequent, despite little scientific understanding of potential aversive effects of

interactions between medications and many of the reported supplements (Levy & Hyman, 2008).

Some actions touted as interventions for ASD not only have little evidence of efficacy,

but also carry significant risk of harm. These practices are not mentioned in the National

Standards Project report, but chelation therapy (an invasive procedure that is medically indicated

for confirmed heavy metal poisoning) and hyperbaric oxygen therapy (medically indicated to

treat decompression sickness in scuba divers, or to treat wounds resistant to healing as a result of

diabetes or radiation injury) have been advertised as potential treatments or even cures for ASD. These invasive procedures place individuals at considerable risk, and yet some desperate (and perhaps ill-informed) caregivers have shelled out thousands of their own dollars chasing the chimeric "cure" for ASD. Some children have lost their lives as a result (Baxter & Krenzelok, 2008; Brown, Willis, Omalu, & Leiker, 2006), thus underscoring the importance of understanding the factors underlying which treatments caregivers pursue and which interventions are eventually secured.

Who Gets Which Services?

In the body of literature surrounding EBP and non-EBP, a common phrase used to describe non-EBP is complimentary or alternative medicine (CAM). CAM approaches consist of various interventions not empirically validated for use in treating ASD. Interestingly, use of CAM approaches does not seem to be lessened with greater access to conventional treatments; rather, CAM use has been positively associated with receipt of 20 or more hours per week of conventional behavioral treatment (Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014). Approximately half of caregivers of children with ASD in the US report use of CAM (Golnik & Ireland, 2009). Salomone and colleagues (2015) found a strong dose-response effect of use of conventional treatment and the concurrent use of mind/body CAM practices; parents who were using more than four conventional treatments were four times as likely to concurrently use CAM. This was not the case for those parents who used three or fewer conventional interventions (Salomone et al., 2015).

Salomone and colleagues (2015) found approximately half (47%) of caregivers reported having used complimentary or alternative medicine (CAM) approaches to treat their children with ASD. Twenty-five percent of caregivers reported using dietary restrictions and/or

supplements, with another 24% of caregivers reporting use of mind/body practices such as sensory integration (14%), massage (7%), and homeopathy (10%). Pet therapy was endorsed by 14% of caregivers (Salomone et al., 2015). The researchers found that 2.4% of parents endorsed using any "invasive, disproven, or potentially unsafe CAM" including chelation, hyperbaric chamber, and packing (being wrapped tightly for up to an hour in wet sheets that have been refrigerated).

Salomone and colleagues (2015) found that predictors of dietary restriction and/or supplements included higher parent education level, low verbal ability in the child, and the use of prescription medications; child's age, gender, or concurrent use of EBPs were not associated with increased likelihood of dietary restrictions or supplements. Mind/body practices including acupuncture, deep pressure therapy, massage, sensory integration therapy, and auditory integration therapy were more likely to be used by highly educated parents to treat female children with ASD; age, verbal ability, and concurrent use of medication were not associated with increased likelihood (Salomone et al., 2015). The finding that caregivers with higher education are more likely to use CAM is in concordance with previous research (Akins, Krakowiak, Angkustsiri, Hertz-Picciotto, & Hansen, 2014; Bernier, Mao, & Yen, 2010). While caregivers with higher educational achievement were more likely to use both types of interventions, the difference in use between higher and lower educated parents was most striking for mind/body interventions.

Parents with a higher educational level may be more likely to use CAM / non-EBP simply because they are more likely to be able to afford them. Non-EBPs are not generally funded by insurance, and many involve direct provision of the therapy by the provider (e.g., massage, acupuncture, auditory integration), thus incurring substantial cost. These therapies are

on average approximately double the cost of dietary supplements and other interventions that parents can administer (Nahin, Barnes, Stussman, & Bloom, 2009). In conclusion, the use of unestablished treatments (CAM) is common, usually in concert with one or more conventional ASD treatments (generally behavioral EBP, though types and definitions vary from study to study). Some factors are more predictive of one type of CAM use versus another, and a small minority of caregivers continues to pursue unsafe or dangerous practices despite active public campaigns against their use (Federal Drug Administration, 2014).

Many primary care physicians of children with ASD report conversing with caregivers regarding biologically based CAM, such as dietary supplements (Golnik & Ireland, 2009). In a survey of 539 physicians, Golnik and Ireland (2009) found primary care physicians treating children with ASD encouraged the use of multivitamins (49%), essential fatty acids (25%), melatonin (25%), and probiotics (19%), and discouraged withholding (76%) or delaying (55%) immunizations, chelation (61%), and secretin (43%). Many of the physicians in this survey reported a desire for additional training on available ASD treatments. This is promising as a focus for advancing accurate information regarding various therapies and relative risk/benefit ratios. Professionals who work with individuals with ASD should recognize the likelihood that many of their clients are using CAM concurrently with EBP, and engage caregivers in discussions about CAM approaches, current state of the evidence, and potential for adverse effects as parents make treatment choices.

CHAPTER 4: BARRIERS TO ACCESSING ASD INTERVENTIONS

Community and Cultural Factors

Ethnicity may impact both the likelihood of receiving an ASD diagnosis and the age at which that diagnosis is given; these factors in turn may affect access to services and insurance eligibility. Differences in service use by individuals from minority racial or ethnic backgrounds have been found in multiple studies. Latino or African American children with ASD are less likely to receive a diagnosis or to be diagnosed at a later age, thus missing out on important opportunities for early intervention to affect developmental trajectories (Mandell et al., 2009). In the Mandell et al. (2009) study, African American children were diagnosed an average of 1.4 years later than Caucasian peers. Black / African American children may be more likely to be misdiagnosed than non-Latino white children. Mandell et al. (2009) found that black children were three times more likely to receive a different diagnosis, most often conduct disorder, before eventually receiving an ASD diagnosis. In this same study, Mandell and colleagues found that children of other minority groups, many of whom were recent immigrants, were more likely to be diagnosed with adjustment disorder before eventually receiving an ASD diagnosis. It is easy to conjecture that a diagnosis of conduct disorder or adjustment disorder would lead to very different types of intervention than if the child had initially received ASD diagnosis.

Latino children are less likely to receive an ASD diagnosis than white non-Latino children (Liptak et al., 2008; Mandell et al., 2007; Palmer et al., 2010), and those who are diagnosed receive a diagnosis on average 2.5 years later (Mandell et al., 2002). Recently, Palmer and colleagues (2010) found that a 10% increase in the number of Latino children in a school district correlated with an 11% decrease in ASD diagnoses, but an 8% increase in ID diagnoses. These researchers contrariwise found that a 10% increase in non-Latino white children

corresponded with a 9% increase in ASD but an 11% decrease in ID (Palmer et al., 2010).

Zuckerman et al. (2014) conducted focus groups with Latina mothers of Mexican origin to discuss perceived barriers to receiving timely diagnosis, and participants reported several cultural or community-specific factors. Parents stated that in their Mexican communities, the concept of ASD was practically non-existent, so a child who exhibited stereotypical ASD symptoms might be seen as being poorly behaved and unintelligent but without medical diagnosis (Zuckerman et al., 2014). Because unusual and potentially disruptive behaviors are not understood as being related to a disorder, the child's behaviors may be seen as particularly shameful and indicative of poor parenting. Parents in this study also recalled significant stigma in their communities surrounding disabilities, particularly those related to mental health (Zuckerman et al., 2014). One mother recounted that in her hometown in Mexico, "parents ignore their children if they have some disability. . . If they are born with a deformed ear, they say, 'this child isn't worth anything,' . . .or if they have a child in a wheelchair [and] . . .the mother goes outside the house to talk with someone selling something, she closes the door so no one can see him" (Zuckerman et al., 2014, p. 304). Due to a lack of awareness of ASD, fear of being seen as a poor disciplinarian, and disability stigma, some parents reported feeling uncomfortable admitting or sharing their concern about their child's behavior (Zuckerman et al., 2014). Some mothers reported *machismo,* traditional view of Latino male gender roles, as a particular problem for their partners. Mothers noted some fathers felt having a "weak" or "disabled" male child was a poor reflection on themselves, thus fathers might discredit mothers' expressed concerns (Zuckerman et al., 2014). This could conceivably lead to disagreement about pursuing diagnostic services and lead to delays in treatment. While this study focused on a narrow range of participants (mothers of Mexican background), there are many areas of the world where the concept of autism is

nascent or entirely absent, as in many African countries (Ruparalia et al., 2016). Wherever there is a lack of understanding of ASD, there exists a risk of misconceptions about the etiology or significance of unusual behaviors to impede appropriate diagnosis and treatment.

Unsurprisingly, language barriers present a significant obstacle to receiving timely ASD diagnosis in the United States when parents are not fluent in English. Limited English proficiency contributes to difficulties with scheduling appointments and arranging transportation; limited access to qualified interpreters make it difficult for parents and clinicians to fully communicate and for parents to navigate the often multi-step diagnostic process (Zuckerman et al., 2014). In Zuckerman et al.'s (2014) study, Latina mothers reported concern that less-acculturated parents are often afraid to speak up for fear of being seen unfavorably; these parents also may not know their child is eligible for certain services for which they could advocate, or that supportive services such as assistance with transportation to and from appointments are available. It is also possible that in families where one or more members are undocumented immigrants, caregivers may be wary of getting involved in the diagnostic process or the pursuit of public insurance for the child despite reassurances of confidentiality due to concerns about how records may be accessed or used.

Ethnicity impacts not only diagnostic but also treatment service access. In a study of 383 families in North Carolina, Thomas and colleagues (2007) found racial and ethnic minority families had only half the odds of using a case manager and a quarter the odds of using a psychologist or developmental pediatrician as part of their child's treatment. Rosenberg, Zhang, and Robinson (2008) found that in the United States, black children are only half as likely as white peers to receive early intervention services. Zuckerman et al. (2014) found that Latina mothers reported purposefully avoiding seeking out services after an ASD diagnosis because the

diagnosis was so stressful and families had to adapt to the idea of the diagnosis before feeling

ready to move on to the next step of accessing treatment. Reported stress from adjusting to the

ASD diagnosis was related to the sense of stigma in having a child with a developmental

disability (Zuckerman et al., 2014). While there has been an increase in research into ethnic

factors related to ASD treatment in the past few years, overall there is a limited representation of

ethnic and cultural minority participants in the research literature, especially pertaining to

evidence-based interventions (West et al., 2016).

Socioeconomic Status and Financial Barriers

Despite state and federal efforts to make assessment and early intervention services

accessible regardless of SES, differences still exist. Durkin et al. (2010) found that those in the

lowest third SES were half as likely to receive an ASD diagnosis as those in the highest third

(Durkin et al., 2010). Interestingly, these statistics held true regardless of whether SES was

measured by percent household income above poverty, parental educational attainment, median

household income, or some combination (Durkin et al., 2010). Thomas et al. (2007) found that

when parents had at least a college degree, families were 2-4 times more likely to use a

neurologist, Picture Exchange Communication System (PECS), or therapeutic horseback riding,

but overall no strong differences were noted in treatments used.

Poverty exacerbates difficulties in receiving assessment services both directly and

indirectly. According to one report, a child with ASD incurs approximately seven times greater

health care costs than a child without ASD (Liptak, Stuart, & Auinger, 2006). Medical and non-

medical care costs for children with ASD are higher than costs for children with other

developmental disabilities (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Liptak, Stuart, &

Auinger, 2006), particularly for children who do not have a medical home coordinating the care

(Kogan et al., 2008). Sharpe and Baker (2007) found that having a lower income was positively associated with having unreimbursed medical or therapy expenses, greater use of medical interventions, and forfeiture of future financial security (e.g., retirement, savings accounts). Even if insurance coverage is adequate, additional financial costs may be incurred due to the necessity of securing transportation, finding childcare for other children, or loss of hourly wages if caregivers must take time away from work. A child with ASD may require specialized care that excludes him/her from typical childcare settings, and may result in the necessity of one or both parents reducing work hours or one parent quitting a job (Gould, 2004). In a study of children with severe disabilities (a category including severe ASD symptomatology), Leiter et al. (2004) found that 20% of the caregivers sampled provided 20 hours per week or more of specialized health care themselves; half of the employed mothers had reduced work hours and half of non-employed mothers had quit work in order to meet their child's needs.

Insurance

Lacking insurance or having inadequate insurance coverage imposes a financial burden for accessing many services. Data from national surveys, private health insurance claims, managed care organizations, and state Medicaid programs point to a high rate of health care utilization by children with ASD, even when compared to children with other types of developmental disorders (Chatterji, Decker, & Markowitz, 2015). Utilization is especially high for psychiatric services and prescription medications (Chatterji, Decker, & Markowitz, 2015). Given that treatment plans for ASD tend to be multidimensional and highly individualized depending on the child's symptom constellation and severity, treatment plans are often quite costly (Amendah et al., 2011). Comparing children with and without ASD using data from the Medicare Expenditure Panel Survey and National Health Interview Survey, Lavelle and

colleagues (2014) found that after controlling for demographic factors and comorbid illnesses, children with ASD incurred an average of $3,020 additional health care costs and $14,061 additional non-healthcare costs annually (including $8,610 additional school-related costs). It is noteworthy that this study was of children who were enrolled in Medicaid. The caregivers of children with ASD did not report significantly higher out-of-pocket costs or report spending more time on caregiving activities compared with the control group (Lavelle et al., 2014). It is possible that parents of children with private insurance have similar experiences, but no comparable studies across different private insurance providers are evident in the literature at present.

Caregivers of children with ASD have reported greater challenges in accessing services and less overall satisfaction with services rendered when compared to caregivers of children with other special health care needs (Montes, Halterman, & Magyar, 2009). Insurance plans generally exclude some types of ASD treatments, especially behavioral treatments (Chatterji, Decker, & Markowitz, 2015), even though several behavioral treatments are efficacious for treating ASD-related challenges (NAC, 2015). With many states having recently mandating ASD coverage for most insurance plans, these exclusions are fortunately on the decline, though extent of reimbursement may still be quite limited.

Thomas et al. (2007) surveyed 383 families of children with ASD, and found that children covered by Medicaid or other public insurance had 2 to 11 times the odds of using the following compared to children covered by private insurance: medication management, therapeutic support services including respite care and case managers, Picture Exchange Communication System (PECS), and speech/language therapy. These same children were only one quarter as likely to use dietary supplements as those on private insurance. Perhaps

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surprisingly, children who lacked health insurance were more likely to receive services that

facilitated entry into the health care system (e.g., case manager, developmental pediatrician;

Thomas et al., 2007). More recently, Parish and colleagues (2014) found that on average,

families of children with ASD spent approximately 4.1% of income per capita on their child's

health care. After controlling for symptom severity and demographic characteristics, families

with private insurance were more than five times as likely to have out-of-pocket expenditures for

ASD treatment compared to families of children covered by public health insurance. The most

frequently cited out-of-pocket costs were medications, outpatient services, and dental care

(Parish, Thomas, Williams, & Crossman, 2014). The disparities between private and public

insurance in these studies indicate significantly greater financial burden for children covered by

private insurance.

To ease the financial burden of ASD, now recognized as the second-most common

developmental disability in childhood (behind intellectual disability; Newschaffer et al., 2007),

many states have recently mandated insurance coverage of ASD-related services. As of

September 2015, 42 states have passed laws that require many private health insurance policies

to include diagnostic and treatment services for ASD (American Speech-Language-Hearing

Association, 2015). It is unclear how efficacious these mandates have been in reducing out-of-

pocket expenses or expanding access to treatment as very little data has yet been published on

the effects. Johnson, Danis, and Hafner-Eaton (2014) studied the variation of insurance coverage

across the United States of America at a time that 30 of the states mandated private insurers to

cover behavioral therapy for autism. The authors found that rather than decreasing the disparity

in service accessibility between states, the states that had passed insurance mandates at that time

were those in which services were already more readily available prior to the new legislation

(Johnson, Danis, & Eaton, 2014). The authors concluded that the mandates resulted in an increase in the disparity in service accessibility between more advantaged and less advantaged states. In a study of the 37 states with ASD insurance mandates at the time, Chatterji and colleagues (2015) found ambiguous results regarding the mandates' effect in reducing out-of-pocket spending and increasing access to services; no statistically significant association between state ASD mandates and caregiver report of financial burden, access to care, or unmet need for services was found. The authors noted that the effect of such a mandate likely varies state to state based on the percentage of the working population included, and further research is needed in this area.

Geography

Geographical location also factors into the likelihood of a diagnosis and access to services. As an example, Louisiana's Office for Citizens with Developmental Disabilities acknowledged geographical disparities in ease of access to services provided by its statewide early intervention program for toddlers with developmental delays. Despite considerable efforts to reach all areas of the largely rural state, OCDD reported concern over a shortage of providers in particular disciplines, as well as a shortage of providers in general in rural areas (OCDD, 2013). This is only one example; other states likely experience similar difficulties in providing services with equanimity in the face of financial restrictions and uneven distribution of qualified providers across regions.

Urban areas with greater density of medical professionals and with closer proximity to medical services may have an advantage in providing diagnostic and treatment services, thus mitigating the effect of some other factors often associated with variability in service access. For example, a population-based study conducted by the CDC in urban Atlanta found no influence of

race, ethnicity, or sex on the age of diagnosis, but that age of diagnosis was affected by degree of impairment (Wiggins, Baio, & Rice, 2006). In this study, children with ASD were initially evaluated at an average of 48 months and received a diagnosis 13 months later (Wiggins, Baio, & Rice, 2006). Kalkbreener et al. (2011) found similar results, with the majority of children living in urban areas having better access to services and receiving diagnoses at an earlier age. Thomas et al. (2007) found that when families lived in nonmetropolitan areas, children with ASD had reduced odds of two treatments in particular: attending summer camp (Odds Ratio = 0.33), and using respite care (Odds Ratio = 0.21).

Systemic Barriers

Possible barriers at the systemic level may include failure to incorporate appropriate screenings into pediatric wellness visits, reluctance of pediatricians to refer young children, or children with less severe symptoms, or lack of coordination between various agencies. Children in child protective services, or otherwise part of child welfare systems, are often under-identified with regard to developmental delays including ASD (Berkoff, Leslie, & Stahmer, 2006). The number of pediatricians available in a given area may play a role in identifying rates of ASD (Mandell & Palmer, 2005), as do medical and educational system funding levels, which affect ability to train providers (Mandell & Palmer, 2005). Sices et al. (2004) found that the type of behavior exhibited in the pediatrician's office had a greater influence on determining referral for diagnostic services than did parents' initial concerns about their child's development, including day to day behavior at home. In this same study, female medical doctors were more likely than males to refer a child to a specialist for evaluation (Sices et al., 2004).

Zuckerman et al. (2014) found that many Latina mothers reported losing faith in healthcare providers throughout the diagnostic process, which was often described as lengthy

and intensely stressful. Declining trust in the healthcare system was related to length of time over which the diagnostic process extended; mothers reported that as time went on they began doubting whether providers were delivering care in the best interest of the child, and wondering if providers were purposefully increasing the difficulty of service access (Zuckerman et al., 2014). Some mothers reported feeling as if the diagnostic visit was primarily for conducting research, rather than for providing thoughtful recommendations or helpful resources. The results of Zuckerman et al.'s (2014) study fit with research reports that ethnic minority families receive less guidance and experience increased obstacles when pursuing heath care in general (Jimenez, Barg, Guevara, Gerdes, & Fiks, 2012; Zuckerman, Perrin, Hobrecker, & Donelan, 2013). Distrust in the medical system could erode a caregiver's willingness to continue on despite the stresses of navigating the healthcare system in pursuit of treatment.

Characteristics of Early Intensive Behavioral Intervention (EIBI)

Sometimes the very nature of the intervention presents barriers to participation, such as the time demands and often-intrusive nature of in-home EIBI. EIBI is, by definition, intense in nature, often multiple hours per day for most days of the week. Although EIBI is widely recognized as one of the most fruitful interventions for young children with ASD, and likely results in better prognosis and cost savings in the long term, in the short term these programs are very expensive (up to $30,000 per year; Sharpe & Baker, 2007). Many insurance policies will not pay for the entire 20-40 hours per week that these programs generally recommend. Accordingly, providing EIBI for a child with ASD often imposes great financial burden on families, even those with medical insurance. EIBI services are often delivered in the individual's home, though they may be provided at a school or therapy center. When they are provided in the home, several therapists may regularly frequent the home; this may present a problem for some

families who highly value privacy. Scheduling constraints may be problematic if a primary caregiver is required to be home during all therapy hours.

Johnston and Hastings (2002) analyzed barriers to the implementation of ABA-based EIBI programs for ASD, concluding that barriers experienced by families fell into the following categories: characteristics of particular service providers (e.g., policies, lack of resources, long wait lists) or their staff (e.g., lack of training and skill), the nature of the programs (e.g., slow to produce noticeable change, perceived inflexibility), and external factors (e.g., family factors). The researchers found that the largest percent (70.9%) of 141 families of children with ASD reported difficulty developing or maintaining a treatment team; these families perceived that problems with staff shortages or lack of appropriate training for staff constituted a significant barrier. Of note, this study was conducted in the United Kingdom at a time when ABA-based programs were relatively new to the ASD treatment scene. The authors noted a paucity of well-trained supervisory staff, which they conjectured may not be as large a barrier in the United States where EIBI has been widely promoted for a longer period of time (Johnston & Hastings, 2002). Other common barriers to implementing intensive behavioral intervention included difficulty in funding services (68.1%); and personal/family constraints such as amount of time required, scheduling around other family members, or other obligations (42.6%). Johnson & Hastings' (2001) list of perceived barriers to EIBI also included problems with educational systems such as negative attitudes or unwillingness to provide services (17.7%), negative impact on families such as disruption of family life or feeling that home space was invaded (13.5%), lack of support from specific schools or teachers (9.2%), child-specific concerns such as illness or lack of concentration (5.7%), and lack of physical resources (e.g., necessary equipment or space) in home (5.0%; Johnson & Hastings, 2001). In this same study of barriers to ABA-based

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early intervention programs, Johnson and Hastings (2001) found that facilitators of participation in ABA-based programs included perceptions of having a stable, supportive care team (75.9%); being motivated by observable progress (26.2%); flexible work schedules (4.3%), and a number of other factors falling broadly under "social support" (e.g., support of family, friends, support groups, and/or school faculty).

<p style="text-align:center">Comorbid Conditions</p>

ASD used to be considered as a singular condition; however, research has evolved our understanding of etiology of autism, and researchers have demonstrated that ASD commonly occurs with other psychopathology (Matson & Nebel-Schwalm, 2007; Smith & Matson, 2010a, 2010b, 2010c). Children with ASD have a high rate of other mental and physical difficulties, with some estimates as high as 80% or more having psychiatric comorbidity (Joshi et al., 2010; Kogan et al., 2009; Matson & Nebel-Schwalm, 2007). In a study of families of children with ASD only and children with ASD plus a comorbid psychiatric condition, Ahmendani and Hock (2012) found higher overall healthcare utilization among the 66.2% of participants with comorbid conditions, but these families were also more likely to be dissatisfied with care, dissatisfied with coordination between providers, and to report delay or non-receipt of needed services. Delay or non-receipt of services was most likely for children with comorbid depression or conduct problems. The most frequently cited reasons for delaying or not receiving treatments among those with comorbid conditions were out-of-pocket cost and denials of coverage by insurance. Delays were also likely when parents perceived that providers did not communicate effectively with the parent and did not make the parent feel like a partner in care (Ahmendani & Hock, 2012). Children with comorbid conditions may be more likely to need services from multiple locations, contributing to the challenges of coordinating care among providers, and

paying via multiple sources (e.g., public, private, self-pay). The increased challenges to receiving care in Ahmendani and Hock's (2012) study provide evidence that the existence of comorbidities predisposes one to experience greater challenges in meeting health care needs, but does not provide a direct link between the presence of a comorbid condition acting as the limiting factor in receiving treatment. However, it is not difficult to imagine scenarios in which challenging behavior could be prohibitive to intervention. For example, a child who becomes very aggressive when angry or engages in unsafe behaviors in the car may cause parents to second guess their ability to safely take their child to the session, or weigh the long-term gains against the short-term struggles.

Burden of ASD Diagnosis

The process of obtaining an ASD diagnosis can be complex and time-consuming; once a diagnosis is given, parents and caregivers face additional future stressors related to navigating health, educational, and other service systems for their child. The direct costs of medical and nonmedical services plus indirect costs such lost opportunities and income for individuals with ASD and their families have been estimated to total approximately $3.2 million per child in the United States (Ganz, 2006). The emotional burden of caring for a child with ASD can be significant for the entire family. Compared to families of children with ASD, families of children with special health care needs (CSHCN) who do not have an ASD diagnosis are significantly less likely to report problems with referrals, coordinating care, and obtaining family support services (Kogan et al., 2008). Parents must often shoulder the burdens of physical and emotional stress, divorce, and job loss, which then impact the entire family system (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Bromley, Hare, Davison, & Emerson, 2004; Hastings et al., 2005; Järbrink, Fombonne, & Knapp, 2003).

Early identification can lead to better outcomes for children and families if identification leads to receipt of appropriate intervention services and supports for the family (Council on Children with Disabilities, 2006), but when parents have to act as coordinators for intervention services across several disconnected systems (healthcare, education, social services, transition services upon starting school and aging out of child-focused services), there are many potential barriers that can stymie the parents' efforts. Investigating the difficulty of coordinating care, Carbone, Behl, Azor, and Murphy (2010) noted that pediatricians reported little to no dialogue with school systems for the purposes of developing intervention plans. The researchers noted lack of uniform eligibility requirements for interventions that were not integrated across the several different systems serving the family. "This lack of coordinated care," they stated, "results in confusion for families, mixed messages from different treatment providers, and promotes adversarial relationships between various disciplines" (Carbone et al., 2010, p. 322). Woodgate, Ateah, and Secco (2008) found that many parents described their contact with various systems as patently unsupportive. Thomas, Ellis, McLaurin, Daniels, and Morrissey (2007) found that parents who reported greater family stress were more likely to engage in intervention services. Other researchers have found that the struggle to access services is a significant stressor for families of children with autism, due to a variety of barriers including financial cost and limited availability (Mackintosh, Goin-Kochel, & Meyers, 2012).

CHAPTER 5: PURPOSE

Disparities in service use indicate a need to develop policy, practice, and family-level strategies to address barriers to ASD services. Research about how families experience diagnosis and coordination of intervention services, along with perceived barriers and facilitators, can inform the development of efforts to this end. Federal and state policies and practices within service systems will be better able to improve with understanding of their clients' experiences. The goal of this study is to investigate current patterns in perceived barriers experienced in accessing both diagnostic and intervention services, including the most significant barriers associated with evidence-based interventions.

CHAPTER 6: METHOD

Participants

Inclusion criteria for this study included self-identified caregivers of individuals with an ASD diagnosis (Autism Spectrum Disorder, Asperger's Disorder, PDD-NOS, or Autistic Disorder) who completed an online survey (see Appendix A) and reside in the United States of America. Participants were recruited through information distributed to health care clinics, parent advocacy/support groups, outpatient therapy clinics, and similar organizations. A total of 150 individuals began the online survey. Participants were excluded from analyses for the following reasons: Selected "Decline to participate" after reading introductory page and confidentiality information ($n = 1$), dropped out during initial demographics questions ($n = 58$), diagnosis listed as something other than ASD (i.e., "sensory processing disorder," ($n = 2$), or misunderstanding the questionnaire ($n = 1$) in the case of an employee at a residential center who attempted to complete the survey about multiple clients in general rather than a single individual). This left a total of 88 participants to be included in analyses, with a dropout rate of 42.33%. This is somewhat higher than the roughly 30% dropout rate often observed in shorter online surveys (Galesic, 2006), but Galesic found a similar dropout rate for a similar study of 41.8% for an online survey without compensation of similar length (180 questions) in a study of effects of interest and burden affecting dropout rates on online surveys. It is likely that a shorter survey would have had a higher completion rate, but the completion rate is within the expected range given the characteristics of the survey.

The 88 participants whose data were retained for analysis reported residing in 20 different states, with the states most frequently represented including South Carolina ($n = 18$), Louisiana ($n = 9$), Pennsylvania ($n = 8$), and Indiana ($n = 6$). The majority of participants were

parents (69 mothers, 5 fathers) or grandparents ($n = 7$) of individuals with ASD; other

participants included miscellaneous caregivers, generally other relatives ($n = 6$). Demographic

information for the caregiving participants and families is presented in Table 1. Breakdown of

participants by research question can be found in Appendix D, as not all participants were

included in all questions for various reasons (e.g., dropout, had not begun receiving treatment

yet, etc.).

Table 1. Demographic Information for Caregivers and Families ($N = 88$)

Demographic	n (percent)
Caregiver's Ethnicity	
White	75 (85.23)
African American	4 (4.54)
Latino	1 (1.13)
Asian	2 (2.26)
Other	0 (0.00)
Combination	4 (4.54)
Declined Answer	2 (2.26)
Child's Ethnicity	
White	70 (79.54)
African American	4 (4.54)
Latino	1 (1.13)
Asian	0 (0.00)
Other	2 (2.26)
Combination	10 (11.36)
Declined Answer	1 (1.13)
Caregiver's Gender	
Male	6 (6.81)
Female	81 (92.04)
Decline Answer	1 (1.14%)
Child's Gender	
Male	68 (77.27)
Female	4 (4.54)
Reported Diagnosis	
Autistic Disorder	18 (20.45)
PDD-NOS	12 (13.64)
Asperger's Disorder	7 (7.95)
ASD	51 (57.95)

<center>**Measures**</center>

Survey

An online survey was conducted to collect all required information from participants. After informed consent was given, the second page of the survey took the participant to a page with questions about demographic information. Questions included demographic information for both caregiver and child, questions surrounding diagnostic and treatment service use and access, and a measure of autism symptom severity (the Autism Spectrum Disorder-Diagnostic for Children). The survey was designed such that all questions must be answered before the participant can go on to the next page to decrease likelihood of missing data; however, "other, write in" and "prefer not to answer" options were utilized in case participants found the provided options to be insufficient.

Before recruitment for the study, a group of 8 parents served as a pilot group for the survey. Three of these parents were primary caregivers for individuals with ASD and one was a parent of a young child with special needs. Minor wording and formatting changes were made in accordance with feedback from the pilot study prior to active recruitment. The survey was designed in and administered through Qualtrics; see Appendix A for more detailed survey information.

The first page of the online survey was the consent form, which informed participants that information collected would be devoid of personally identifiable information (PII), outlined measures to ensure data security, reminded participants that they could exit the survey at any time by closing the survey window. They were also notified that they could withdraw all previously entered data by contacting the researchers at the provided email, and provided the email contact of the researchers and the LSU IRB in case any further information was desired.

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The last page of the survey included information on what to look for when pursuing ASD interventions, information on evidence based versus non-evidence based practices, and links to reputable sources of information, followed by contact information for the researchers for any follow-up questions.

Autism Spectrum Disorder-Diagnostic for Children (ASD-DC)

The ASD-DC (Matson & González, 2007) is a 40-item, informant-based rating scale to assess ASD under the *DSM-IV-TR* diagnostic criteria. The ASD-DC was designed to be a cost- and time-efficient measure of symptoms associated with Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger's Disorder, all considered Autism Spectrum Disorders under the *DSM-IV-TR* criteria. It is the diagnostic portion of a four-part assessment battery (the Autism Spectrum Disorder- Child Version; Matson & Gonzalez, 2007 a, b, c); the full battery is designed to also assess comorbid symptoms and problem behaviors in children ages 2-16 suspected of having an ASD. The battery also includes a direct observation portion for the clinician to use in conducting a brief observational play session with the child. For this study, only the caregiver report section assessing ASD symptoms, the ASD-DC, will be used. In this measure, the clinician reads the items to caregivers, who are asked to rate the items on a 4 point scale in which they compare the behavior of their child with the behavior of typically developing, same-aged peers and rate the item for "extent that it is/was ever a problem" as follows: 0 = "not different; no impairment"; 1 = "somewhat different; mild impairment"; 2 = "very different; severe impairment." Although typically the clinician reads each item for this measure, for the purposes of this survey, caregivers will read each item themselves as part of the survey.

According to factor analysis, the ASD-DC measures behaviors on four factors corresponding with areas impaired by ASD symptoms: nonverbal communication/socialization, verbal communication, social relationships, and insistence of sameness/restricted interests (Matson, Boisjoli, & Dempsey, 2009). Internal consistency of the measure is .99 and test-retest and inter-rater reliability are satisfactory at $\kappa\omega=$. 77 and $\kappa\omega=$. 67, respectively (Matson, Gonzales, Wilkins, & Rivet, 2008). The measure has good sensitivity and specificity to diagnose ASD with total correct classification rates between typically developing children and atypically developing children/possible ASD of 84.3%, and between atypically developing children/possible ASD and children with probable ASD at 87.8% (Matson, González, & Wilkins, 2009). Cronbach's alpha for this particular sample was computed (40 items, $\alpha = 0.94$), with results indicating a high degree of internal consistency for this sample.

Procedure

Prior to participant solicitation, the research procedures and protocol were approved by the Louisiana State University Institutional Review Board (see Appendix C for IRB approval). Participants were recruited via posts to electronic forums (e.g., Facebook, Twitter, Reddit, Postwaves, NextDoor), newsletters from state and regional Autism Society chapters, fliers posted at a variety of places likely to be frequented by caregivers of children with ASD (e.g., doctor or therapy provider offices, community centers), and word of mouth. An effort was made to distribute across a wide geographic area (e.g., multiple states, national online forums), particularly to organizations known to provide free or low-cost services (e.g., state organizations that offer free/low cost diagnostic services to state citizens and treatment costs on a sliding scale) in order to attract participants across a wider range of SES. Use of internet-only survey was deemed appropriate due to rapid increases in internet access across demographics in recent years.

According to a 2013 Pew Research study, only 15% of Americans do not regularly use the internet; half of these individuals stated that they do not use the internet because it is "irrelevant to them" rather than citing access/financial barriers. Based on past trends, it is likely that in the three years since this study was published, an even greater percentage of individuals regularly access the internet, and that internet access would not pose a significant barrier to completion of this survey (Pew Research Center, 2013).

Recruitment information included inclusion criteria (i.e., primary caregiver of individual with diagnosis of Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder not otherwise specified, or Autism Spectrum Disorder) and a brief description of the type of information sought (i.e., information related to treatments utilized, difficulty accessing services, and demographic factors devoid of personally identifiable information). Recruitment information stated that no compensation would be provided for survey completion and included a link to the online survey. No incentive was offered due to inability to reliably screen out participants who might complete the survey multiple times. Estimated time to complete the study based on pilot testing was also included.

The information necessary for this study was collected via an online survey set up through Qualtrics, a company with software by the same name used for online research data collection and analysis. See Appendix B for detailed information regarding Qualtrics privacy policies, certifications, and security measures. Louisiana State University currently has a contract with Qualtrics, through which account the survey data was collected. After reading the consent form, participants manually selected an acknowledgement button indicating they read and agreed with the statements outlined in the consent form. Participants then completed the survey, which collected the information outlined in Appendix A. Once data from a sufficient number of

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participants was collected, data was imported from Qualtrics into Statistical Package for the

Social Sciences (SPSS; IBM Corporation, 2013) for analysis.

CHAPTER 7: HYPOTHESES

A series of analyses were performed to address several research questions: What are the most commonly reported perceived barriers to diagnostic services? What are predictors of experiencing the greatest number of perceived barriers to diagnostic services? What are predictors of professional reassurances and family factors as perceived barriers to diagnosis? What are the most commonly perceived barriers resulting in discontinuation of previous interventions? What are the predictors of reporting the greatest number of barriers causing discontinuation of EPBs? What factors predict length of time between diagnosis and receiving treatment for ASD? What interventions are currently most desired? Finally, what factors are predictive of caregivers hoping to obtain EBP over non-EBP?

It was expected that wait list for diagnostic services would be the most commonly reported barrier to diagnosis. It was hypothesized that living in an urban area, higher household income, higher educational attainment, and greater ASD symptom severity would be correlated with fewer reported barriers to diagnostic services, whereas identifying as an ethnic minority would be correlated with an increase in barriers, perhaps in part due to correlation in the United States between minority status and greater barriers to achieving higher education and income. It was hypothesized that increased ASD symptom severity would correspond with a decreased likelihood of perceiving professional reassurances as a barrier to diagnosis, and also hypothesized that increased education of parents would also correspond with a decrease in perceiving this barrier, as more educated parents may be better able to engage researching symptoms prior to appointments, thus able to speak more precisely about their child's symptoms and ask more pointed questions about autism-specific concerns. Based on literature reviewed in

the section on Community and Cultural Factors, it was hypothesized that ethnicity would impact likelihood of perceiving caregiver disagreement as a barrier to diagnosis.

With regard to interventions, it was hypothesized that changes in eligibility would be the most frequent cause of discontinuation for early intensive behavioral interventions due to the nature of the state- and federally-funded programs to target children in early childhood and younger to receive these subsidized services. With regard to EBP and non-EBP in general, it was hypothesized that while out of pocket cost would be a significant barrier, it would be more highly cited as a cause for discontinuation of non-EBP services due to decreased likelihood of insurance reimbursement for such services. Similarly to hypothesized results for barriers to diagnosis, it was hypothesized that lower household income would predict higher numbers of reported barriers to EBPs. It was also hypothesized that rural indication would also be correlated with higher number of barriers to EBPs, while higher ASD symptom severity would be correlated with fewer barriers. With regard to gap between diagnosis and treatment, it was hypothesized that ethnicity would be most highly correlated with a gap between diagnosis and treatment, with minorities experiencing the greatest gap. With regard to desired future EBPs, it was expected that the barriers would follow the same trends found for reasons for discontinuing past EBPs, with cost being highly ranked as a barrier. It was also expected that difficulties with scheduling would also rank highly, since many treatment centers operate during normal working hours (9am-5pm) and it could be that services had not yet been accessed due to difficulty with parent work schedules or interference of time required for desired therapies conflicting with currently received services or school.

CHAPTER 8: STATISTICAL ANALYSES

First, preliminary analyses were conducted to determine the sample size needed to answer the research questions. Second, descriptive analyses were run to provide additional demographic information (e.g., income, insurance type, education level of caregivers). The third set of analyses included descriptive analyses of factors related to perceived barriers to diagnostic services, followed by a multiple regression to investigate factors related to reporting a greater total number of barriers to diagnostic services. The author was particularly interested in factors predicting barriers that could potentially be addressed with targeted educational initiatives (e.g., education for healthcare professionals or families to address related barriers). Accordingly, a logistic regression was run to investigate factors related to professional provider reassurances as a reported barrier to diagnostic services. Chi-squared test was run to investigate whether identifying as being of ethnic minority status was correlated with increased likelihood of family disagreement as a barrier to diagnostic services.

The fourth set of analyses investigated barriers to previously tried interventions that resulted in discontinuation of interventions. Descriptive analyses outline the discontinued treatments and barriers experienced to EBPs and non-EBPs. Multiple regression was used to investigate predictors of experiencing greater number of barriers resulting in discontinuation of EBPs. As insurance coverage is closely related to the out of pocket costs of treatment, follow-up testing via Kruskal-Wallis analysis was conducted to investigate the relationship between insurance type and number of perceived EBP barriers reported.

Fifth, multiple regression was used to investigate whether various demographic factors predicted variations in time between receiving a formal ASD diagnosis and treatment of ASD symptoms.

Sixth, the author inspected the answers of those participants who had indicated a current desire to pursue additional interventions for their child with ASD. A total of 51 participants indicated they were either in the process of gaining access or were preparing to soon attempt to access additional interventions. Of these, 41 participants gave answers that could be categorized into EBP or non-EBP practices. Descriptive analyses provided information regarding perceived barriers to desired interventions. A binomial regression was utilized to inspect factors related to whether a participant who desired additional services was seeking EBP vs. non-EBP treatments.

CHAPTER 9: RESULTS

Preliminary Analysis

G*Power 3, a power analysis computer program (Faul, Erdfelder, Lang, & Buchner, 2007), was used to determine the sample size needed for the analyses with the greatest number of planned variables (regression analyses on factors affecting number of perceived barriers reported). A medium effect size of $f^2 = 0.2$, power of .80, and alpha of .05 were used. These methods are conventional and accepted levels for use in psychological research for alpha and power (Cohen, 1988; Hinkle, Wiersma, & Jurs, 2003). A medium effect size was also chosen due to the widely varying results of studies investigating various factors associated with barriers to ASD services. The power analysis indicated a minimum of 75 participants would be sufficient for the planned analyses.

Descriptive Analyses

 The first set of analyses provided descriptive information for the participants and their children with ASD. The majority of participants lived in urban areas (50,000+ residents), and only 8 resided in rural areas (less than 2,500 people). The majority of the sample had family incomes of 70,000 or more and an unusual number had some graduate school education ($n = 30$; 34.10%). Additional demographic details are presented in Table 2.

Table 2. Additional Demographic Details (*N* = 88)

Demographic	*n* (percent)
Geography of Residence	
Urban	38 (43.18)
Suburban	42 (47.72)
Rural	8 (9.09)
Family Income*	
<10k	7 (7.95)
10k-25k	5 (5.68)
25k-40k	6 (6.82)
40k-55k	14 (15.91)
55k-70k	11 (12.50)
70k-100k	20 (22.73)
>100k	18 (20.45)
Declined Answer	7 (7.95)
Child's Insurance Type	
Private Only	30 (34.09)
Public Only	27 (30.68)
Private and Public	24 (27.27)
None	0 (0.00)
Not Sure/Declined	7 (7.95)
Caregiver Education	
Some high school	2 (2.27)
High school graduate	5 (5.68)
Technical degree	8 (9.09)
Some college	13 (14.77)
College graduate	30 (34.09)
Some graduate school	2 (2.27)
Graduate degree	28 (31.82)
Caregiver Marital Status	
Single	8 (9.09)
Married or Cohabiting	62 (70.45)
Separated/Divorced	14 (15.91)
Widowed	4 (4.54)
Not sure/decline	0 (0.00)

*k = $1,000 US Dollars

Mean ASD-DC scores ranged from 58-119 (*M* = 92.36, *SD* = 14.79). Of note, 20

individuals were out of the age range of 2-16 years for which the ASD-DC was normed.

Excluding these 20 individuals, total ASD-DC scores were virtually unchanged, ranging from

59-118 (*M* = 92.25, *SD* = 14.06).

Current ages of participants' children with ASD ranged from 1.5 years to 32 years ($M =$ 11.49; $SD = 6.52$). Age at diagnosis ranged from 1 to 21 years ($M = 4.70$; $SD = 3.87$). Many individuals ($N = 24$) reported their child began receiving therapy to treat ASD symptoms before actually receiving a formal ASD diagnosis. Age at first treatment for ASD symptoms ranged from 1 year to 18.5 years ($M = 4.24$; $SD = 3.35$). Four participants reported they have not yet been able to access treatment services. Twelve individuals reported beginning treatment within one month of receiving diagnosis. Of those who experienced a delay between diagnosis and treatment, time delay ranged from one month to 31 months. ($M = 5.42$; $SD = 7.36$). Time elapsed between diagnosis and completion of survey were computed to be used as a covariate in analysis on discontinued treatments; time ranged from 0 months to 278 months ($M = 80.27$; $SD = 70.89$). Additional information regarding ages and time delay is presented in Table 3.

Table 3. Age / Time Information

Occasion	N	In Months M (SD)	In Years M (SD)
Child's Age:			
Present	88	137.93(78.27)	11.49 (6.52)
At Diagnosis	88	56.39 (46.45)	4.70 (3.87)
First Treatment*	84	50.90 (40.16)	4.24 (3.35)
Time Lapse			
Diagnosis to Treatment*	84		
Gap Diagnosis to Treatment**	60	5.42 (7.36)	---
Diagnosis to Present	88	80.27 (70.89)	6.70 (5.91)

*Excluded individuals who have not begun receiving treatment yet ($n = 4$)
**Excluded individuals who have not begun receiving treatment ($n = 4$) or began
  receiving treatment prior to diagnosis ($n = 23$).

Perceived Barriers to Diagnostic Services

Descriptive Analyses

The most frequently reported perceived barriers to diagnostic services were long waitlists, reassurances from professionals that the child would "grow out of it" or that symptoms

were due exclusively to some comorbidity (e.g., intellectual disability, Down Syndrome, partial agenesis of the corpus callosum), and difficulties with scheduling. Out of the 88 participants, 75 reported experiencing at least one barrier to receiving diagnosis. Many families experienced multiple barriers to diagnosis. Overall, caregivers reported a mean of 1.68 (SD = 1.38) perceived barriers to diagnosis, with a range of 0-7 barriers experienced. Additional details regarding barriers to diagnostic services can be seen in Table 4.

Table 4. Perceived Barriers to Diagnostic Services (N = 88)

Barrier	n	Percent
Wait list	49	55.68
Transport/Proximity	6	6.82
Scheduling	19	21.59
Cost	15	17.05
Family	14	15.91
Practitioner Reassurances	33	37.50
Other	12	13.64
None	13	14.77

Predictors of Greatest Number of Past Barriers

Multiple regression was used to investigate factors related to experiencing greater numbers of perceived barriers to diagnostic services. Investigated factors included geography (living in urban, suburban, or rural areas), family income, ethnicity (minority or not), caregiver education level, and ASD-DC Total Score. All factors were entered simultaneously. As previously noted, 20 of the ASD-DC scores were for individuals outside of the designed age range (2-16 years). To account for this, the analysis was run both with and without these individuals included. Results of both analyses are reported below.

All participants included. Overall, caregivers experienced a mean of 1.68 (SD = 1.38) perceived barriers to diagnostic services. There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values, and independence of residuals as assessed by a Durbin-Watson statistic of 2.16. There was homoscedasticity, as

assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. There was one studentized deleted residual greater than ±3 standard deviations for an individual reporting 7 of 10 possible barriers to diagnosis (studentized residual = 3.51), but inspection of the data point indicated no probable error in data entry or other reason for removal, and leverage value of 0.112 was within the acceptable range so this data point was maintained. There were no leverage values greater than 0.2, and were no values for Cook's distance above 1. The assumption of normality was met, as assessed by P-P Plot.

The multiple regression model did not predict number of barriers in a statistically significant way, $F(6, 81) = 0.842$, $p = .542$. R^2 for the overall model was 5.9% with an adjusted R^2 of -0.10%, a negligible effect size according to Cohen (1988). None of the five variables added statistically significantly to the prediction, $p > .05$. Regression coefficients and standard errors can be found in Table 5. Correlation coefficients within the context of the regression analysis can be found in Table 6.

Table 5. Summary of Multiple Regression Analysis: Barriers to Diagnosis ($N = 88$)

Variable	B	SE_B	β
Intercept	1.70	1.19	
Geography	-0.08	0.05	-0.18
Income	-0.05	0.10	-0.07
Ethnicity	-0.45	0.43	-0.12
Education	1.24	0.11	0.15
ASD-DC Total Score	0.01	0.01	0.02

Note: B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

Table 6.Correlation Coefficients of Multiple Regression Analysis: Barriers to Diagnosis ($N = 88$)

Variable	r	partial	semipartial	p
Geography	-0.13	-0.17	-0.17	0.12
Income	-0.01	-0.06	-0.06	-0.55
Ethnicity	-0.09	-0.12	-0.11	0.30
Education	0.09	0.13	0.12	0.25
ASD-DC Total Score	0.01	0.02	0.02	0.83

Excluding participants outside the ASD-DC range. This analysis excluded individuals whose children with ASD were outside of the ASD-DC age range (2-19 years) at the time of survey completion. This left a total of 68 participants for the following analysis, which is slightly lower than the sample size recommended via *a-priori* G*Power analysis. All factors were entered into the regression simultaneously.

Overall, caregivers reported experiencing a mean of 1.74 (*SD* = 1.48) perceived barriers to diagnostic services for their child. There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. Homoscedasticity was assessed via visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was one studentized deleted residuals greater than ±3 standard deviations for an individual reporting 7 of 10 possible barriers to diagnosis (studentized residual = 3.29), but inspection of the data point indicated no probable error in data entry or other reason for removal, and leverage value of 0.13 was within the acceptable range so this data point was maintained. There was one leverage value greater than 0.2, with a value of 0.24, but inspection of Cook's distance fell within acceptable limits and the data participant was maintained. There were no values for Cook's distance above 1. The assumption of normality was met, as assessed by P-P Plot.

The multiple regression model did not predict number of barriers in a statistically significant way, $F(5, 61) = 0.97$, $p = .455$. R^2 for the overall model was 7.3% with an adjusted R^2 of -0.2%, a small effect size according to Cohen (1988). None of the five variables added statistically significantly to the prediction, $p > .05$. Regression coefficients and standard errors can be found in Table 7. Correlation coefficients within the context of the regression analysis can be found in Table 8. Of note, examination of correlation tables independent of the regression analysis revealed that ethnicity was significantly correlated with the total number of barriers to diagnosis ($r = -0.2$, $p = .049$).

Table 7. Summary of Multiple Regression Analysis: Barriers to Diagnosis ($N = 68$)

Variable	B	SEB	β
Intercept	2.67	1.56	
Geography	-0.98	0.07	-0.15
Income	-0.08	0.13	-0.10
Ethnicity	-0.97	0.54	-0.23
Education	0.06	0.15	0.06
ASD-DC Total Score	0.00	0.01	-0.02

Note: B = unstandardized regression coefficient; SEB = Standard error of the coefficient; β = standardized coefficient

Table 8. Correlation Coefficients of Multiple Regression Analysis: Barriers to Diagnosis ($N = 68$)

Variable	r	partial	semipartial	p
Geography	-0.12	-0.15	-0.14	0.25
Income	-0.07	-0.08	-0.08	0.53
Ethnicity	-0.20	-0.22	-0.22	0.08
Education	0.24	0.05	0.05	0.71
ASD-DC Total Score	0.01	-0.02	-0.02	0.86

Predictors of Professional Reassurances as Perceived Barrier to Diagnosis

Descriptive analyses revealed that 33 (37.50%) of participants reported having received reassurances from professionals (e.g., pediatricians) that assessment was not needed at the time of parents' expressed concerns. Binomial logistic regression was used to investigate factors

related to likelihood of encountering these barriers including geography, income, ethnicity, education, and ASD symptom severity.

Linearity of continuous variables with respect to the logit of the dependent variable (reporting professional reassurances as a perceived barrier to diagnosis) was assessed using Box-Tidwell statistic. Bonferroni correction was applied resulting in accepting statistical significance of $p = .005$ (Tabachnick & Fidell, 2007). All continuous variables were found to be linearly related to the logit of the dependent variable (practitioner reassurances). No outliers were identified. The logistic regression model was not statistically significant, $\chi2(6) = 3.46$, $p = .750$. The model explained 5.3% (Nagelkerke R^2) of the variance in whether professional reassurances were experienced as a barrier and correctly classified 63.6% of cases. None of the predictor variables were statistically significant. Specificity was 94.5% and sensitivity was 12.1%. Additional details are presented in Table 9. As with the regression analysis for total number of barriers to diagnosis, the regression was also run excluding those participants who were outside of the age range for which the ASD-DC was designed. No significant differences from the below results were noted, thus those results are not included here.

Table 9. Logistic Regression Predicting Professional Reassurances as Barrier to Diagnosis

	B	SE	Wald	df	p	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Minority	-0.53	0.65	0.68	1	.408	0.59	0.17	2.08
Education	0.20	0.18	1.27	1	.259	1.22	0.86	1.72
Geography			0.44	2	.804			
Geo (1)	-0.55	0.84	0.44	1	.510	0.11	0.11	2.98
Geo (2)	-0.45	0.83	0.29	1	.590	0.13	0.13	3.24
ASD-DC Total	0.02	0,02	1.29	1	.255	1.10	0.98	1.05
Income	-0.10	0.16	0.31	1	.580	0.92	0.92	1.25
Constant	-1.97	1.85	1.12	1	.289	0.14		

Ethnic and Familial Barriers to Diagnostic Services

Fourteen (15.91%) participants encountered disagreement among caregivers or other family factors that impacted receiving first diagnosis. Chi-square test was implemented to test for association between ethnic status (minority or majority) and likelihood of reporting family factors as a barrier to diagnostic services. Due to one expected cell frequency less than 5, Fisher's exact test was interpreted. One of 13 participants who identify as ethnic minorities (7.69%) and 13 of 75 self-identified white participants (17.33%) reported family disagreement as a barrier to diagnostic service. This did not represent a statistically significant association between ethnicity and familial barriers to diagnostic services, $\chi2(1) = .683$, $p = .343$.

Perceived Barriers Resulting in Discontinuation of Previous Interventions

Of the 88 participants initially retained from analyses, four were excluded from questions regarding treatment because they had not yet begun receiving treatment. Additionally, six more were excluded because they dropped out of the survey after answering questions about the diagnostic process and autism symptom severity. This left 78 participants for the following analyses. Of the 78 participants who answered questions about intervention practices, 50 had reported discontinuing at least one EBP, 38 had discontinued at least one Emerging treatment, and 48 had discontinued at least one Complimentary / Alternative practice. Overall, a total of 48 participants had discontinued some non-EBP (either Emerging or Complimentary / Alternative practice). Additional details regarding discontinued EBPs are presented in Table 10. Details regarding discontinued non-EBPs are presented in Table 11.

Table 10. Discontinued EBPs (Total $N = 78$)

Intervention	n	Percent
Evidence-based practice (EBP)		
ABA-Based Behavior Therapy	22	28.21
Cognitive Behavioral Therapy	7	8.97
Modeling	4	7.84
Pivotal Response Training	2	2.56
EIBI	19	24.36
Language Production	3	3.85
Parent Training	2	2.56
Peer Training	1	1.28
Visual Schedules	6	7.69
Scripting	1	1.28
Self Management Training	1	1.28
Social Skills Package	3	3.85
Speech Therapy	22	28.21
Social Stories	9	11.54

Table 11. Discontinued non-EBPs (Total $N = 78$)

Intervention	n	Percent
Emerging (Non-EBP)		
Functional Communication	3	3.85
Exercise	3	3.85
Massage Therapy	2	2.56
Music Therapy	8	10.26
Occupational Therapy	16	21.51
Physical Therapy	7	8.97
Picture Exchange (PECS)	3	3.85
Sign Instruction	3	3.85
Structured Teaching	1	1.28
Complimentary/Alternative (Non-EBP)		
Acupuncture	0	0.00
Animal-Based	4	7.84
Art Therapy	1	1.28
Sensory Integration	7	8.97
Osteopathy	4	7.84
Facilitated Communication	0	0.00
Floor Time	5	6.41
Oxytocin	1	1.28
Play Therapy	5	6.41
Special Diet	12	15.38
Vitamins	8	10.26
Chelation	3	3.85
Hyperbaric Chamber	2	2.56
Packing / Holding	0	0.00

Caregivers endorsed a variety of reasons for quitting previously tried interventions. The 78 participants reporting on intervention history endorsed a range of 0-5 ($M = 1.04$; $SD = 1.22$) of 10 possible barriers resulting in discontinuation of EBPs. Of the 50 participants who reported having discontinued at least one EBP, the most commonly cited reasons for discontinuation were changes in eligibility (most commonly cited for EIBI), out of pocket expense, and "other." The "other" category provided an option for caregivers to explain the reasons for discontinuation. Write-in answers included a variety of reasons such as moving to a new geographic location, changing schools, or caregiver separation/divorce. Of note, analysis excludes those who reported in the "other" column that they had discontinued services for a non-barrier related reason (e.g., the intervention improved symptoms such that the intervention was no longer needed). Table 12 provides additional details about reasons for quitting EBPs.

Table 12. Reasons for quitting past EBPs ($N = 78$)

Barrier	n	Percent
Not Working	8	10.26
Expense	14	17.95
Eligibility (total)	18	23.08
Eligibility (excluding EIBI)	7	8.97
Insurance change	2	2.56
Scheduling	4	5.13
Provider relationship	7	8.97
Did not like in home	1	1.28
Proximity	2	2.56
Challenging behaviors	2	2.56
Other barrier	13	16.67

Similar to EBPs, the 48 caregivers who reported discontinuation of a non-EBP endorsed a variety of reasons for discontinuation. Of the reasons for discontinuing non-EBP interventions, most commonly cited were treatment was not working, out of pocket expense too great, and "other." Reasons listed as "other" included child losing interest, providers quitting or moving to a different location, or family relocating. The 78 participants reporting on intervention history

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endorsed a range of 0-6 ($M = 1.24$; $SD = 1.48$) of 10 possible perceived barriers resulting in

discontinuation of non-EBPs. Additional detail is provided in Table 13.

Table 13. Reasons for Quitting Past Non-EBP ($N = 78$)

Barrier	n	Percent
Not Working	24	30.77
Expense	17	21.79
Eligibility	10	12.82
Insurance change	2	2.56
Scheduling	6	7.69
Provider relationship	3	3.85
Did not like in home	0	0.00
Proximity	2	2.56
Challenging behaviors	5	6.41
Other	14	17.95

Factors Predicting Barriers to EBPs

Multiple regression was used to investigate factors related to experiencing greater

numbers of perceived barriers to diagnostic services. Investigated factors included geography

(living in urban, suburban, or rural areas), family income, ethnicity (minority or not), caregiver

education level, and ASD-DC Total Score. Because individuals who have experienced a longer

period of time between diagnosis and present have had greater opportunity to seek, begin, and

discontinue treatment, this time span was included in the regression as a covariate. Subsequently,

all variables of predictive interest were entered simultaneously. As previously noted, 20 of the

ASD-DC scores were for individuals outside of the designed age range (2-16 years). To account

for this, the analysis was run both with and without these individuals included. Results of both

analyses are reported below.

All participants included. For this participant sample of $N = 78$, linearity was demonstrated by

partial regression plots and a plot of studentized residuals against the predicted values. There was

independence of residuals, as assessed by a Durbin-Watson statistic of 1.85. The assumption of

homoscedasticity was met, as assessed by visual inspection of a plot of studentized residuals

versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. Inspection of residuals revealed one studentized deleted residual greater than ±3 standard deviations for an individual reporting 5 of 8 possible barriers to diagnosis (studentized residual = 3.53), but inspection of the data point indicated no probable error in data entry or other reason for removal, and leverage value of 0.08 was within the acceptable range so this data point was maintained. In one case, a leverage value greater than 0.2 was found; levels of 0.2 to 0.5 are considered "risky," and values of 0.5 are considered unacceptable (Cook & Weisberg, 1982; Laerd, 2015). The leverage value of .26 indicated a need to look more closely at the possibility of undue influence on results. Inspection of Cook's distance values indicated no values greater than 1 (range was 0.00 to 0.14), thus all participants were retained. The assumption of normality was met, as assessed by P-P Plot. The first model, accounting for time elapsed since diagnosis, did not predict number of barriers causing discontinuation of EBP, $R^2 = 0.02$, $F(1, 76) = 1.34$, $p = .251$, adjusted $R^2 = 0.004$. The addition of ethnicity, geography, income, ASD-DC score, and education did not lead to a statistically significant increase in R^2, which increased by 0.06. The full model of time elapsed since diagnosis, caregiver education level, autism symptom severity, family income, caregiver ethnicity, and geography did not predict number of perceived barriers causing discontinuation of EBP in a statistically significant way, $R^2 = 0.07$, $F(5, 71) = 0.82$, $p = .478$, adjusted $R^2 = -0.01$. Regression coefficients and standard errors can be found in Table 12 (below). Correlation coefficients within the context of the regression analysis can be found in Table 13 (below). Of note, inspection of correlation matrix independent of regression analysis revealed a significant correlation between barriers to EBP and income ($r = -.21$, $p = 0.31$). Regression coefficients and

standard errors can be found in Table 14. Correlation coefficients within the context of the

regression analysis can be found in Table 15.

Table 14. Hierarchical Multiple Regression Predicting Number of Barriers Resulting in Discontinuation of EBPs ($N = 78$)

Variable	Model 1 (Covariate)			Model 2		
	B	SE_B	β	B	SE_B	β
Constant	0.86	0.21		0.44	1.16	
Months since diagnosis	0.01	0.01	0.13	0.01	0.01	0.17
Geography				-0.02	0.05	-0.05
Income				0.12	0.09	0.18
Ethnicity				-0.22	0.40	-0.07
Education				0.05	0.10	0.06
ASD-DC Total Score				-0.01	0.01	-0.03
R^2	0.02			0.07		
F	1.34			0.93		
ΔR^2	0.02			0.06		
ΔF	1.34			0.52		

Note: B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

Table 15. Correlation Coefficients of Multiple Regression: Barriers to EBPs ($N = 78$)

Variable	r	partial	semipartial	p
Model 1				
Months since diagnosis	0.13	0.13	0.13	0.251
Model 2				
Months since diagnosis	0.13	0.16	0.15	0.182
Geography	0.02	-0.05	-0.05	0.656
Income	0.21	0.15	0.15	0.204
Ethnicity	-0.20	-0.07	-0.06	0.577
Education	0.15	0.06	0.05	0.639
ASD-DC Total Score	-0.03	-0.03	-0.03	0.784

Excluding participants outside the ASD-DC age range. This regression analysis excluded data

from participants whose children with ASD were outside of the ASD-DC age range (2-16 years)

at the time of survey completion. This left a total of 60 participants for the following analysis,

which is slightly lower than the sample size recommended via *a-priori* G*Power analysis. In

analyzing that necessary assumptions were met, linearity was present as assessed by partial

regression plots and a plot of studentized residuals against the predicted values. The assumption

of homoscedasticity was met as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as all tolerance levels were greater than 0.1. There was one studentized deleted residual greater than ±3 standard deviations for an individual reporting 5 of 8 possible barriers to diagnosis (studentized residual = 3.44), but inspection of the data point indicated no probable error in data entry or other reason for removal, and leverage value of 0.139 was within the acceptable range so this data point was maintained. There were seven instances of leverage values greater than 0.2; as noted above, levels of 0.2 to 0.5 are considered "risky" and values of 0.5 are considered unacceptable (Cook & Weisberg, 1982; Laerd, 2015). The leverage values ranging from 0.21 to 0.26 indicated a need to look more closely at the possibility of undue influence on results using Cook's distance. Inspection of Cook's distance values indicated no values greater than 1 (range was 0.00 to 0.22), thus all participants were maintained. The assumption of normality was met, as assessed by P-P Plot. The first model, accounting for time elapsed since diagnosis, did not predict number of barriers causing discontinuation of EBP, $R^2 = 0.05$, $F(1, 58) = 2.82$, $p = .098$, adjusted $R^2 = 0.03$. The addition of ethnicity, geography, income, ASD-DC score, and education did not lead to a statistically significant increase in R^2, which increased by 0.123. The full model of time elapsed since diagnosis, caregiver education level, autism symptom severity, family income, caregiver ethnicity, and geography did not predict number of barriers causing discontinuation of EBP in a statistically significant way, $R^2 = 0.17$, $F(6,53) = 1.79$, $p = 0.118$, adjusted $R^2 = 0.08$; however, income was significantly correlated with barriers to EBP ($r = 0.35$, $p = .040$). Regression coefficients and standard errors can be found in Table 16. Correlation coefficients within the context of the regression analysis can be found in Table 17.

Table 16. Hierarchical Multiple Regression Predicting Number of Barriers Resulting in Discontinuation of EBPs ($N = 60$)

Variable	Model 1 (Covariate)			Model 2		
	B	SE_B	β	B	SE_B	β
Constant	0.68	0.27		0.43	1.33	
Months since diagnosis	0.01	0.01	0.22	0.01	0.01	0.21
Geography				-0.03	-0.06	-0.45
Income				0.25	0.12	0.34
Ethnicity				-0.10	0.46	-0.03
Education				-0.02	0.13	-0.03
ASD-DC Total Score				-0.01	0.01	-0.08
R^2	0.05			0.17		
F	2.82			1.79		
ΔR^2	0.05			0.12		
ΔF	2.82			1.56		

Note: B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

Table 17. Correlation Coefficients of Multiple Regression: Barriers to EBPs ($N = 60$)

Variable	r	partial	semipartial	p
Model 1				
Months since diagnosis	0.22	0.22	0.22	0.098
Model 2				
Months since diagnosis	0.22	0.21	0.20	0.120
Geography	-0.02	-0.06	-0.06	-0.660
Income	0.35	0.28	0.26	0.040*
Ethnicity	-0.20	-0.03	-0.03	0.828
Education	0.18	-0.02	-0.02	0.863
ASD-DC Total Score	0.01	-0.02	-0.02	0.564

The direction of the correlation between income and perceived number of treatment barriers indicated that higher income was related to increased difficulty maintaining EBP services. As insurance is closely related to the out of pocket costs of treatment, follow-up testing was conducted to investigate the relationship between insurance type and number of perceived EBP barriers reported. Due to non-normal distribution of data (thus violating assumptions for one-way ANOVA), a Kruskal-Wallis H test was run to determine if there were differences in number of barriers reported among three groups based on insurance type: public only, private only, or both public and private. Distributions of total number of perceived EBP barriers were

not similar for all groups, as assessed by visual inspection of a boxplot. The distributions of scores were not statistically significant among groups, $\chi^2(2) = 3.46$, $p = .178$. Participants were classified into three groups: private insurance only ($n = 29$), public insurance only ($n = 26$), and having both private and public insurance ($n = 22$). Information on number of barriers reported per group is presented in Table 18.

Table 18. Perceived Number Barriers Causing Discontinuation of EBP x Insurance Type

Group	N	Mean(SD)	Range
Public Insurance	26	0.69 (0.88)	0-5
Private Insurance	29	1.28 (1.56)	0-3
Both Types Insurance	22	1.14 (1.04)	0-3

SD = Standard Deviation

Predictors of Time Between ASD Diagnosis and First ASD Symptom Treatment

Multiple regression was utilized to investigate the relationship between various demographic factors of interest (geography, caregiver education, family income, ethnicity, and ASD-DC total score) and the time between formal ASD diagnosis and receipt of services targeting ASD symptoms. As previously noted, 24 participants reported their child had begun receiving treatment for ASD symptoms prior to receiving a formal ASD diagnosis. Additional information about the types of treatment or how these individuals came to receive the pre-diagnostic services is not available. Twelve individuals reported beginning treatment within one month of receiving diagnosis. Of those who have experienced a delay between diagnosis and treatment, time delay ranged from one month to 31 months. ($M = 5.42$; $SD = 7.36$).

Overall, caregivers reported a mean of -0.51 ($SD = 13.83$) months from diagnosis to treatment, indicating a slight tendency to receive therapeutic services of some type prior to receiving formal diagnosis. It is possible that some were enrolled in state-funded early intervention programs due to conditions often seen early in development for individuals later diagnosed with ASD, including delayed speech or other milestones. Factors investigated

included geography (rural, suburban, or urban), child ethnicity, caregiver level of education, family income, and ASD symptoms severity as reported via the ASD-DC. As with previous regression analyses, multiple regression to investigate these relationships was conducted first with all participants and then excluding those participants whose children were outside of the ASD-DC age range. Results were not significantly different.

All Participants Included

Four of the 88 participants were excluded from this analysis because they reported their children have not yet begun receiving ASD interventions. A total of 84 participants remained for this analysis. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.1. There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. Inspection of casewise diagnostics revealed two cases with studentized residuals greater than 3 (SR = -8.50 and -4.47, respectively). In each of these cases, caregivers reported having accessed treatment for ASD symptoms many months prior to receiving a formal ASD diagnosis (112 months and 168 months, respectively). Further inspection revealed neither of these points had leverage values greater than 0.2, nor did they have Cook's distance values greater than 1. Accordingly, these two cases were retained for the following analysis. A cubed root transformation was applied to the data due to observed deviations from normality upon inspection of P-P histogram.

The multiple regression model did not predict time between diagnosis and first treatment for ASD symptoms in a statistically significant way, $F(5, 78) = 1.55$, $p = .183$. R^2 for the overall model was 9.1% with an adjusted R^2 of 0.03%, a negligible effect size according to Cohen

(1988). Overall, the model did not predict time from diagnosis to treatment in a statistically significant way, though ethnicity did contribute significantly to the model ($r = .22$, $p = .046$). Regression coefficients, correlations, and standard errors can be found in Tables 19 and 20.

Table 19. Summary of Multiple Regression Analysis: Diagnosis to Treatment Time ($N = 84$)

Variable	B	SE_B	β
Intercept	-1.20	1.72	
Geography	0.01	0.07	0.01
Income	0.27	0.14	0.25
Ethnicity	1.26	0.62	0.23
Education	-0.15	0.16	-0.13
ASD-DC Total Score	0.01	0.01	0.05

Note: B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

Table 20. Correlation Coefficients of Multiple Regression: Diagnosis to Treatment Time ($N = 84$)

Variable	r	partial	semipartial	p
Geography	-0.05	-0.01	0.01	0.962
Income	0.16	0.21	0.21	0.065
Ethnicity	0.22	0.22	0.22	0.046*
Education	-0.12	-0.11	-0.11	0.337
ASD-DC Total Score	-0.03	-0.03	-0.05	0.649

Excluding Participants Outside the ASD-DC Age Range

Sixty-three participants remained after excluding those whose children were outside of the ASD-DC age range at time of survey completion. Of note this is slightly below the sample size recommended by G*Power (Faul, Erdfelder, Lang, & Buchner, 2007)). There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was homoscedasticity, as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. Inspection of casewise diagnostics revealed no problematic outliers. Leverage values and Cook's distance were all within acceptable limits. The

cubed root transformation used in the previous analysis was similarly applied to this analysis due

to observed deviations from normality upon inspection of P-P histogram.

The multiple regression model did not predict time between diagnosis and first treatment

for ASD symptoms in a statistically significant way, $F(5, 57) = 0.96$, $p = .449$. R^2 for the overall

model was 7.8% with an adjusted R^2 of -0.01%, a negligible effect size according to Cohen

(1988). Overall, the model did not predict time from diagnosis to treatment in a statistically

significant way, all predictor variables $p > .05$ Regression coefficients, correlations, and standard

errors can be found in Tables 21 and 22 (below).

Table 21. Summary of Multiple Regression Analysis: Diagnosis to Treatment Time ($N = 63$)

Variable	B	SE_B	β
Intercept	-0.01	1.81	
Geography	-0.28	0.08	-0.05
Income	0.10	0.16	0.10
Ethnicity	1.17	0.66	0.24
Education	-0.01	0.19	-0.01
ASD-DC Total Score	-0.01	0.02	-0.02

Note: B = unstandardized regression coefficient; SE_B = Standard error of the coefficient; β = standardized coefficient

Table 22. Correlation Coefficients of Multiple Regression: Diagnosis to Treatment Time ($N = 63$)

Variable	r	partial	semipartial	p
Geography	-0.10	-0.05	-0.04	.728
Income	0.08	0.08	0.08	.542
Ethnicity	0.26	0.23	0.23	.080
Education	0.00	-0.01	-0.01	.947
ASD-DC Total Score	-.11	-0.02	-0.22	.862

Currently Desired Interventions

Participants were asked about treatments that they would like to try in the future. A total

of 51 participants stated they were seeking additional services. Of those, 41 of the answers could

be clearly categorized into EBP or non-EBP interventions. Twenty-seven desired EBPs; 14

desired non-EBP interventions. Twenty-one participants indicated they were not interested in additional services at this time and were thus excluded from these analyses.

Descriptive Analysis

Interventions most frequently desired were related to ABA-based therapy ($n = 11$), social skills ($n = 8$), services from a psychologist specially trained in ASD and/or CBT ($n = 5$), and speech therapy ($n = 5$). A wide variety of both EBPs and non-EBPs were desired, including hippotherapy (horseback riding used as a therapeutic intervention), off-label medication, help with transitioning to adulthood or learning job skills, peer modeling, floor time, sensory integration therapy, art or music therapy, dietary changes, pivotal response training, massage, acupuncture, osteopathy, academic tutoring, and programs that incorporated typically developing peers.

The most frequently cited barriers to desired future interventions were expense, scheduling / time required, and "other," closely followed by waitlist and proximity (too far) or other transportation issues. Of caregivers seeking additional interventions, a range of 1-5 barriers ($M = 2.02$; $SD = 1.17$) was reported. Participants were also asked to rank the perceived barriers in order of difficulty each posed, with 1 indicating "most problematic." Information about perceived barriers to the desired services is provided in Table 23.

Table 23. Perceived Barriers to Desired Interventions ($N = 51$)

Barrier	N (%)	Ranked #1 (N%)
Cost	26 (50.98)	15 (29.41)
Scheduling or time required	18 (35.29)	5 (9.80)
Other	17 (33.33)	10 (19.61)
Proximity or transport	15 (29.41)	8 (15.68)
Wait list	15 (29.41)	5 (9.80)
Process to access	10 (19.61)	3 (5.89)
Problem Behaviors	5 (9.80)	2 (3.92)

Regarding the rank of how problematic the above barriers were perceived, cost was perceived as the number one barrier for 15 of the participants (29.41%). Ten participants (19.61%) perceived "other" barriers as most problematic based on rank ordering, and distance/transportation was most problematic for 8 participants (15.69%). The "other" responses of some caregivers indicated significant frustration. For example, responses included "Have you ever tried to get the school to provide something?!" and "So many treatments without proof- so much Snake Oil. Where to turn?"

Predictors of Desiring EBP Over Non-EBP

A binomial regression was utilized to inspect factors related to whether a participant who desired additional services was seeking EBP vs non-EBP treatments. Of the 51 participants who indicated a desire for additional services, 41 answers were able to be categorized into EBP ($n = 27$) or non-EBP ($n = 14$) approaches. (The remaining 10 responses were not evident, and included comments such as "more of what she's already getting" or "tutoring by someone trained in ASD"). Due to smaller sample size (Laerd, 2015a), predictive variables were limited to education, income, and ethnicity. Income and ethnicity were chosen due to evidence of correlation with past treatment experience in previous analyses; education level was retained based on previous studies indicating that parental education affected treatment choices, with higher education corresponding with increased used of non-EBPs (e.g., Salomone and colleagues, 2015).

Linearity of the continuous variables with respect to the logit of the dependent variable was assessed via the Box-Tidwell (1962) procedure. A Bonferroni correction was applied using all eight terms in the model resulting in statistical significance being accepted when p < .00625

(Tabachnick & Fidell, 2007). Based on this assessment, all continuous independent variables were linearly related to the logit of the dependent variable. There were no observed outliers.

A binomial logistic regression was performed to ascertain the effects of years of caregiver education, income, and ethnicity on the likelihood that they were seeking additional EBP rather than non-EBP. The logistic regression model was not statistically significant, $\chi^2(3) = 9.512$, $p = .301$. The model explained 2.6% (Nagelkerke R^2) of the variance in treatment choice and correctly classified 65.9% of cases. None of the predictor variables were statistically significant. Additional details are presented in Table 24.

Table 24. Logistic Regression Predicting Likelihood of Seeking EBP at Present Based on Minority Status, Education, and Income

	B	SE	Wald	df	p	Odds Ratio	95% CI for Odds Ratio	
							Lower	Upper
Minority	-0.75	0.90	0.71	1	.401	0.47	0.08	2.27
Education	-0.02	0.24	0.01	1	.983	0.98	0.62	1.56
Income	-0.01	0.20	0.00	1	.995	1.0	0.67	1.46
Constant	1.376	1.58	0.76	1	.617	3.96		

CHAPTER 10: DISCUSSION

Limitations

There are a few notable limitations to this study. Non-Latino white individuals and higher-SES individuals were over-represented in this sample compared to the United States averages. Caregivers were self-identified and self-reported their child's ASD diagnosis; diagnoses were not independently verified. A larger and more demographically representative sample would have been desirable. There was a 42% dropout rate for the survey. Nonetheless, the dropout rate is in line with other online surveys of similar length without compensation (Galesic, 2006). Additionally, results of this study are in line with previous research indicating families experience a wide range of barrier types, and some groups (e.g., minority ethnic groups) are more likely to experience multiple barriers.

Descriptive Analyses

Overall, the study sample accurately represented the higher prevalence of ASD in males than females. It has been estimated that ASD occurs approximately 4:1 male to female ratio (Bertaglio & Hendren, 2009); in this sample, 77% male and 23% female distribution closely mirrors what we would expect in the general population. The sample was not so closely representative of the United States' ethnic makeup. In the 2010 United States Census, approximately 33% of the U.S. population reported their ethnicity as something other than non-Latino white alone, thus qualifying as being of minority ethnic identification (United States Census Bureau, 2010a). In this sample, minorities were slightly under-represented. Based on the US Census data, a representative sample would be comprised of approximately 66% white, non-Latino caregivers, but in actuality the sample included approximately 85% white, non-Latino caregivers. There were slightly fewer white children with ASD (79.5%). For the purpose of

analysis, ethnicity of the caregiver was used, as this was a study of the caregivers' experiences. Families on the higher end of the SES spectrum were also over-represented with a full 34% of the sample having achieved at least some graduate school education. Only 8% of the sample had no more education beyond high school. Given a roughly 20% high school dropout rate in this country (some of whom later go on to receive General Education Development / GED degrees; Stetser & Stillwell, 2014), a representative sample would include more individuals with high school or less education than the achieved sample. Although the education and income variables were not overly correlated, families with higher income were also over-represented. In 2014, the median household income in the United States was $53,657 (DeNavas-Walt & Proctor, 2015); in this study sample, only 36% reported family incomes of $55,000 or less. The over-representation of highly educated, financially well-resourced families may be related to the study being shared on a listserv for medical doctors who have children with special needs. The rural population was also somewhat underrepresented. According to the 2010 United States Census (United States Census Bureau, 2010b), 19.3% of the population resides in rural areas; in this sample, 9.09% reported living in a rural area.

In this sample, the range of age at first diagnosis varied widely; some variation is expected as there were several children with reported diagnosis of Asperger's Disorder, which under the *DSM-IV-TR* was often not diagnosed until school age (CDC, 2012). The mean age of diagnosis was 4.7 years (*SD* = 3.87 years). In general, recent studies of age at diagnosis have found that although ASD can sometimes be reliably diagnosed at age 2 years or younger (Council on Children with Disabilities, 2006; Kim & Lord, 2012), the median age is somewhere from 4-6 years depending on symptom severity (CDC, 2012; Chakrabarti, 2009; Shattuck et al., 2009, Yeargin-Allsopp et al., 2003). The children in this sample may have been diagnosed

slightly earlier on average than expected, but the widely varying ages are representative of the wide ranges reported in the aforementioned studies.

Fifty-four of the participants in this study reported a gap between diagnosis and treatment. Of those individuals who did experience a gap from diagnosis to treatment, the mean wait time was 5.42 months (SD = 7.36 months). The fact that 24 caregivers reported their child began receiving services for ASD symptoms prior to receipt of a formal diagnosis was unexpected. It is possible that these children benefitted from state-wide early intervention services. While each state has their own early intervention program for infants and toddlers with disabilities through the Grants for Infants and Families Program Part C (United States Department of Education, 2016), different states may have different criteria for receiving services. Children generally qualify for services by scoring below a certain cutoff on one or more developmental domains during standardized testing of abilities after referral for evaluation from a healthcare provider or family member (the cutoff scores or number of domains that must be lower than expected may vary from state to state). As discussed under the Diagnosis section of this paper, developmental delays are often evident in children with ASD before they receive an ASD diagnosis, and thus these children may qualify for services (e.g., speech therapy) prior to a formal ASD diagnosis.

Perceived Barriers to Diagnostic Services

The majority of participants (n = 75; 85.23%) reported at least one barrier to diagnostic services, with the majority reporting multiple barriers (M = 1.68; SD = 1.38). Most frequently reported were long wait lists, reassurances from professional providers, and difficulties with scheduling (e.g., having to balance work schedules with clinic visits, or juggling other family responsibilities). The high number (n = 19; 21.59%) who experienced problems with scheduling

suggests that professionals may consider offering occasional scheduling outside of the typical 9am-5pm workday to accommodate families who have difficulty scheduling. For example, occasional evening or weekend hours may alleviate some of the difficulty caregivers face in scheduling diagnostic services. Anecdotally per the authors' experience, difficulty with childcare for other children also presents a difficulty; for example, if a parent has another child with special needs, or has to travel to a clinic, stay on campus during the assessment period, and then drive back home, the parent may not be able to pick up other children from school or aftercare programs on time. Flexible scheduling or assisting with figuring out childcare for other children may be approaches clinicians can take to assist families facing these scheduling difficulties.

Regarding perceived barriers to diagnosis, the author was especially interested in those factors that might be ameliorated with educational efforts. Specifically, the author was interested in factors affecting likelihood of experiencing reassurances from professionals or disagreement among primary caregivers as perceived barriers to diagnostic services. While the most common barrier was long wait lists (reported by 49 participants at a rate of 55.68% of the sample), inspection of the most frequently reported perceived barriers to diagnostic services revealed a surprising number (33, representing 37.5% of the sample) reported reassurances from professionals as a factor delaying diagnosis. It is perhaps important to note that this represents perceived reassurances against diagnostic services; it is possible that healthcare professionals did not intend to send this message. It is also possible that caregivers are counting non-healthcare professionals in this category since they were not asked to specify from whom they received this message, although the examples provided in the survey were all healthcare professionals. Qualitative data (where participants were given the option to type in additional responses) indicates that ASD symptoms presented in the context of other developmental problems (e.g.,

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Down Syndrome, partial agenesis of the corpus callosum, global developmental delay) may have been attributed to the comorbid disorders despite parental concerns that "something else" was going on. For example, one respondent answered "Pediatrician thought symptoms were due to Down Syndrome." Similarly, a second respondent stated of their child with partial agenesis of the corpus callosum that "we were told that because of [her condition] she could not have autism. We fought for years before someone would finally do research and discovered she can have both." Another respondent replied, "We were told the answers to an 8 question screening indicated possible autism. We were surprised when the doctor suggested that we might want to change some of our answers. We didn't change our answers, but it did make us concerned about our child's doctor." Presumably, these parents were able to get a referral for diagnostic services that ultimately validated their concerns. It was hypothesized that a binomial regression to inspect factors predicting this experience would show that an increase in ASD symptom severity (as measured by the ASD-DC) would correspond with a decreased likelihood of perceiving professional reassurances as a barrier to diagnosis. It was also hypothesized that increased education of parents would also correspond with a decrease in perceiving this barrier, as more educated parents may be better able to engage in good-quality research prior to appointments and thus may be able to speak more precisely about their child's symptoms and ask more pointed questions about autism-specific concerns. However, while ASD-DC total score and caregiver educational attainment were closer to statistical significance than the other variables (at $p = 2.89$ and $p = .259$ respectively), these values are still far from statistical or clinical significance. In the context of the available information, there were no statistically significant predictors of perceiving professional reassurances as a barrier to diagnostic services.

On at least two occasions, parental stressors or comorbidities interfered with pursuit of diagnostic services. One participant who reported lack of insurance as a barrier added "in fairness, I did not attempt to get insurance coverage… I have ADHD, I was exhausted and disorganized." Another participant (who was not a biological parent) reported that the child's parents were too wrapped up in drug addiction to pursue appropriate medical care at the time despite concerns from others. Regarding familial factors, the author was more specifically interested in disagreement among caregivers about whether or not to pursue diagnostic services as a perceived barrier. With 14 (15.91%) of the participants reporting this as a barrier, family disagreement was the 4th most common barrier reported, after waitlist (55.68%), professional reassurances (37.50%), and cost (17.05%). Based on literature review (see the section on Community and Cultural factors) revealing widely varying cultural beliefs about autism causes and the stigma associated with the disorder, it was hypothesized that ethnicity would impact likelihood of perceiving caregiver disagreement as a barrier. In actuality, results of the chi-square test did not indicate a statistically significant increase in experiencing this barrier for participants who identify as ethnic minorities. This result should be interpreted cautiously, as non-white participants were under-represented in this sample, and relatively few (15.91%) endorsed this barrier. Additional research into this topic would benefit from larger sample sizes that contain a greater number of individuals endorsing this perceived barrier.

The author was also interested in factors that predict greater likelihood of experiencing multiple barriers to diagnosis. Multiple regression was used to investigate ethnicity, geographical location, household income, caregiver educational attainment, and ASD symptom severity based on ASD-DC Total Score as predictive factors for experiencing increased numbers of perceived barriers. It was hypothesized that living in an urban area, higher household income, higher

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educational attainment, and greater ASD symptom severity would be correlated with fewer reported barriers to diagnostic services, whereas identifying as an ethnic minority would be correlated with an increase in barriers, perhaps in part due to a correlation in this country between minority status and greater barriers to achieving higher education and income. In this sample, ethnicity was not overly correlated with any of the predictive variables, thus avoiding the problem multicollinearity in the analysis. The analysis was run both with and without the individuals who were technically outside of the age range for which the ASD-DC was designed. Overall, the model did not show statistical significance in predicting the number of barriers experienced in pursuit of diagnostic services in either case. Interestingly, in the smaller sample that excluded those outside the ASD-DC age range, ethnicity was significantly correlated with the outcome variable (number of perceived barriers reported) independent of the model. One must be cautious of reading too much into this result as the descriptive correlations provided do not account for multiple comparisons in the same way that running the full analysis does, and minorities were somewhat under-represented in this sample as previously discussed. However, this area may be worthy of additional research in the future with a larger sample size in which individuals who identify as ethnic minorities are better represented.

Perceived Barriers Causing Discontinuation of Past Interventions

Descriptive analyses of information related to discontinued past interventions revealed that the most frequently discontinued EBPs were ABA-based behavior therapy and speech therapy ($n = 22$; 28.21% for each), followed by EIBI ($n = 19$; 24.36%). Of note, 11 of the individuals who quit EIBI reported the service was discontinued due to changes in eligibility; this is unsurprising as many of the state-funded early intervention programs or other regional/local programs that help fund EIBI have age cutoffs of 3 or 5 years (and indeed, the

very title *Early* Intensive Behavior Intervention indicates it is a treatment for use during early childhood). Due to the way the survey was streamlined based on feedback from dissertation committees and pilot participants, it is impossible to determine what was the most common cause for discontinuation of ABA-based therapy. It is surprising that only 2 participants (2.56%) endorsed distance/proximity to treatment as a major barrier leading to discontinuation of past EBP interventions; it may be that individuals take this into account before beginning treatments and are unlikely to begin interventions at all if they perceive distance as too great. On the other hand, perhaps EBP service provision is improving in less populated areas. On the whole, the most frequently reported reasons for discontinuing EBPs were eligibility, expense, and "other." Excluding EIBI, top-ranked reasons for quitting EBPs were expense, "other," and "not working." The "other" category offered the option for caregivers to elaborate on their answers, and several indicated frustration with quality of services provided. For example, one individual stated "the county-sponsored stuff was nearly worthless… and private stuff was hugely expensive." Another stated "services were poor quality." Other barriers reported in the "other" category included "facility closed," "only helpful if it's a whole bunch of it, but nobody here provides that," "therapists all geared towards younger patients," "therapist took a break," "therapist left now we are back on a wait list," and "unable to find new service providers when old ones quit." Seven individuals (8.97%) reported having discontinued an EBP due to poor relationship with the provider, and one due to disliking having services provided in the home. It is discouraging that many individuals discontinued EBPs due to difficulties with provider relationships or due to discontinuation of services due to therapists leaving or facilities closing. Certainly, service providers should engage in internal quality assessment to ascertain the fidelity of the provided services; an EBP is no longer evidence-based if it is not accurately administered. Service

providers should also work to ameliorate any difficulties that may arise in the relationship with the caregivers when possible. It may be that the caregivers who discontinued due to problems with providers never raised their concerns to the providers, thus providers may not have had an opportunity to work to rectify the problems. Periodically checking in regarding caregiver satisfaction with services provided may be a way to address this concern without taking much time, as in periodically asking parents to complete a brief satisfaction questionnaire. It is encouraging that far fewer individuals discontinued EBP due to the practice not working ($n = 8$; 10.26%) compared to the 24 participants (30.77%) who discontinued non-EBPs for the same reason. Overall, it was hypothesized that cost would be more frequently reported as a barrier to non-EBP over EBP because insurance is far more likely to reimburse for EBP. While the hypothesized result was true with 17.95% reporting cost as a barrier to EBP and 21.79% reporting cost as a barrier to non-EBP, overall out-of-pocket cost was one of the top barriers for both types of interventions.

The most frequently discontinued non-EBPs included occupational therapy ($n = 16$; 21.51%), special diets such as gluten or casein-free ($n = 12$; 15.38%), vitamins ($n = 8$; 10.26%), and sensory integration therapy ($n = 7$, 8.97%). The top reported reasons for quitting non-EBPs included "not working," expense ($n = 17$; 21.79%), and "other" ($n = 14$; 17.95%). As with EBPs, a variety of reasons for discontinuation were reported in the "other" category. Examples include death of providing practitioner, "therapist had no clue," "therapy became unavailable," and "therapist feeling he didn't respond." Of note, three participants endorsed having used chelation therapy and two reported having used hyperbaric chamber therapy in an attempt to treat ASD symptoms (one participant endorsed both). It is unsurprising that three of the four participants who had tried one of these interventions reported discontinuation because the practices were not

working. (The participant who tried both was apparently undeterred by inefficacy, but discontinued due to out of pocket cost being too expensive). There is not only substantial research to support the ineffectiveness of these approaches, but also that these practices present considerable risk of substantial harm. It is on the one hand fortunate that only four participants (5.13%) of the 78 in this analysis endorsed having tried these dangerous and sometimes invasive techniques; on the other hand, it is troubling that any health care provider would provide these interventions without clear medical indication. The author wonders where participants encountered spurious claims of efficacy for these dangerous practices; despite the comparatively low number of caregivers pursuing hyperbaric chamber or chelation therapies, future research into which caregivers are likely to pursue dangerous and invasive practices and where they are getting information and treatment could help inform targeted educational efforts to decrease use of these ineffective practices in efforts to treat ASD symptoms.

Given that EBPs for ASD are by definition generally effective at improving ASD symptoms, the author was especially interested in factors predicting experiencing a greater number of barriers leading to discontinuation of EBPs. Similar to hypothesized results for barriers to diagnosis, it was hypothesized that lower household income would predict higher numbers of reported barriers. Financial providers in families with lower income may have low-paying entry-level jobs; many of these jobs entail hourly wages rather than salary. This can make it more difficult to take time away from work as any time away entails loss of income. Low-income families may be more likely to be headed by a single parent, amplifying problems with scheduling or transportation. It was also hypothesized that rural location would be indicative of higher number of reported barriers, followed by lower educational attainment as a predictor of greater perceived barriers. It was hypothesized that higher ASD symptom severity as measured

by the ASD-DC would be predict fewer barriers as it may be easier to qualify for multiple services or more comprehensive programs, including programs to provide financial assistance for healthcare services, when symptoms are more severely impacting functioning. After co-varying time elapsed since diagnosis, multiple regression investigating geography, family income, ethnicity, caregiver education level, and ASD-DC total scores as predictors revealed the model was not effective at predicting increased number of reported barriers to past EBP. As with the analysis on barriers to diagnostic services, the analysis was run both with and without the participants who were outside of the age range for which the ASD-DC was designed. The results were slightly different; in the all-inclusive analysis, income was found to be significantly correlated with the outcome variable (number of perceived barriers to EBP reported) but it was not significantly predictive within the context of the model. In the analysis that excluded the 18 participants outside of the ASD-DC age range, income was significantly correlated with higher rates of reported EBP barriers. In summary, while the models did not significantly predict number of barriers experienced in continuing EBPs, a surprising trend indicated that families with higher incomes are more likely to report multiple barriers resulting in discontinuation of services.

In light of the surprising trend that participants from higher-income families were more likely to report multiple barriers resulting in discontinuation of EBPs, it was then hypothesized that insurance may play a role in this finding, with those with public insurance facing fewer challenges to maintaining services. Thomas and colleagues (2007) found that children covered by public insurance had much greater odds of using a variety of therapeutic services as well as medication management than those covered by private insurance; children covered by public insurance were also less likely to use some complimentary/alternative approaches (e.g.,

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supplements) compared to those covered only by public insurance. These same authors also found that children without insurance were most likely to receive services that facilitated entry into the healthcare system. In 2014, Parish and colleagues found that after controlling for symptom severity and demographic characteristics, families with private insurance were more than five times as likely to have out of pocket costs for ASD treatments compared to those children covered by public health insurance. Most frequently, these costs were related to outpatient services, medications, and dental care. The results found in this study may be because children from families with lower income are more likely to be covered by Medicaid, which may cover more ASD treatment services than the average private insurance plan. Accordingly, families who do not qualify for Medicaid due to higher family income may incur significantly greater financial burdens for their child's ASD-related healthcare. Additionally, it is possible that these middle- or higher-income families would benefit from some of the services (e.g., transportation to and from therapy or medical appointments) that are available to individuals who receive Medicaid.

Inspection of means and standard deviations of number of barriers resulting in discontinuation of EBPs indicated that on average, individuals with private insurance reported greater difficulty maintaining EBPs than those with public insurance, which is in line with previous research. Additionally, individuals who had both public and private insurance reported more barriers than those with public only, but fewer than those with private only. The results of the Kruskal-Wallis analysis were not significant; however, it is possible that in this sample there was a "basement effect" since many individuals (fortunately) reported relatively few barriers to EBP. It is possible that more nuanced information regarding insurance type and access to services might shed light on the validity of this trend and reveal significant results consistent

with results of previously published studies. It is possible that individuals who have both public and private insurance experience significantly more frustration in accessing services due to difficulties inherent in having both public and private insurance. In particular, public insurance (e.g., Medicare) often requires that individuals who have both types of insurance file with their primary (private) insurance first. However, the private insurance may not cover the desired ASD treatment. Attempts to resolve this issue and obtain coverage can require appeals and multiple communications between each insurance provider; even once the process is resolved and public insurance agrees to cover what the primary/private insurance does not, periodic reauthorization may be required. As laws surrounding ASD coverage by private insurance continue to change and more states mandate coverage of at least some EBPs for ASD, continued research into the effects of insurance coverage on access to services will remain an important area of research.

Predictors of Time Between ASD Diagnosis and First ASD Symptom Treatment

Overall, caregivers reported a slight tendency for their children to begin receiving treatment prior to receiving formal ASD diagnosis ($M = 0.51$ months prior to diagnosis; $SD = 13.83$ months). Particularly in light of the mean age of first diagnosis ($M = 4.70$ years, $SD = 3.87$ years), the large standard deviation of time between diagnosis and treatment fits with the hypothesis that many individuals may have been enrolled in early intervention programs for children with developmental delays. Unfortunately the contents of the survey do not allow for verification of this hypothesis. If, however, state early intervention programs are identifying children at risk for a later diagnosis of ASD, the children would likely be receiving interventions targeting communication, a core ASD symptom that is often evident early in development. Engagement with early intervention programs would also be likely to facilitate later diagnostic assessment for ASD. The large standard deviation also indicates that a considerable number of

children experienced a substantial lag between diagnosis and treatment. Results of the regression model did not predict time between treatment and diagnosis in a statistically significant way. However, ethnicity was significantly correlated with time between diagnostic and treatment services; minority caregivers were more likely to report a lag time between diagnosis and treatment. This is consistent with previous research; for example, Rosenberg and colleagues (2008) found that black children were only half as likely as their white peers to receive early intervention services. Zuckerman and colleagues (2014) found that some Latina mothers reported avoided seeking out treatment services directly following an ASD diagnosis because the diagnosis was so stressful that families needed time to adjust and cope with the news before moving on in the process of accessing treatment. Disparities in service access and utilization indicate a continued need to develop public policies and culturally-sensitive educational and outreach programs to address the gap in service use.

<div align="center">**Currently Desired Interventions**</div>

Fortunately, the majority of caregivers seeking additional ASD interventions for their children were seeking EBPs. Similar to the reported barriers to diagnosis and previously tried intervention services, cost presented the most frequently cited barrier for desired future treatments, and was also the most frequently mentioned as "most problematic or challenging" barrier. This is in line with results from the previous analysis regarding barriers to diagnostic and previous treatment services. Scheduling or time required was second most frequently ranked, though "other" barriers were viewed as slightly more problematic. Regarding scheduling, clinic-based providers able to offer evening or weekend hours or a combination of clinic and in-home services might be well-suited to help address the scheduling difficulties many families face. "Other" barriers were the third most frequently and second most highly ranked. "Other" barriers

were highly variable, and included desiring services not provided by the child's assigned school system, ineligibility due to age, difficulty getting insurance approval, not knowing where to find the services or difficulty locating providers, and comorbid medical diagnoses requiring specialized health care. The wide range of difficulties faced in accessing ASD services highlights the need for individualized care and, in some cases, assistance with care coordination to help connect families with other service providers.

CHAPTER 11: CONCLUSION

ASD is a lifelong neurodevelopmental disorder, but early and accurate diagnosis paired with developmentally appropriate interventions across the lifespan can significantly improve long-term outcome and quality of life for individuals with ASD and their families. Many of the families in this study reported having received some services for ASD symptoms. It is not known how many of these children were getting services specifically through state-wide early intervention programs for children with developmental delays, but but it is promising that these individuals became involved so early on with some type of service provision. It is likely that being involved with early intervention services makes it easier to follow up and get in touch with the appropriate diagnostic and additional services as ASD symptoms become more apparent or problematic as a child ages. Scheduling diagnostic services can be challenging. More than half of caregivers cited long wait lists as a barrier to diagnostic services, and accessing diagnostic services can be further complicated by difficulties with scheduling around work, childcare, and other obligations. Service providers may consider offering occasional scheduling outside of the typical 9am-5pm workday to accommodate families who have difficulty scheduling during these times. For example, periodic weekend or evening hours may alleviate some of the difficulty caregivers face in scheduling diagnostic services.

It was surprising how many caregivers (37.5%) reported having been told by professionals (e.g., pediatricians) "not to worry" about their child's difficulties. Caregivers reported being reassured that their child would grow out of their problems, felt their concerns were dismissed, or were told that their child could not have autism (e.g., due to presence of another condition, such as Down Syndrome) and so pursuing diagnostic services was not needed. Granted, these were *perceived* reassurances and it is possible that the message the caregivers

heard was not the intended message on the part of the provider; regardless, these high rates of

misguided professional reassurances perceived as barriers to diagnostic services is disturbing and

more research into this area is warranted to discover whether additional education of healthcare

providers on ASD, consideration of more effective communication techniques with parents, or

both would be beneficial in reducing these rates.

Although sample size and low rates of caregivers identifying as ethnic minorities is a

limitation of this study sample, ethnicity was positively correlated with number of perceived

barriers to diagnosis. Minority caregivers were also more likely to report a lag time between

diagnosis and treatment. Despite substantial strides in addressing ethnic disparities in healthcare

over the past couple of decades, differences still persist. Disparities in services access and

utilization indicate a continued need to develop public policies and culturally-sensitive

educational and outreach programs to address gaps in service use.

The results of this study also highlight the variety of barriers caregivers may face when

pursuing therapeutic services for their child with ASD. In particular, out of pocket expense

remains the most often-reported barrier to accessing and maintaining evidence-based

interventions to treat ASD. Interestingly, those with higher income reported greater number of

barriers to EBPs. This may be in part related to likelihood of higher income families having

private, rather than public, insurance. Insurance type appears to be related to number of

difficulties experienced in treatment and future research in this area is warranted as insurance

policies continue to change their coverage for ASD-related services. In this study, although

statistical significance was not reached, the trend was in line with previous research indicating

that individuals with private insurance tended to report greater difficulties in accessing services

than those with public insurance. Interestingly, those with both public and private insurance fell

in the middle with regard to number of barriers to evidence based treatments. It is possible that those who have both types of insurance experience significantly more frustration in accessing services due to the process of being told to file first with private insurance, even if that insurance does not cover the service, before applying to Medicaid, and then having to content with periodic appeals and re-authorization. Each additional required step represents another chance for clients to fall through the cracks. Additional research into factors related to insurance-related difficulties is warranted.

Many caregivers reported having discontinued previous EBPs due to difficulties in their relationship with the provider or the way in which services were rendered. Based on these results, perhaps service providers should more strongly consider engaging in systematic internal quality assessment to ascertain the fidelity of the provided services as well as periodically checking in regarding caregiver satisfaction with the provided services. For example, providers may consider periodically asking parents to complete a brief satisfaction questionnaire as a way to scan for areas of dissatisfaction without taking too much time away from clinical services. Others discontinued because their therapist left or facility closed, which leads one to wonder what factors prohibited these individuals from continuing the same services with a different provider.

It was encouraging that only a small number (4 total) in the sample endorsed having tried any invasive, dangerous non-EBPs in the past. Three of these quit due to the treatments not working; one discontinued due to expense. On the other hand, it is disturbing that these participants were able to access chelation and hyperbaric chamber treatments for their children with no medical indication. Not only are these practices expensive and ineffective at treating ASD symptoms, but they also carry risk of significant harm. Continuing research into what leads

caregivers to pursue these treatments and what types of providers are providing these potentially detrimental services is warranted.

While significant strides have been made in recent years towards improving timely and affordable access to high quality, evidence-based diagnostic and treatment services, many caregivers still experience considerable challenges and frustrations when seeking services for their children. Clinicians, researchers, and public policy advocates should continue to bear these differences in mind as efforts continue to eliminate disparities in access to care.

REFERENCES

Ahmedani, B. K., & Hock, R. M. (2012). Health care access and treatment for children with co-morbid autism and psychiatric conditions. *Social Psychiatry and Psychiatric Epidemiology*, *47*(11), 1807-1814.

Akins, R. S., Krakowiak, P., Angkustsiri, K., Hertz-Picciotto, I., & Hansen, R. L. (2014). Utilization patterns of conventional and complementary/alternative treatments in children with autism spectrum disorders and developmental disabilities in a population-based study. *Journal of Developmental and Behavioral Pediatrics*, *35*(1), 1-10.

Amendah, D., Grosse, S. D., Peacock, G., & Mandell, D. S. (2011). The economic costs of autism: A review. In D. Amaral, D. Geschwind, & G. Dawson (Eds.), *Autism spectrum disorders* (pp. 1347–1360). Oxford: Oxford University Press.

American Academy of Pediatrics Committee on Children with Disabilities (2001). The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics, 107,* 1221-1226.

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.).* Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders (4th ed., text revision).* Washington, DC: Author.

American Psychological Association. (2002). Criteria for evaluating treatment guidelines. *American Psychologist, 57,* 1052-1059.

American Speech-Language-Hearing Association [ASHA] (2015). State insurance mandates for Autism Spectrum Disorder. http://www.asha.org/Advocacy/state/States-Specific-Autism-Mandates/. Retrieved 9/14/2015.

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders *Research and Practice for Persons with Severe Disabilities, 30*(4), 194-204.

Baxter, A. J., & Krenzelok, E. P. (2008). Pediatric fatality secondary to EDTA chelation. *Clinical Toxicology*, *46*(10), 1083-1084.

Baxter, A. J., Brugha, T. S., Erskine, H. E., Scheurer, R. W., Vos, T., & Scott, J. G. (2015). The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, *45*(03), 601-613

Ben-Itzchak, E., & Zachor, D. A. (2007). The effects of intellectual functioning and autism severity on outcome of early behavioral intervention for children with autism. *Research in Developmental Disabilities, 28,* 287 – 303.

Berkoff, M. C., Leslie, L. K., & Stahmer, A. (2006). Accuracy of caregiver identification of developmental delays among young children involved with child welfare. *Journal of Developmental & Behavioral Pediatrics, 27*(4), 310-318.

Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: autism. *Child and Adolescent Psychiatric Clinics of North America*, *19*(4), 855-867.

Bertoglio, K., & Hendren, R. L. (2009). New developments in autism. *Psychiatric Clinics of North America, 32,* 1 – 14.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mother supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409-423.

Brown, M. J., Willis, T., Omalu, B., & Leiker, R. (2006). Deaths resulting from hypocalcemia after administration of edetate disodium: 2003-2005. *Pediatrics*, *118*(2), e534-e536.

Centers for Disease Control and Prevention (2007). *Prevalence of Autism Spectrum Disorders (ASDs).* Retrieved August 23, 2013, from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm

Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders - autism and developmental disabilities monitoring network, 14 Sites, United States, 2008. *MMWR Surveillance Summaries, 61*(3), 1-19.

Chakrabarti, S. (2009). Early identification of autism. *Indian Pediatrics, 46*, 412-414.

Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 43*, 289.

Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L. E., & Volkmar, F. (2006). Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*(1), 62-72.

Cohen, J. (1988). *Statistical power analysis for the behavior* sciences (2nd ed.). Hillsdale, NJ: Erlbaum.

Cook, R. D., & Weisberg, S. (1982). *Residuals and influence in regression*. New York, NY: Chapman & Hall.

Committee on Educational Interventions for Children with Autism. (2001). *Educating children with autism.* Washington, DC: National Academy Press.

Council on Children With Disabilities. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118*(1), 405-420.

Crane, J. L., & Winsler, A. (2008). Early autism detection: implications for pediatric practice and public policy. *Journal of Disability Policy Studies, 18*(4), 245- 253.

Croen, L. A., Najjar, D. V., Ray, G. T., Lotspeich, L., & Bernal, P. (2006). A comparison of health care utilization and costs of children with and without autism spectrum disorders in a large group-model health plan. *Pediatrics, 118*(4), e1203-1211.

Dawson, M., Mottron, L., & Gernsbacher, M. A. (2008). Learning in autism. In H. L. Roediger, III (Ed.), *Cognitive psychology of memory, Vol 2.* 759 – 772.

DeNavas-Walt, C., & Proctor, B. D. (2015). Income and poverty in the United States: 2014. *Current Population Reports (P60-252)*. Washington, DC: United States Census Bureau.

Deyro, M. C., Simon, E. W., & Guay, J. (2014). Parental awareness of empirically established treatments for autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 1-12. doi: 1088357614559210

Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., ... & Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a US cross-sectional study. *PLoS One*, *5*(7), e11551.

Eaves, L. C., & Ho, H. H. (2004). The very early identification of autism: Outcome to age 4½–5. *Journal of Autism and Developmental Disorders, 34*(4), 367-378.

Elder, J. H., Shankar, M., Shuster, J., Theriaque, D., Burns, S., & Sherrill, L. (2006). The gluten-free, casein-free diet in autism: results of a preliminary double blind clinical trial. *Journal of Autism and Developmental Disorders*, *36*(3), 413-420.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.

Federal Drug Administration (2014) U.S. Food and Drug Administration website: Beware of false or misleading claims for treating autism. http://www.fda. gov/ForConsumers/ConsumerUpdates/ucm394757.htm. Accessed 16/10/2014

Fisher, W. W., & Piazza, C. C. (Eds.). (2013). *Handbook of Applied Behavior Analysis*. New York, NY: Guildford Press.

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65,* 591–598.

Fombonne, E., Quirke, S., & Hagen, A. (2009). Prevalence and interpretation of recent trends in rates of pervasive developmental disorders. *Mcgill Journal of Medicine: An International Forum for the Advancement of Medical Sciences by Students, 12*, 73-73.

Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., ... & Eng, C. (2012). Validation of proposed DSM-5 criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(1), 28-40.

Galesic, M. (2006). Dropouts on the web: Effects of interest and burden experienced during an online survey. *Journal of Official Statistics*, *22*(2), 313-328.

Ganz, M. L. (2006). The costs of autism. In S. Moldin & J. Rubenstein (Eds.), *Understanding Autism: From Neuroscience to Treatment*. Boca Raton: Taylor and Francis Group.

Golnik, A. E., & Ireland, M. (2009). Complementary alternative medicine for children with autism: a physician survey. *Journal of Autism and Developmental Disorders*, *39*(7), 996-1005.

Gould, E. (2004). Decomposing the effects of children's health on mother's labor supply: Is it time or money? *Health Economics, 13*(6), 525–541.

Gutierrez, A., Jr., Hale, M. N., O'Brien, H. A., Fischer, A. J., Durocher, J. S., & Alessandri, M. (2009). Evaluating the effectiveness of two commonly used discrete trial procedures for teaching receptive discrimination to young children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*, 630-638.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), 377-391.

Hayward, D. W., Gale, C. M., & Eikeseth, S. (2009). Intensive behavioral intervention for young children with autism: A research-based service model. *Research in Autism Spectrum Disorders, 3*, 571-580.

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

Hinkle, D. E., Wiersma, W., & Jurs, S. G. (2003). *Applied statistics for the behavioral sciences*. Boston, MA: Houghton Mifflin Company.

IBM Corporation (2013). IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corporation.

Inglese, M. D., & Elder, J. H. (2009). Caring for children with Autism Spectrum Disorder, part I: Prevalence, etiology, and core features. *Journal of Pediatric Nursing, 24,* 41 – 48.

Järbrink, K., Fombonne, E., & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism and Developmental Disorders, 33*(4), 395-402.

Jimenez, M. E., Barg, F. K., Guevara, J. P., Gerdes, M., & Fiks, A. G. (2012). Barriers to evaluation for early intervention services: parent and early intervention employee perspectives. *Academic Pediatrics*, *12*(6), 551-557.

Johnson, E., & Hastings, R. P. (2002). Facilitating factors and barriers to the implementation of intensive home- based behavioural intervention for young children with autism. *Child: Care, Health and Development*, *28*(2), 123-129.

Johnson, R. A., Danis, M., & Hafner-Eaton, C. (2014). US state variation in autism insurance mandates: Balancing access and fairness. *Autism*, *18,* 803-814.

Jónsdóttir, S. L., Saemundsen, E., Antonsdóttir, I. S., Sigurdardóttir, S., & Ólason, D. (2011). Children diagnosed with autism spectrum disorder before or after the age of 6 years. *Research in Autism Spectrum Disorders, 5,* 175-184.

Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., ... & Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders*, *40*(11), 1361-1370.

Kalkbrenner, A. E., Daniels, J. L., Emch, M., Morrissey, J., Poole, C., & Chen, J. C. (2011). Geographic access to health services and diagnosis with an autism spectrum disorder. *Annals of Epidemiology*, *21*(4), 304-310.

Kim, S. H., & Lord, C. (2012). New autism diagnostic interview-revised algorithms for toddlers and young preschoolers from 12 to 47 months of age. *Journal of Autism and Developmental Disorders, 42*(1), 82-93.

Kishore, M. T., & Basu, A. (2011). Early concerns of mothers of children later diagnosed with autism: Implications for early identification. *Research in Autism Spectrum Disorders, 5,* 157-163.

Knivsberg, A. M., Reichelt, K. L., Høien, T., & Nødland, M. (2002). A randomised, controlled study of dietary intervention in autistic syndromes. *Nutritional Neuroscience*, *5*(4), 251-261.

Koenig, K., Rubin, E., Klin, A. & Volkmar, F. (2000). Autism and the pervasive developmental disorders. In C. Zeanah (Ed.), *Handbook of infant mental health*, *2nd ed*., pp. 298-310. New York, NY: Guilford Press.

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., ... & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, *124*(5), 1395-1403.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*(6), e1149-1158.

Laerd Statistics (2015a). Binomial logistic regression using SPSS Statistics. *Statistical tutorials and software guides.* Retrieved June 23, 2016 from https://statistics.laerd.com/

Laerd Statistics (2015b). Hierarchical multiple regression using SPSS Statistics. *Statistical tutorials and software guides*. Retrieved June 12, 2016 from https://statistics.laerd.com/

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, *133*(3), e520-e529.

Leonard, H., Dixon, G., Whitehouse, A. J.O., Bourke, J., Aiberti, K., Nassar, N.,…Glasson, E. J. (2010). Unpacking the complex nature of the autism epidemic. *Research in Autism Spectrum Disorders, 4,* 548 – 554.

Levy, S. E., & Hyman, S. L. (2008). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America*, *17*(4), 803-820.

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in diagnosis and access to health services for children with autism: data from the National Survey of Children's Health. *Journal of Developmental & Behavioral Pediatrics*, *29*(3), 152-160.

Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: data from U.S. national samples. *Journal of Autism & Developmental Disorders, 36*, 871-879.

Mackintosh, V., Goin-Kochel, R. P., & Meyers, B. J. (2012). "What do you like/dislike about the treatments you're currently using?": A qualitative study of parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 27,* 51-60.

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *37*(9), 1795-1802.

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry,41*(12), 1447-1453.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., ... & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*(3), 493-498.

Mandell, D., & Palmer, R. F. (2005). Differences among states in the identification of autistic spectrum disorders. *Archives of Pediatrics & Adolescent Medicine, 159*, 266-269.

Manning-Courtney, P., Brown, J., Molloy, C. A., Reinhold, J., Murray, D., Sorensen-Burnworth, R., … Kent, B. (2003). Diagnosis and treatment of autism spectrum disorders. *Current Problems in Pediatric and Adolescent Health Care, 23,* 283 – 304.

Martinez-Pedraza, F. L., Carter, A. S. (2009). Autism spectrum disorders in young children. *Child and Adolescent Psychiatric Clinics of North America, 18,* 645 – 663.

Matson, J. L. (2007). Determining treatment outcome in early intervention programs for autism spectrum disorders: A critical analysis of measurement issues in learning based interventions. *Research in Developmental Disabilities, 28,* 207 – 218.

Matson, J. L. (Ed.) 2009. *Applied behavior analysis for children with autism spectrum disorders.* New York, NY: Springer.

Matson, J. L., Belva, B. C., Horovitz, M., Kozlowski, A. M., & Bamburg, J. W. (2012). Comparing symptoms of autism spectrum disorders in a developmentally disabled adult population using the current DSM-IV-TR diagnostic criteria and the proposed DSM-5 diagnostic criteria. *Journal of Developmental and Physical Disabilities, 24*(4), 403-414.

Matson, J. L., Dempsey, T., & Fodstad, J. C. (2009). Stereotypies and repetitive/restrictive behaviours in infants with autism and pervasive developmental disorder. *Developmental Neurorehabilitation*, *12*(3), 122-127.

Matson, J. L., & González, M. L. (2007a). *Autism Spectrum Disorders – Behavior Problems – Child Version*. Baton Rouge, LA: Disability Consultants, LLC.

Matson, J. L., & González, M. L. (2007b). *Autism Spectrum Disorders – Comorbidity – Child Version*. Baton Rouge, LA: Disability Consultants, LLC.

Matson, J. L., & González, M. L. (2007c). *Autism Spectrum Disorders – Diagnosis for Children*. Baton Rouge, LA: Disability Consultants, LLC.

Matson, J. L., & Kozlowski, A. M. (2011). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*(1), 418-425.

Matson, J. L., & Nebel-Schwalm, M. S. (2007). Comorbid psychopathology with autism spectrum disorders in children: an overview. *Research in Developmental Disabilities, 28,* 341-352.

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, *30*(6), 1107-1114.

Matson, J. L., Wilkins, J., & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early? *Research in Autism Spectrum Disorders, 2*, 75-84.

Mattila, M., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., & ... Moilanen, I. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning autism: A community- and clinic-based study. *Journal of Autism and Developmental Disorders*, *40*, 1080-1093.

McPartland, J. C., Reichow, B., & Volkmar, F. R. (2012). Sensitivity and specificity of proposed DSM-5 diagnostic criteria for autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*, 368-383.

Montes, G., Halterman, J. S., & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for U.S. Children with ASD. *Pediatrics, 124,* S407–S413.

Nahin, R., Barnes, P., Stussman, B., & Bloom, B. (2009) Costs of complementary and alternative medicine (CAM) and frequency of visits to CAM practitioners: United States, 2007. *National Health Statistics Reports, 18*. Hyattsville, MD: National Center for Health Statistics.

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., . . . & Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health, 28,* 235–258.

Office for Citizens with Developmental Disabilities [OCDD], Louisiana Department of Health and Hospitals (2013). *Louisiana's Early Steps, Part C Annual Performance Report.* Retrieved from http://dhh.louisiana.gov/assets/docs/OCDD/EarlySteps/la-apr-2011c-2-1-2012_final.doc

Palmer, R. F., Walker, T., Mandell, D., Bayles, B., & Miller, C. S. (2010). Explaining low rates of autism among Hispanic schoolchildren in Texas. *American Journal of Public Health*, *100*(2), 270.

Parish, S. L. (2014, January). Autism spectrum disorders and families' financial burden: The association with health insurance coverage. In *Society for Social Work and Research 18th Annual Conference: Research for Social Change: Addressing Local and Global Challenges*. Retrieved Sept. 7, 2015 from https://sswr.confex.com/sswr/2014/webprogram/Paper20103.html

Pew Research Center (2013). Broadband Technology Fact Sheet. Retrieved June 6, 2016 from
http://www.pewinternet.org/fact-sheets/broadband-technology-fact-sheet/

Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral
intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane
Database System Review*, *10.*

Rice, C., Nicholas, J., Baio, J., Pettygrove, S., Lee, L., Van Naarden Braun, K., … Yeargin-
Allsopp, M. (2010). Changes in autism spectrum disorder prevalence in 4 areas of the
United States. *Disability and Health Journal, 3,* 186 – 201.

Rosenberg, S. A., Zhang, D., & Robinson, C. C. (2008). Prevalence of developmental delays and
participation in early intervention services for young children. *Pediatrics*, *121*(6), e1503-
e1509.

Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., ... & Skuse, D.
(2016). Autism Spectrum Disorders in Africa: Current challenges in identification,
assessment, and treatment. A Report on the International Child Neurology Association
Meeting on ASD in Africa, Ghana, April 3-5, 2014. *Journal of Child Neurology*.
Advance online publication. doi: 0883073816635748

Salomone, E., Charman, T., McConachie, H., & Warreyn, P. (2015). Prevalence and correlates
of use of complementary and alternative medicine in children with autism spectrum
disorder in Europe. *European Journal of Pediatrics*, *174,* 1277–1285.

Sevin, B. M., Knight, C. L., & Braud, S. A. (2007). Autism and pervasive developmental
disorders. In J. L. Matson (Ed.), *Handbook of assessment in persons with intellectual
disability* (pp. 163-195). London: Academic Press.

Sharpe, D. L., & Baker, D. L. (2007). Financial issues associated with having a child with
autism. *Journal of Family Economic Issues, 28,* 247-264.

Shattuck, P. T. (2006). The contribution of diagnostic substitution to the growing administrative
prevalence of autism in US special education [corrected] [published erratum appears in
PEDIATRICS 2006 Aug;118(2):852]. *Pediatrics, 117*, 1028-1037.

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., . . .
Cuniff, C. (2009). Timing of identification among children with an autism spectrum
disorder: Findings from a population-based surveillance study. *Journal of the American
Academy of Child & Adolescent Psychiatry, 48*(5), 474-483.

Sices, L., Feudtner, C., McLaughlin, J., Drotar, D., & Williams, M. (2004). How do primary care
physicians manage children with possible developmental delays? A national survey with
an experimental design. *Pediatrics, 113*(2), 274-282.

Smith, K. R. M., & Matson, J. L. (2010a). Behavior problems: differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy. *Research in Developmental Disabilities, 31,* 1062-1069.

Smith, K. R. M., & Matson, J. L. (2010b). Psychopathology: differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy. *Research in Developmental Disabilities, 31,* 743-749.

Smith, K. R. M., & Matson, J. L. (2010c). Social skills: differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy. *Research in Developmental Disabilities, 31,* 1366-1372.

Stetser, M., & Stillwell, R. (2014). Public high school four-year on-time graduation rates and event dropout rates: School years 2010–11 and 2011–12. *First Look (NCES 2014-391).* U.S. Department of Education. Washington, DC: National Center for Education Statistics. Retrieved June 20, 2016 from http://nces.ed.gov/pubsearch.

Stevens, J. P. (2001). *Applied multivariate statistics for the social sciences, 4th edition.* London: Taylor & Francis.

Tabachnick, B.G., & Fidell, L.S. (2007). *Using multivariate statistics, 5th edition.* Boston: Pearson Education, Inc.

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal for Autism and Developmental Disorders, 37,* 1902-1912.

Tonge, B. J., Bull, K., Brereton, A., & Wilson, R. (2014). A review of evidence-based early intervention for behavioural problems in children with autism spectrum disorder: the core components of effective programs, child-focused interventions and comprehensive treatment models. *Current Opinion in Psychiatry*, *27*(2), 158-165.

United States Census Bureau (2010a). "2010 Census shows America's diversity." Retrieved June 20, 2016 from https://www.census.gov/newsroom/releases/archives/2010_census/cb11-cn125.html

United States Census Bureau (2010b). "Frequently Asked Questions." Retrieved June 21, 2016 from https://ask.census.gov/faq.php?id=5000&faqId=5971.

United States Department of Education (2016). Early intervention program for infants and toddlers with disabilities. Retrieved June 20, 2016 from http://www2.ed.gov/programs/osepeip/index.html.

van Dyke, K. V. (2012). Oxidative stress, mitochondrial hormesis, and hyperbaric therapy in autism. *Autism Science Digest, 3*, 33-42.

West, E. A., Travers, J. C., Kemper, T. D., Liberty, L. M., Cote, D. L., McCollow, M. M., & Brusnahan, L. L. S. (2016). Racial and Ethnic Diversity of Participants in Research Supporting Evidence-Based Practices for Learners With Autism Spectrum Disorder. *Journal of Special Education*. Advance online publication. doi: 0022466916632495

Winburn, E., Charlton, J., McConachie, H., McColl, E., Parr, J., O'Hare, A., ... & Le Couteur, A. (2014). Parents' and child health professionals' attitudes towards dietary interventions for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *44*(4), 747-757.

Worley, J. A., & Matson, J. L. (2012). Comparing symptoms of autism spectrum disorders using the current DSM-IV-TR diagnostic criteria and the proposed DSM-V diagnostic criteria. *Research in Autism Spectrum Disorders, 6*, 965-970.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of Autism in a US Metropolitan Area. *Journal of the American Medical Association, 289*(1), 49-55.

Zuckerman, K. E., Perrin, J. M., Hobrecker, K., & Donelan, K. (2013). Barriers to specialty care and specialty referral completion in the community health center setting. *Journal of Pediatrics*, *162*(2), 409-414.

APPENDIX A: SURVEY

Survey for Caregivers of Individuals with Autism Spectrum Disorder

CONSENT TO PARTICIPATE

Thank you for your interest in the "Autism Spectrum Disorders Survey of Experiences, Interventions, and Resource Availability" research project.

The experience of getting an ASD diagnosis and subsequently obtaining treatment services varies widely based on many factors, but it is not unusual for caregivers to report some difficulties obtaining services, or feel overwhelmed at times in the process of deciding which interventions to pursue.

The purpose of this research is to learn more about the experiences of caregivers of individuals with Autism Spectrum Disorder (ASD). For this study, we want to hear from primary caregivers of individuals with ASD. We want to learn more about YOUR experience navigating the path to diagnosis and treatment for your child. We are collecting this data to inform efforts to improve this process, making it easier to get effective services for individuals with ASD.

The procedure involves filling an online survey that will take approximately 15-20 minutes. The survey questions will be about experiences related to assessment and interventions for Autism Spectrum Disorder.

Your responses will be confidential and combined with the answers of other survey participants. To protect your privacy, we will not be collecting any information that could be traced to you individually, and the survey software (Qualtrics) allows us to block IP addresses from being collected. All data is stored in a password protected electronic format on a secure server. The results of this study will be used for scholarly purposes only and may be shared with Louisiana State University representatives.

Your participation in this research study is voluntary. You may choose not to participate or withdraw from participation at any time during the survey by closing the window. Most questions will have a "prefer not to answer" or "not applicable" option. There is no incentive or payment for your participation, but we sincerely appreciate your contribution towards helping us understand how to improve services for individuals with ASD. If you wish to withdraw any information collected from the analysis, contact Lindsey Williams at lwil175@lsu.edu.

This research project being conducted by graduate students in Clinical Psychology at Louisiana State University. If you have any questions about this research, you can contact Lindsey Williams at lwil175@lsu.edu .

This research has been reviewed and approved according to Louisiana State University Institutional Review Board procedures for research involving human subjects. Questions about subjects' rights or other concerns can be directed to Robert C. Mathews, Chairman, Institutional Review Board, (225) 578-8692, irb@lsu.edu, or via www.lsu.edu/irb.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below indicates that:

• you have read the above information
• you voluntarily agree to participate
• you are at least 18 years of age

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

Respondent Demographics
- How did you learn about this survey? (Write in)

- Your relationship to individual with ASD
  - Biological mother
  - Biological father
  - Adoptive mother
  - Adoptive father
  - Other (Write in)

- Ethnicity
  - Caucasian
  - Latino
  - Middle Eastern
  - African American
  - Caribbean
  - South Asian
  - East Asian
  - Combination (Write in)
  - Other (Write in)
  - Prefer not to answer

- Gender
  - Identify as male
  - Identify as female
  - Prefer not to answer

- Highest level of education completed

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- Some high school
- High school graduate
- Technical, associate, or professional degree
- Some college
- College graduate
- Some graduate school
- Graduate degree (e.g., Masters or above)
- Prefer not to answer

o Annual household income (US$)
- Less than 10,000
- 10k-25k
- 25k-40k
- 40k-55k
- 55k-70k
- 70k-100k
- More than 100k
- Prefer not to answer

o Current marital status
- Single, never married
- Married or in long-term relationship
- Separated or Divorced
- Widowed
- Other
- Prefer not to answer

o Current state where you currently live (drop down)

Designation of urban, suburban, and rural use the 2010 US Census criteria

o How would you describe your city/town?
- Urban (50,000+ people)
- Suburban (2,500 to 49,000 people)
- Rural (less than 2,500 people)

Child/Adolescent Information
o Age (years, months)

o Ethnicity
- Caucasian
- Latino
- Middle Eastern
- African American
- Caribbean

- South Asian
- East Asian
- Combination (Write in)
- Other (Write in)
- Prefer not to answer

o Gender
- Identify as male
- Identify as female
- Prefer not to answer

o Current Autism Spectrum Disorder diagnosis
- Autistic Disorder
- PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified)
- Asperger's Disorder
- Autism Spectrum Disorder
- Not sure
- Write in: _____

o How old was your child when he or she received the autism diagnosis you indicated above? (write in __ years and __ months)

Now you will see some questions related to different behaviors.

Rate each item for the extent that it is/was **ever** a problem. Compare the child to other children his/her age based on the following:

0 = Not different; no impairment
1 = Somewhat different; mild impairment
2 = Very different; severe impairment

1 Communication skills.
2 Age appropriate self-help and adaptive skills (i.e., able to take care of self).
3 Engages in repetitive motor movements for no reason (e.g., hand waving, body rocking, head banging, hand flapping).
4 Verbal communication.
5 Prefers foods of a certain texture or smell.
6 Ability to recognize the emotions of others.
7 Maintains eye contact.
8 Social interactions with others his/her age.
9 Response to others' social cues.
10 Use of language in conversations with others.
11 Shares enjoyment, interests, or achievement with others (e.g., parents, friends, caregivers).
12 Ability to make and keep friends.
13 Interest in participating in social games, sports, and activities.

14 Interest in another person's side of the conversation (e.g., talks to people with intention of hearing what others have to say).
15 Able to understand the subtle cues or gestures of others (e.g., sarcasm, crossing arms to show anger).
16 Use of too few or too many social gestures.
17 Body posture and/or gestures.
18 Communicates effectively (e.g., using words, gestures or sign language).
19 Displays a range of socially appropriate facial expressions.
20 Restricted interests and activities.
21 Eye-to-eye gaze.
22 Reaction to sounds and sights.
23 Walks or runs on toes/balls of feet (If unable to walk/run, rate "0").
24 Reads nonverbal cues (body language) of other people. (If blind, rate "0").
25 Expects others to know their thoughts, experiences, and opinions without communicating them (e.g. expects others to "read his/her mind").
26 Use of facial expressions.
27 Saying words and phrases repetitively (If nonverbal, rate "0"). _____
28 Make-believe or pretend play. _____
29 Understanding of age appropriate jokes, figures of speech, or sayings. _____
30 Gives subtle cues or gestures when communicating with others (e.g., hinting).
31 Becomes upset if there is a change in routine.
32 Needs reassurance, especially if events don't go as planned.
33 Language development.
34 Responds to others' distress.
35 Socializes with other children.
36 Use of nonverbal communication.

Diagnosis

- o   Which, if any, difficulties did you experience when you were trying to get a diagnosis? Select all that apply.
    - Long wait list (longer than 1 month) for assessment
    - Transportation problems (too far to drive or we did not have easy access to transportation)
    - Scheduling problems (e.g., could not get time off of work, or could not arrange for necessary childcare for other children)
    - Insurance would not cover assessment
    - Insurance would cover part of assessment but out of pocket cost was still too high
    - Caregivers were unsure or disagreed with one another about whether to get assessment
    - Professionals reassured us that there was no problem or my child would "grow out of it"
    - Other (write in)

- o   How old was your child when he or she began receiving any treatment for the autism diagnosis you indicated above? (Write in: ___ years and ___ months)

- o Is your child currently taking prescribed medication meant to address symptoms related to autism, mood/anxiety, or Attention-Deficit/Hyperactivity Disorder?
  - Yes, currently taking medication for autism symptoms (Write in)
  - Yes, currently taking medication for mood or anxiety symptoms (Write in)
  - Yes, currently taking medication for Attention-Deficit/Hyperactivity Disorder (Write in)
  - No, not currently taking medication for any of these reasons

- o Please indicate which, if any, of the following apply to your child:
  - Has received a diagnosis of Intellectual Disability (may be referred to as mental retardation in older reports)
  - Currently exhibits aggressive behavior toward other people (e.g., hitting, pinching, biting)
  - Currently exhibits self-injurious behavior (e.g., head banging, biting self, or other methods of injuring him or herself)
  - Sleep problems on a regular basis (more nights than not; e.g., takes more than 30 minutes to go to sleep, wakes up frequently during the night)
  - Has received a diagnosis of seizure disorder or epilepsy

Insurance Information
- o What type of insurance coverage does your child have?
  - None
  - Private Insurance only (e.g., through a parent's employer)
  - Medicaid or other public insurance
  - Both private insurance and Medicaid / public insurance
  - Not sure or prefer not to answer

- o If your child has insurance, does the insurance offer coverage for any autism treatment?
  - Yes, and I am satisfied with the coverage. They provide adequate coverage for both the types services and the amount of those services that my child needs.
  - Yes, for some things, but I have had difficulty getting them to cover services, or they don't provide the types of services I want.
  - No
  - Not sure

Autism Interventions
- o For the next few questions, we will be asking about types of treatments your child <u>currently</u> receives.

The lists below is presented in randomized order. The titles in italics will be the ones used by the researchers for the purposes of classification/analysis but will not be visible for the participants.

Each list below will be prefaced with: Does your child currently use any of the following treatments? (yes/no)

- List 1 *EBP - EIBI*
  - Early Intensive Behavioral Intervention
- List 2 *EBP - Behavioral*
  - Applied Behavior Analysis (ABA)
  - Modeling
  - Pivotal Response Training
  - Natural Teaching Strategies
- List 3 *EBP – Cognitive Behavioral*
  - Cognitive Behavioral Intervention Package
  - Cognitive Behavioral Therapy
- List 4 *EBP – Language*
  - Language Training (Production)
  - Speech therapy
- List 5 *EBP – Non-clinician as Therapist*
  - Parent Training
  - Peer Training Package
  - Self-Management Training
  - Schedules
- List 6 *EBP – Social Skills*
  - Scripting
  - Social Skills Package
  - Story-Based Intervention (e.g., Social Stories)
- List 7 *CAM – Social/Communication*
  - Alternative Communication Devices
  - Functional Communication Training
  - Picture Exchange Communication System
  - Sign Instruction
  - Facilitated Communication
  - Music Therapy
  - Animal-assisted Therapy
  - Floor Time
  - Play Therapy
- List 8 *CAM – Mind/Body*
  - Exercise
  - Massage Therapy/Deep Pressure
  - Auditory and/or Sensory Integration

- Chiropractic
- Art Therapy
- Acupuncture
- List 9 *CAM – Biomedical*
  - Vitamins and supplements
  - Special or restricted diets (e.g., gluten-free, casein-free, yeast-free)
  - Oxytocin
- List 10 *CAM – 2*
  - Chelation
  - Hyperbaric oxygen therapy (HBOT)
  - Packing
- List 11 *CAM – Other*
  - Occupational therapy
  - Physical therapy
- Other (Write in)

Once these questions are completed, the participant will continue to the next page, which will have an additional question related to each treatment group option endorsed as currently in use.
- How many hours <u>per week</u> does your child spend receiving and/or using any of these treatments? (write in)

Autism Intervention Information Sources
- Where do you get information about autism treatments? (Select all that apply.)
  - Websites
  - Online forum/support group
  - Word of mouth from someone who is a caregiver of individual with ASD
  - Word of mouth from someone who is <u>not</u> a caregiver of individual with ASD
  - Doctor (pediatrician or primary care physician)
  - Magazines
  - Books
  - School/classroom teacher
  - ABA therapist
  - Occupational therapist
  - Physical therapist
  - Psychologist
  - Parent support group that meets in person
  - TV
  - Newspaper
  - Other (Write in)

Once these questions are completed, the participant continues to the next question, which will only include the information sources endorsed in the previous question as options.

- o Of the sources of information about autism treatments you use, which is your most trusted source?

Intervention Barriers
- o Now you will again see some lists of interventions sometimes used for autism symptoms. Maybe your child currently uses some of these treatments; perhaps there are some he/she has never used. We would like to know if within each list of treatments you see <u>any</u> that your child <u>used</u> to use, <u>but then quit</u> using for some reason. There are 6 lists; some lists will be different than the lists you saw previously.

Presentation of the following lists is randomized. Each list is preceded by the instruction below:
- o For the following list please select any treatments your child <u>used</u> to use <u>but then quit</u>. You can select as many as apply in each list. (If none of these apply, select "none of the above.")
  - ▪ List 1 *EBP – Past EBP List 1*
    - • Applied Behavior Analysis (ABA)
    - • Cognitive Behavioral Intervention Package
    - • Cognitive Behavioral Therapy
    - • Modeling
    - • Pivotal Response Training
    - • None of the above
  - ▪ List 2 *EBP—Past EIBI (listed separately due to high likelihood of "aged out of services" listed as reason no longer used)*
    - • Early Intensive Behavioral Intervention
    - • None of the above
  - ▪ List 3 *EBP – Past EBP List 3*
    - • Language Training (Production)
    - • Natural Teaching Strategies
    - • Parent Training
    - • Peer Training Package
    - • Schedules
    - • Scripting
    - • Self-Management Training
    - • Social Skills Package
    - • Speech therapy
    - • Story-Based Intervention (e.g., Social Stories)
    - • None of the above
  - ▪ List 4 *non-EBP – Past*
    - • Alternative Communication Devices
    - • Exercise
    - • Functional Communication Training
    - • Massage Therapy/Deep Pressure
    - • Music Therapy

- Occupational Therapy
- Physical Therapy
- Picture Exchange Communication System
- Sign Instruction
- Structured Teaching
- None of the above
  - List 5 *CAM – Past*
    - Acupuncture
    - Animal-assisted Therapy
    - Art Therapy
    - Auditory and/or Sensory Integration
    - Chiropractic/osteopathy
    - Facilitated Communication
    - Floor Time
    - Oxytocin
    - Play Therapy
    - Special or restricted diets (e.g., gluten-free, casein-free, yeast-free)
    - Vitamins and supplements
    - None of the above
  - List 6 *non EBP – Dangerous*
    - Chelation
    - Hyperbaric Oxygen Therapy (HBOT)
    - Packing / Holding Therapy
    - None of the above
  - List 7
    - Other (Write in)
    - None of the above

For each list, if any answer other than "this question does not apply," is selected, a drop-down box appears.
- You said your child used to use but quit using the intervention(s) you selected above. Why? Think about the treatment(s) he/she quit using from this list. Below, select any of the reasons for quitting the intervention(s) you just listed.

  - Not seeing enough benefit from the treatment
  - Financial- out of pocket expense too great
  - My child was no longer eligible due to age or change in diagnosis
  - Change in insurance coverage
  - Took too much time or the scheduling was too inconvenient with other family obligations
  - Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent)
  - Did not like having service providers in my home
  - Proximity to my area- distance was too far to travel

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- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car)
- Other (write in)

o Is there any treatment you *wish* your child were currently receiving? If you select "yes" you can list up to three.
- No
- Yes
  - (Write in)
  - (Write in)
  - (Write in)

If "yes" is selected above, the next question appears, with a drop down box next to each option so the participant may select numbers 1-9 or "does not apply":

o Think about the treatments you wish your child could receive right now. Which of the following are the most frustrating/problematic right now? Select as many reasons as you think apply and rank them in order with 1 being the most frustrating/problematic. (If an option does not apply select "does not apply")
- Waitlists are too long
- Distance- I have reliable transportation but the distance is just too far
- Lack of Transportation- lack of reliable access to a vehicle and/or driver
- Financial- out of pocket expense too great
- Scheduling is too inconvenient for me / family (e.g., therapy time interferes with employment or other family obligations)
- My child's current treatments take so much time that I don't want to add another at this time
- I have tried or am trying to access this treatment, but the enrollment process is confusing/difficult
- My child has challenging behaviors need to be addressed first (e.g., is aggressive, destructive, or runs away)
- I just have not gotten around to it yet, no real barriers
- Other (write in)

END OF SURVEY

Thank you for your participation in this study to help us understand more about services for Autism Spectrum Disorder (ASD). Below we have listed some additional information you may find to be useful.

I'm looking for treatment for my child. What should I look for?
ASD is a complex disorder that impacts each child differently; no single therapy works equally for every child. Some therapies are supported by research showing their efficacy, whereas others are not. The skill, experience, and style of the therapist are critical to the effectiveness of the

intervention. Before you choose an intervention, you will need to investigate the claims of each therapy so that you understand the possible risks and likely benefits for your child.

As noted by the Autism Science Foundation, anyone can start a journal or post a study on the Internet to make scientific-sounding claims about dangerous or useless interventions. Fringe treatment providers prey on desperation and fear and deceive parents with numerous unfounded claims. These fringe treatments are often expensive and cumbersome, consuming time and money that could be more effectively used elsewhere. Remember there is no cure for ASD, but there are some treatments that have been reliably shown to help individuals with autism. We call these evidence-based treatments.

The Autism Science Foundation sums this concept up nicely: "To be considered evidence-based, a treatment must be thoroughly investigated in multiple well-designed scientific studies and show measurable, sustained improvements in targeted areas. A study's design largely depends on its focus and purpose, but there are some characteristics that well-designed studies tend to have." See their list and brief explanations of these characteristics, along with an overview of some non-evidence based practices, here:
http://www.autismsciencefoundation.org/what-is-autism/autism-diagnosis/beware-non-evidence-based-treatments

Additionally, you should beware of any so-called interventions that can carry significant risk of physical harm—there are some purported interventions that are not only ineffective at treating ASD but have caused documented harm.

What do you mean "dangerous practices?"
Remember that there is no "cure" for ASD, and any treatment that claims to be one should be immediately questioned. Some of the "too good to be true" practices are medically invasive. Not only is there no indication that they treat ASD at all, but there have been documented cases of serious harm. These practices include: chelation therapy, bleach therapy, packing/holding therapy, and Miracle Mineral Solution. You can find some information on these practices on the Autism Science Foundation site: http://www.autismsciencefoundation.org/what-is-autism/autism-diagnosis/beware-non-evidence-based-treatments
Here are some tips from the Federal Drug Administration, which has been investigating false treatment claims:
> • Be suspicious of products that claim to treat a wide range of diseases.
> • Personal testimonials are no substitute for scientific evidence.
> • Few disorders can be treated quickly, so be suspicious of any therapy claimed as a "quick fix."
> • "Miracle cures" which claim scientific breakthroughs and secret ingredients may be a hoax.

(From here: http://www.fda.gov/downloads/ForConsumers/ConsumerUpdates/UCM394800.pdf)

How do I know what the best treatments for autism are?
It is helpful to think about treatments based on the strength of scientific support that they reliably are helpful for most individuals they are designed to treat. The National Autism Center embarked on the National Standards Project to evaluate the evidence for different ASD treatments, specifically to make this information easy for families, caregivers, and practitioners to access quickly when making treatment choices. They use the following categories:

- *Established Interventions:* Have the most research support including multiple well-conducted research studies. Examples: behavioral interventions, parent training, schedules, social skills packages
- *Emerging Interventions:* Have some evidence but not as much evidence as Established Treatments. Before we can be assured these interventions are consistently effective, additional high quality studies are needed. Based on the available evidence, we are not able to rule out the possibility that these interventions are not effective. We need more research for a definitive answer. Examples: functional communication training, music therapy, picture exchange communication system, structured teaching
- *Unestablished Interventions:* There is little to no scientific evidence to support the effectiveness of these interventions. There is no reason to assume these are effective; furthermore, there is no way to rule out the possibility they are ineffective or even harmful. Examples: animal assisted therapy, floor time, facilitated communication, sensory intervention package

For the complete list and more information on the interventions identified by the National Standards Project in the above categories, please do the following:
- Go to http://www.nationalautismcenter.org/national-standards-project/phase-2/
- Click on "download the free report."
- Follow the instructions to access a PDF.
- The coverage of individual interventions begins on page 42.

In summary:
Remember that while every individual with ASD is unique, each has the potential to learn new skills to decrease problematic behavior, increase his/her independence, and enable him/her to engage in productive, enjoyable interactions with the environment and people in his/her life. Interventions targeting an individual's specific needs can be very helpful in reaching these goals, but some interventions are more likely to be helpful than others. You should carefully consider the probable benefits and potential costs when deciding which treatments best fit the needs of your child and family.

Contact Information:
- If you would like to contact the researchers, you may email Lindsey Williams at lwil175@lsu.edu or Hilary Adams at hadams15@lsu.edu   **Note:** Up until this point, all information has been unidentifiable and anonymous; if you choose to email us, your email will in no way be linked to your participation data.
- This research has been reviewed and approved according to Louisiana State University Institutional Review Board procedures for research involving human subjects. Questions about subjects' rights or other concerns can be directed to Robert C. Mathews, Chairman, Institutional Review Board, (225) 578-8692, irb@lsu.edu, or via www.lsu.edu/irb.

Disclosure statement: The researchers have no ties with the National Autism Center, May Institute, or Autism Science Foundation. We simply provided the above links and related information because we think they contain useful information for making informed choices about ASD interventions.

APPENDIX B: LOUISIANA STATE UNIVERSITY IRB APPROVAL

ACTION ON EXEMPTION APPROVAL REQUEST

LSU

TO: **Lindsey Williams**
    Psychology

FROM: Dennis Landin
    Chair, Institutional Review Board

Institutional Review Board
Dr. Dennis Landin, Chair
130 David Boyd Hall
Baton Rouge, LA 70803
P: 225.578.8692
F: 225.578.5983
irb@lsu.edu | lsu.edu/irb

DATE: January 8, 2016

RE: **IRB#** E9711

TITLE: Autism Spectrum Disorder Caregiver Survey of Experiences, Interventions, and Resource Availability

New Protocol/Modification/Continuation: New Protocol

Review Date: 1/4/2016

Approved   X   **Disapproved**

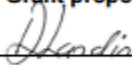**Approval Date:** 1/4/2016   **Approval Expiration Date:** 1/3/2019

Exemption Category/Paragraph: 2a

Signed Consent Waived?: Yes

Re-review frequency: (three years unless otherwise stated)

LSU Proposal Number (if applicable):

Protocol Matches Scope of Work in Grant proposal: (if applicable)

By: Dennis Landin, Chairman _____

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING –
Continuing approval is CONDITIONAL on:

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU's Assurance of Compliance with DHHS regulations for the protection of human subjects*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
7. Notification of the IRB of a serious compliance failure.
8. **SPECIAL NOTE:** When emailing more than one recipient, make sure you use bcc.

All investigators and support staff have access to copies of the Belmont Report, LSU's Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb

APPENDIX C: NUMBER OF PARTICIPANTS BY RESEARCH QUESTION

Various analyses had different numbers of participants due to reasons such as survey dropout and not yet having received treatment services. Additionally, the ASD-DC measure included in the study was developed for use with children ages 2-16; 20 participants fell outside of that age range and accordingly some analyses were run both with and without these participants when autism symptom severity was used as a dependent variable in the analysis. This guide is to outline how many participants were included in each set of analyses and for each individual analysis, as well as to outline reasons for exclusion at each stage. Research questions are italicized for easy reference.

Participants in Initial Analyses
- Started survey: 150
- Retained for initial descriptive analyses: 88

Participants in Analyses on Barriers to Diagnosis
- *Predictors of greatest number of diagnostic barriers*:
    - 88 for inclusive analysis
    - 68 for analysis excluding those outside of ASD-DC age range
- *Predictors of professional reassurances as a perceived barrier*: 88
- *Ethnic and familial barriers to diagnostic services:* 88

Analyses on Past Treatment
- Of the initial 88, 4 participants were removed at this stage because they have not begun receiving treatment.
- *Time from diagnosis to treatment*
    - 84 participants for inclusive analysis
    - 63 for analysis excluding those outside ASD-DC age range
- For future questions on treatment, 6 more were removed because they dropped out of survey before answering questions on past treatments, leaving 78 participants for remaining questions on treatment services.
- *Factors predicting barriers to EBPs*:
    - 78 for inclusive analysis
    - 60 excluding those outside of age range for ASD-DC
- *Predictors of time between ASD diagnosis and first ASD symptom treatment*:
    - 84 for inclusive analysis (4 excluded because had not begun receiving treatment yet)
    - 63 excluding those outside of ASD-DC range

Analyses on Currently Desired Interventions
- 51 total participants indicated they were interested in future services; of these, 41 of the answers could be clearly categorized into EBP or non-EBP.
- *Descriptive analysis:* 51
- *Predictors of desiring EBP over non-EBP:* 41

VITA

Lindsey Williams is from the Carolinas. She has worked with individuals with a broad range of developmental disabilities across the lifespan in residential, inpatient, and outpatient treatment settings. She received her Bachelor of Arts degree in Psychology and Philosophy from Erskine College in 2006, and Master's degree in Rehabilitation Counseling and Psychology from University of North Carolina, Chapel Hill in 2009. She is expected to graduate with her PhD in Clinical Psychology from Louisiana State University in 2016 following completion of internship at Indiana University School of Medicine. She will subsequently begin a postdoctoral position at University of North Carolina's TEACCH program for individuals with Autism Spectrum Disorder with a focus on both clinical work and research.