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# Caregiver Choice in Autism Intervention: Selections and Influential Factors

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CAREGIVER CHOICE IN AUTISM INTERVENTION:  
SELECTIONS AND INFLUENTIAL FACTORS

A Dissertation

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

in

The Department of Psychology

by

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I dedicate this scholarly effort to my family (Barb, Rick, and Brent Adams), my partner (David Hall), and my fellow graduate students and interns (particularly Lindsey Williams). Without each of you, this project would have remained simply a brainstorm session.

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## Abstract

Although research on Autism Spectrum Disorder (ASD) continues to increase, there is not yet a “cure” for the disorder. There is a lack of consensus regarding most effective treatments, much less an accepted treatment plan or course. Families may feel alone and lost in the treatment decision process. In order to best assist caregivers, psychologists must understand the selections caregivers make, their sources of information, and what influences them in their decision-making process. With this knowledge, clinicians may best effect change in caregiver choice by encouraging informed decision-making and use of empirically-based interventions. Thus, the purpose of the current study was to examine the choices that caregivers make in terms of treatment for their children with ASD, the sources from which they obtain information about interventions, and the child and caregiver characteristics that predict evidence-based practice versus complementary and alternative medicine use. Caregivers of children or adolescents with ASD completed an online survey that included questions about these factors and a parent-report measure of ASD symptom severity. Results of treatment selections and sources of information were fairly consistent with extant research. However, the results of regression analyses indicated that only respondent education statistically significantly contributed to predicting hours of CAM treatment, whereas only subject symptom severity of ASD statistically significantly contributed to predicting hours of EBP treatments. Additional results, discussion, future directions, and limitations of the study are provided.

## Introduction

Autism Spectrum Disorder (ASD) is a neurobehavioral disorder that affects 1 out of 68 children in the United States according to recent estimates (Center for Disease Control, 2014). The syndrome is characterized by core deficits of socialization and communication, as well as the presence of repetitive behavior, restricted interests, and sensory issues (Brereton, Tonge, & Einfeld, 2006; Fodstad, Matson, Hess, & Neal, 2009; J. L. Matson & Dempsey, 2009; Tidmarsh & Volkmar, 2003). Autism has become an increasingly studied topic over the past few decades due to the rising number of diagnoses throughout the world (Conrad & Tan, 2014). Despite additional focus on the disorder, much about ASD remains unknown.

In the forefront of ASD research is the topic of intervention. At present, a “cure” has yet to be determined (Bölte, 2014). As such, professionals and affected families seek the most effective options to decrease social and language problems, idiosyncratic behaviors, and comorbid issues. Treatment of these issues subsequently improves the quality of life of the individual and his or her support network. However, information available to caregivers varies in quality and accuracy, with different sources making conflicting claims about the numerous current intervention options (Stephenson, Carter, & Kemp, 2012).

Caregivers of children with ASD employ a variety of interventions, including those with less empirical support and those methods that have been proven to be potentially harmful to individuals with ASD. As professionals assigning diagnoses and serving as a major source of information, clinical psychologists would be well served to investigate why this is occurring and how this pattern can be changed. In doing so, the amount of time between diagnosis of ASD and start of effective, data-based intervention can be decreased. The earlier that risk for ASD is identified and effective intervention begun, the greater the chance to guide an abnormal



trajectory toward a neurotypical pathway of brain and behavioral development (Dawson, 2008).

The purpose of the present study is to use an original, caregiver-reported Internet survey to ascertain information about a number of facets of autism intervention. The authors wish to find not only what intervention options are chosen, but also what factors among the children and adolescents and among the caregivers themselves that impact choice. The present document describes the examination of caregiver intervention choice and influences on these decisions (including child and caregiver characteristics).

## **Autism Treatment Options**

Caregivers generally engage in a variety of autism interventions concurrently, both evidence-based and not (Green et al., 2006). Knowledge about the types of treatments available, their efficacy, and their popularity among caregivers allows professionals to more effectively collaborate with and guide intervention decisions, thereby providing support and enhanced outcomes (Mire, Raff, Brewton, & Goin-Kochel, 2015). A discussion of the use of evidence-based practice and complementary and alternative medicine in the field of autism follows.

### **Evidence-Based Practice for Autism**

Evidence-based practice (EBP) is atheoretical and aims to improve performance outcomes by basing treatment on objective and scientifically credible evidence (Ollendick & King, 2004). The current study uses the strength of evidence categorizations from the recent second phase of the National Standards Project by the National Autism Center out of May Institute (National Autism Center, 2015). Using these categorizations, treatments can be considered established, emerging, or unestablished. Interventions categorized as established have sufficient evidence available to confidently determine that an intervention produces favorable outcomes for individuals on the autism spectrum. Emerging interventions have one or more studies that suggest favorable outcomes for individuals with ASD, but additional high quality studies must consistently show this outcome before firm conclusions about intervention effectiveness can be drawn. Finally, interventions categorized as unestablished have little or no evidence to allow firm conclusions about intervention effectiveness among individuals with ASD to be drawn, and additional research may show the intervention to be effective, ineffective, or harmful (National Autism Center, 2015). In considering a treatment, including

those categorized as established, psychologists should continually question treatment components, client characteristics that predict success, and mechanisms of change (Ollendick & King, 2004). Category assignments are fluid and change as research is conducted (Ollendick & King, 2004).

Using the National Autism Center's categorizations, for persons with autism under 22 years of age, there are 14 established interventions, 18 emerging interventions, and 13 unestablished interventions. Results of this project for individuals with autism over 22 years of age are beyond the scope of the current study. The 14 established interventions are: Behavioral Interventions, Cognitive Behavioral Intervention Package, Comprehensive Behavioral Treatment For Young Children, Language Training (Production), Modeling, Natural Teaching Strategies, Parent Training, Peer Training Package, Pivotal Response Training (PRT), Schedules, Scripting, Self-Management, Social Skills Package, And Story-Based Intervention. These treatments will be discussed in the following sections.

Practitioners may combine EBP options based on their professional judgment and clinical expertise to address the individual needs of their clients (C. Wong et al., 2015). Many researchers and clinicians use a continuum of teaching approaches that vary by individual. Ultimately, use of these different strategies should not be arbitrary but rather determined by individual response to intervention.

**Applied behavior analysis (ABA).** Several of the below National Standard Project's established interventions are either entirely or partially based on ABA, warranting a brief discussion of the science. Interventions based on the principles of Applied Behavior Analysis (ABA) have garnered the most empirical support and thus have been identified as the treatment of choice for ASD (Vismara & Rogers, 2010; C. Wong et al., 2015). A common

misconception among laypersons is that ABA is a treatment itself. In actuality, ABA is a science of analyzing how changes in the environment affect behavior (Schreibman et al., 2015). Goals of ABA include teaching new skills, promoting generalization of emerging skills, and decreasing challenging behavior (Weitlauf et al., 2014). This is accomplished in the use of multiple empirically based practices founded on operant learning procedures (Schreibman et al., 2015).

Structured ABA has been developed into comprehensive programs that primarily utilize discrete trial training (DTT) of skills as determined by a professional. DTT is an example of operant learning in which skills are separated into components that are taught using massed trials of antecedent-behavior-consequence sequences initiated by the therapist (Landa, 2007; Schreibman et al., 2015). Due to some issues with regimented DTT (e.g., lack of generalization of skills, presence of escape-maintained challenging behavior, overdependence on prompts), research has progressed toward expanding the use of ABA to methods that may decrease the likelihood of these problems (Schreibman et al., 2015). Additionally, research on typical and atypical childhood development revealed a discrepancy between early learning theory and DTT (Schreibman et al., 2015).

As such, Naturalistic Developmental Behavioral Interventions (NDBI) were developed to make use of natural contingencies and engage children within developmental sequences, allowing them to connect novel experiences with prior learning (Schreibman et al., 2015). This is accomplished by choosing target skills that are within a child's "zone of proximal development" and by reinforcing child-initiated behaviors that contribute to learning of targeted skills (Schreibman et al., 2015). Using natural contexts increases the likelihood that new skills generalize to other settings (Schreibman et al., 2015).

At present, there have not yet been any published large scale randomized controlled trials (RCT) comparing DTT and NDBIs (Schreibman et al., 2015). Nevertheless, NDBIs are ABA- based interventions supported by a large body of evidence (Schreibman et al., 2015). Evidence- based features of NDBIs include the three-part contingency (antecedent-response-consequence), manualized practice, fidelity of implementation assessments, individualized treatment goals, ongoing measurement of progress, child-initiated teaching episodes (i.e., child choice), environmental arrangement to cause child initiation or interaction with the treatment provider, natural reinforcement and motivation enhancement, prompting and prompt fading, reciprocal interactions (i.e., shared control or turn-taking), modeling, adult imitation of child behavior, and normalizing the child's attentional focus (Schreibman et al., 2015). Some of the most researched models of NDBI include: incidental teaching, PRT, Early Start Denver Model (ESDM), enhanced milieu teaching, reciprocal imitation training, Project ImPACT, Joint Attention Symbolic Play Engagement and Regulation (JASPER), Social Communication/Emotional Regulation/Transactional Support (SCERTS), and Early Achievements (Schreibman et al., 2015).

### **Established interventions per National Standards Project**

**Behavioral interventions.** Behavioral interventions include antecedent and consequent packages. These interventions can be, but do not have to be, based on ABA. Studies of behavioral interventions included a single component or multiple components and targeted a wide array of behaviors. Targets of interventions ranged from social and communication deficits to behavioral excesses including stereotypy or challenging behavior. Examples of interventions consisting of only one identified component reportedly used joint attention intervention, chaining, imitation training, reinforcement schedule, standard echoic training, etc.

in isolation (National Autism Center, 2015). For instance, Baltruschat et al. (2011) used positive reinforcement to improve central-executive working memory abilities as measured by a counting span task. A single strategy was also used by Bartlett, Rapp, Krueger, and Henrickson (2011); the authors found that response cost was effective in reducing spitting exhibited by a child with ASD. Other behavioral interventions that the project included encompassed two or more identified components, such as a package that included prompt delay, auditory scripts, manual prompts, behavioral rehearsal, and tokens (National Autism Center, 2015). For instance, Stokes, Cameron, Dorsey, and Fleming (2004) used a 10-step task analysis, general case instruction, and correspondence training to teach personal hygiene behaviors.

**Cognitive behavioral intervention package (CBIP).** CBIP is now considered established for persons with autism. CBIPs include identifying and describing emotions and associated physical responses, cognitive restructuring, homework, and parent sessions (National Autism Center, 2015). Manualized programs (e.g., Coping Cat, Exploring Feelings) have been adapted for audiences with ASD and target co-occurring symptoms, such as anxiety or anger (National Autism Center, 2015). For example, cognitive behavioral therapy (CBT) has a strong evidence base for improvements in anxiety among school-aged, high functioning children with comorbid anxiety symptoms (Weitlauf et al., 2014).

**Comprehensive behavioral treatment for young children.** Comprehensive behavioral treatment for young children include interventions described as ABA, Early Intensive Behavioral Intervention (EIBI), or behavioral inclusive programs (National Autism Center, 2015). These are intensive services (e.g., 25-40 hours per week for 2-3 years) based on ABA (National Autism Center, 2015). Strategies include DTT, incidental teaching, errorless

learning, behavioral momentum, shaping, modeling, and other ABA foundational strategies (National Autism Center, 2015). Programs are individualized to the client.

EIBI results in positive outcomes for young children with ASD in terms of cognitive functioning, communication skills, adaptive behavior, and educational placement (Dillenburger, 2014; Estes et al., 2015; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Weitlauf et al., 2014). Researchers of EIBI have demonstrated that intervention started at preschool age and sustained for several years results in positive change among many children with ASD (Dawson, 2008). In their review of early intensive behavioral and developmental interventions, Weitlauf et al. (2011) identified 25 unique studies including use of UCLA/Lovaas-based interventions, ESDM, Learning Experiences and Alternate Program for Preschoolers and their Parents (LEAP) program, and eclectic variants. The authors found that improvements were most often reported in cognitive and language abilities, with fewer positive results for adaptive skills, core ASD symptom severity, and social functioning. Some better quality studies included reports of improvements in symptom severity, but overall, the reviewers considered evidence for these outcomes as limited and mixed. In particular, they noted that studies delivering low-intensity interventions have not resulted in the substantial gains that more intensive options have. Despite promising evidence for these intensive interventions, long-term effects have not been studied sufficiently to determine if improvements persist over development (Weitlauf et al., 2014).

Another area necessitating further research is optimal treatments based on age. Thus far, EBP for autism has primarily been studied among 3 to 11 year olds, with fewer treatments studied among toddler/infant, high school, and older age groups (Mire et al., 2015). Given the growing evidence that supports diagnosis as early as infancy (Dover & Le Couteur, 2007;

Klaiman, Fernandez-Carriba, Hall, & Saulnier, 2015; Zwaigenbaum, Bryson, & Garon, 2013), research on early intervention is of particular importance. In order to achieve greatest treatment gains, techniques need to be designed and adapted for younger intervention recipients (Dawson, 2008; Landa, 2007). As such, recently focus has shifted to incorporating developmental orientations into traditional ABA-based interventions (Schreibman et al., 2015). That is, tailoring behavioral interventions that have proven effective among older children to the developmental level of 2 and 3 year olds. This approach has spawned increased interest in methods that are more naturalistic and less regimented but that still meet requirements of ABA, such as making treatment less structured (Schreibman et al., 2015). Intervention may take place during interactive social contexts (e.g., play, daily routines) and involve child-directed teaching (e.g., use of preferred items) (Schreibman et al., 2015). These changes make intervention better suited for recipients of early intervention.

**Language training (production).** Language training for production uses a variety of methods to elicit verbal communication, including modeling for imitation, prompting, cue-pause-point, music, and reinforcement (National Autism Center, 2015). These components are commonly presented in a multi-component package format. For instance, a language package consisting of noncontingent reinforcement and repeated verbal modeling increased independent requests and word approximations (Ganz, Flores, & Lashley, 2011). Other procedures may be used in isolation. For instance, the cue-pause-point procedure is used to teach individuals who exhibit persistent immediate echolalia “to remain quiet when the trainer [holds] up his index finger before, during, and briefly after the presentation of targeted questions and then to use a pre-trained verbal label as the correct response when the trainer [points] to the appropriate environmental cue” (McMorrow, Foxx, Faw, & Bittle, 1987, p.11).



This particular strategy has been found effective in promoting functional use of verbal labeling repertoires and in decreasing echolalia of instructions (i.e., including “say” following a “say [word]” instruction) (McMorrow et al., 1987; Valentino, Shillingsburg, Conine, & Powell, 2012).

**Modeling.** Modeling involves teaching by showing the targeted skill, allowing for imitation. This task can be accomplished in the presence of the individual with ASD (live) or by delivering a pre-recorded video of the target behavior to be imitated. Instructional modeling, which involves a therapist demonstrating expected behaviors, complements the visual processing abilities of persons with ASD (McCoy & Hermansen, 2007). The subject of video modeling can be an adult, a peer, or the client, either by self-modeling or point-of-view modeling (McLay, Carnett, van der Meer, & Lang, 2015). Each of these approaches has proven effective to teach skills to children with ASD (McCoy & Hermansen, 2007). Following the imitation behavior, the therapist may provide feedback on accuracy and appropriateness of the client’s response, as well as additional suggestions for further improvement (J. Matson, Matson, & Rivet, 2007).

**Naturalistic teaching strategies.** Naturalistic teaching strategies are a variety of methods to increase adaptive skills across settings. These strategies include focused stimulation, incidental teaching, milieu teaching, embedded teaching, responsive education, and prelinguistic milieu teaching (National Autism Center, 2015). These methods, which stem from a behavioral perspective, have significant evidence for promoting functional language skills using direct prompting and reinforcement (Ingersoll, 2011). Incidental teaching, for example, is a naturalistic language intervention that aims to increase spoken language within adult-child interactions. This goal can be accomplished by structuring the setting to encourage

the child to initiate interaction (e.g., requesting help reaching a preferred item) using indirect, environmental prompting (McDuffie, 2013). Methods are frequently child-directed but structured by the therapist and include materials and consequences the child would naturally encounter (National Autism Center, 2015).

**Parent training packages.** Parent training packages include the use of caregivers to provide a therapeutic environment for individuals with autism. Training can be in-vivo individual or group training, support groups with educational components, or training manuals (National Autism Center, 2015). Skills taught may include strategies to encourage imitation, joint attention, expectant waiting to elicit communication, etc. (National Autism Center, 2015). Professionals may provide instruction on behavior management skills, which has been shown to decrease challenging behaviors when used by caregivers (Osborne, McHugh, Saunders, & Reed, 2008a). Parents may also serve as a therapist to deliver EIBI or other ABA-based therapy (M. L. Matson, Mahan, & Matson, 2009), filling the need for therapy in a high-demand context and/or increasing the number of hours of evidence-based therapy a child is able to receive. Advantages of parent training beyond availability of treatment include greater generalization of skills, less expensive and resource intensive options, and increased likelihood of maintenance of treatment gains (M. L. Matson et al., 2009).

**Peer training packages.** Peer training packages include facilitation of social skill growth across settings using the child's peers. Strategies should include teaching peers how to gain the child's attention, facilitate sharing, provide help, model appropriate play skills, etc., then allowing the peers to practice with the children with ASD in the presence of a group instructor who can provide feedback (National Autism Center, 2015). This approach includes Project LEAP, peer networks, circle of friends, buddy skills package, integrated play groups,

peer initiation training, peer-mediated social interaction training, etc. (National Autism Center, 2015). In order to increase benefits, programs should include academic and social mediation, peer groups across settings, and involvement of novel peers to test newly acquired skills (Kamps et al., 2002). Generalization of targeted social skills leads to social interaction becoming more naturally reinforcing for children with ASD, which subsequently increases the likelihood the targeted social skills will be exhibited by participants (Kamps et al., 2002).

**Pivotal Response Treatment.** Pivotal Response Treatment (PRT; aka Pivotal Response Training, Pivotal Response Teaching, and the Natural Language Paradigm), based on ABA, is a naturalistic approach that targets “‘pivotal’ behaviors related to motivation to engage in social communication, self-initiation, self-management, and responsiveness to multiple cues” (National Autism Center, 2015, p. 59). Parent involvement and implementation across natural settings with direct natural consequences are key components. Such programs include child-choice, reinforcing attempts at target skills, incorporating new and mastered tasks into the program, and generalization (National Autism Center, 2015).

Recently, Mohammadzaheri, Koegel, Rezaee, and Rafiee (2014) conducted a RCT to compare PRT and structured ABA among children ages 6 to 11 years. They aimed to determine whether therapist- vs. client-led trials led to greater gains in social communication domains, as measured by mean length of utterance in a speech sample and by a standardized communication checklist completed by teachers and parents. They found that their PRT intervention was more effective in terms of gains in social communication skills than their structured ABA intervention. The authors attributed this to components of child choice (e.g., preferred toys and activities), the natural play context, and the effect of motivational components (e.g., less escape-maintained disruptive behavior to interfere with intervention).

**Schedules.** Schedules come in many forms (e.g., pictures, written, 3D objects, digital assistance programs), but all identify activities for a time period and in a certain order, allowing children with ASD to increase their independence. They may be used in any setting and to section apart any activity (e.g., leisure time, self-care, housekeeping or educational tasks). For instance, visual activity schedules have been used to teach transition behavior and staying on- task, to reduce challenging behavior, and to promote social initiation, independent play tasks, and many other skills (Knight, Sartini, & Spriggs, 2014). Prerequisite skills include picture identification and/or reading ability (National Autism Center, 2015). Schedules may be incorporated with other methods, including graduated guidance and reinforcement schedules (Knight et al., 2014).

**Scripting.** Scripting is verbal or written guidance for initiating or responding in a certain situation. Scripts are imitated and practiced before use, usually in conjunction with behavioral interventions, such as prompting or reinforcement (National Autism Center, 2015). They may address topics such as responding to a greeting, describing a recent activity, or asking questions to gain information (R. Lee & Sturmey, 2014). Training to say scripted sentences results in greater frequency of initiations (R. Lee & Sturmey, 2014). Scripts are faded as mastery is obtained, allowing for greater independence, generalization, and spontaneity of speech (National Autism Center, 2015).

**Self-management strategies.** Self-management strategies allow persons with ASD to increase independence and generalize new skills without constant supervision, typically by self- evaluating performance and self-delivering reinforcement (Vismara & Rogers, 2010). Targeted tasks are those in which supervision is not needed, accepted, or expected. Clients are taught to evaluate steps of an activity and deliver reinforcement independently. Therapists

provide prompts that are gradually faded. Reinforcement initially targets accuracy in monitoring rather than in task performance (National Autism Center, 2015). Self-management has been used across a variety of skill domains, including academic performance, conversation skills, stereotypy, and play (Vismara & Rogers, 2010).

**Social skills packages.** Social skills packages teach skills necessary to meaningfully participate in social environments, including eye contact, gestures, recognizing facial expressions, reciprocating information, initiating or ending interaction with others, etc. This can be accomplished individually, in peer dyads, or in small groups. These packages generally include behavioral components (e.g., reinforcement, prompting, modeling) (National Autism Center, 2015). Social skills interventions vary widely in their procedures, scope, and intensity. As such, accumulating evidence to support use is difficult. Nonetheless, Weitlauf et al. (2011) reviewed two good-quality and ten fair-quality studies. These studies used peer- and group-based approaches, emotion identification, and theory of mind training, among other methods. Most of the studies reported short-term improvement in directly tested or parent-rated social skills (e.g., emotion recognition).

**Story-based interventions.** Story-based interventions (including Social Stories) use a written description of a target behavior, situations in which the behavior is appropriate, and potential outcomes. Stories may include comprehension questions to check for understanding (National Autism Center, 2015). The stories may promote appropriate behavior, discourage inappropriate behavior, or teach routines, skills, or coping with transitions and novel situations (Constantin, Pain, & Waller, 2013). Individualization of teaching materials should address the needs and skills of the client, including reading and comprehension abilities, learning style, attention, and preferred topics or interests (Constantin et al., 2013).

## **Complementary and Alternative Treatments for Autism**

Many individuals with ASD are exposed to health care approaches outside of mainstream or conventional medicine, either to replace standard medical care or as a supplement (Levy & Hyman, 2015). These options are known as complementary and alternative medical treatments (abbreviated as CAM). For ASD, CAM is reportedly used to treat core symptoms as well as comorbid conditions (e.g., attention, hyperactivity, gastrointestinal symptoms, seizures, sleep, sensory sensitivity (H. H. Wong & Smith, 2006)). CAM treatments develop as rapid responses to new scientific information, but these options have not been empirically tested for appropriate use prior to implementation (Levy & Hyman, 2015).

How do CAM treatments begin to gain popularity? For many intended to treat autism, early case reports indicated improvement after treatment, which triggered searches for a biological mechanism and additional studies. Small, uncontrolled studies resulted in some added support, occasioning continued use by encouraged families, followed by refutation of early positive results by scientifically rigorous trials (Akins, Angkustsiri, & Hansen, 2010). Despite this disproof of efficacy, there is a striking disparity between use of CAM for ASD and evidence to support its use (Brondino et al., 2015). In one survey, more than 70% of parents of children with ASD reported having used at least one CAM therapy (Christon, Mackintosh, & Myers, 2010; Hanson et al., 2007).

Unfortunately, many caregivers do not have sufficient knowledge of potential side effects, yet they do not disclose use of CAM to health care providers (Levy & Hyman, 2015). Lack of disclosure may be due to shortage of time or perceived necessity for discussion, concern regarding the professionals' judgment of their choices, and/or beliefs that the

professional is not sufficiently knowledgeable about the options (Akins et al., 2010; H. H. Wong & Smith, 2006). As a result, health care providers must routinely inquire about use of CAM treatments and encourage shared and informed decision-making. Professionals should discuss the efficacy and safety of CAM treatments, including possible interactions other treatments and medications (Brondino et al., 2015). Treatments with evidence of efficacy and safety should be suggested. Treatments that are expensive, interfere with evidence-based intervention, have little or no efficacy, and/or have high risk of harm should be discouraged by medical professionals (Akins et al., 2010; Brondino et al., 2015). Some clinicians believe that options falling between these categories can be tolerated if they are monitored closely for positive and negative outcomes (Akins et al., 2010).

Fortunately, some organizations and professionals are combatting those treatment options that have little or no efficacy or have high risk of harm. For instance, the U.S. Food and Drug Administration (FDA) has threatened legal action against companies making false or misleading claims about autism treatments (e.g., hyperbaric oxygen therapy [HBOT], chelation, Miracle Mineral Solution, detoxifying clay baths, probiotic products; FDA, 2014). Additionally, their website offers tips to help caregivers spot potential scams. These include being skeptical of products that claim to treat a range of maladies or provide a “miracle cure.”

As awareness of the importance of empirical basis for treatment use grows among caregivers, demand for accurate information should follow. However, data from methodologically sound studies need to accrue in order to elucidate what works and what does not. Biomedical and non-biomedical treatments for autism are considered non-EBP because of their lack of scientific support, either because support has not yet been gathered or because researchers have indicated the intervention does not result in positive outcomes.

As with the established treatments, the current study uses the National Standards Project, Phase 2 (National Autism Center, 2015) results to distinguish treatments that are considered non- EBP (i.e., CAM), whether labeled as emerging or unestablished. However, because of the large number of these interventions identified, the current paper does not include discussions of all of these treatments. Instead, the lists of identified emerging and unestablished interventions follow, with descriptions of the most popular (i.e., most endorsed by caregivers in extant research) or otherwise noteworthy (e.g., due to high risk of harm) provided afterward.

Interventions categorized as emerging include: Augmentative and Alternative Communication Devices, Developmental Relationship-based Treatment, Exercise, Exposure Package, Functional Communication Training, Imitation-based Intervention, Initiation Training, Language Training (Production and Understanding), Massage Therapy, Multi-component Package, Music Therapy, Picture Exchange Communication System, Reductive Package, Sign Instruction, Social Communication Intervention, Technology-based Intervention, and Theory of Mind Training. Interventions categorized as unestablished include: Animal-assisted Therapy, Auditory Integration Training, Concept Mapping, DIR/Floor Time, Facilitated Communication, Gluten-free/Casein-free diet, Movement-based Intervention, SENSE Theatre Intervention, Sensory Intervention Package, Shock Therapy, Social Behavioral Learning Strategy, Social Cognition Intervention, Social Thinking Intervention, and any other intervention that has no research or research on the topic is published exclusively in non-peer-reviewed journals.

**Biomedical treatments.** Biomedical treatments aim to treat biological causes of disorders. For autism, biomedical treatments include off-label prescribed medications (anti-infectives, immunoglobulins, chelation agents, digestive enzymes, oxytocin, secretin) and



other medical treatments (specialized diets, HBOT), stem cell transplantation, transcranial magnetic therapy, vagus nerve stimulation) with high potential for negative side effects and/or complications and high financial and time costs (Levy & Hyman, 2015). Off-label medications can be provided over the counter or by prescription but used for an unapproved indication, age, or dosage (Levy & Hyman, 2015). Natural products are available over the counter as an oral or topical preparation (e.g., dietary supplements, nutraceuticals), and their use is often guided by non-peer-reviewed sources (Levy & Hyman, 2015). Among biologically-based CAM options, only elimination diets (specifically gluten- and casein-free diets), omega 3, vitamin supplementation, and HBOT have been extensively studied (Brondino et al., 2015).

***Diets and supplements.*** Elimination diets, especially gluten- and casein-free diets, are some of the most popular CAM treatments used for autism (Brondino et al., 2015). Gluten- and casein-free diets have been advertised as intervention for core symptoms and comorbid gastrointestinal issues (Akins et al., 2010). The unproven “opioid excess” hypothesis of ASD is generally the cause for use of such diets, which supposedly decrease endogenous opioids in the brain that contribute to neurobehavioral symptoms. Another rationale is the supposed presence of specific food allergens that could enhance immune response in predisposed individuals (Brondino et al., 2015). Controlled studies of these diets for ASD have been limited, with only two small RCTs meeting review criteria in a 2008 Cochrane review (Millward, Ferriter, Calver, & Connell-Jones, 2008). At this time, elimination diets do not have evidence supporting their use for ASD (Brondino et al., 2015). Individual benefits may be due to subclinical intolerance to food allergens, which may be under-diagnosed or under-treated in ASD due to impaired communication skills (Jyonouchi, 2010). Beyond being time-consuming and expensive, such diets create additional limits on feeding behavior of children

who are frequently already selective about food. Nutritional deficiencies, potentially resulting in bone loss, are a possibility, although little research has been conducted on risks associated with such diets (Akins et al., 2010).

The rationales for vitamin use as a treatment of ASD include dietary deficiencies of vitamins and micronutrients due to food selectivity or gastrointestinal issues (Brondino et al., 2015). Studies of vitamins as a treatment option resulted in inconsistent findings, and more scientifically sound studies are warranted before conclusions can be drawn (Brondino et al., 2015). One potential side effect of dietary supplements and administration of excessive multi-vitamins is vitamin toxicity (Akins et al., 2010).

**Chelation.** The intended purpose of chelation is to remove heavy metals from the body, as in heavy metal poisoning. Removal of heavy metals is accomplished by injecting various chemical substances to bind and withdraw specific metals from the body (Risher & Amler, 2005). The unproven theory to support chelation for autism is that some individuals with ASD have deficits in elimination of mercury and other heavy metals that affect immune and biochemical systems, and eliminating them results in neurocognitive recovery (T. N. Davis et al., 2013; Hertz-Picciotto et al., 2010).

Concerns about elevated mercury levels due to exposure to thimerosal from vaccines have fueled these claims (Akins et al., 2010). In actuality, children ages 2 to 5 years with ASD have been shown to have similar mercury levels in their blood as their typically developing peers (Hertz- Picciotto et al., 2010). Unfortunately, chelation when used inappropriately (i.e., for anything other than heavy metal poisoning) has potential for various negative side effects (e.g., fever, vomiting, diarrhea, loss of appetite, hypertension, hypotension, cardiac arrhythmias, hypocalcemia), including death (Baxter & Krenzelok, 2008; Doja & Roberts,

2006). Due to the potential risks and the extremely limited quantity and quality of existing research, chelation is not supported as a treatment for ASD (T. N. Davis et al., 2013).

**Hyperbaric oxygen therapy.** Hyperbaric oxygen therapy (HBOT) involves placement in a chamber in which the atmospheric pressure is compressed to a pressure greater than sea level, which increases the amount of oxygen in the blood (Gill & Bell, 2004). This treatment is generally used for carbon monoxide poisoning or air embolism (Brondino et al., 2015). In autism, HBOT reportedly targets potential dysfunction caused by hypoxia of brain cells, neuro-inflammation, or deficient mitochondria (Halepoto, Al-Ayadhi, & Salam, 2014). Two studies published in 2006 and 2009 by the same research team reported improvement in ASD symptoms after HBOT (Rossignol & Rossignol, 2006; Rossignol et al., 2009). The Undersea and Hyperbaric Medical Society, a professional organization that maintains scientific rigor in hyperbaric medicine, investigated these claims. In the organization's position paper, Bennett and Hart (2009) noted these studies presented numerous problems, the greatest of which was that the very low oxygen and pressures used in their treatment condition did not constitute HBOT, as the dosage could be delivered without compression (Akins et al., 2010).

Thus far, the few methodologically sound studies on this topic do not provide sufficient evidence to support HBOT for the treatment of autism (Ghanizadeh, 2012; Halepoto et al., 2014; Jepson et al., 2011). Furthermore, although HBOT appears to be safe, little attention has been paid to reporting adverse effects (Halepoto et al., 2014). Reported side effects include barotrauma, sinus squeeze, serous otitis, claustrophobia, reversible myopia, and new onset seizure (Halepoto et al., 2014).

**Secretin.** Secretin, a gastrointestinal hormone, stimulates secretion of bile from the liver and acts as a stress regulatory hormone (Owley et al., 2001). A case series published in

1998 reported significant improvement in eye contact, alertness, and language following secretin administration for diagnostic gastrointestinal tests (Owley et al., 2001). Such anecdotal evidence of positive outcomes following single secretin injections helped spread its popularity (Bowker, D'Angelo, Hicks, & Wells, 2011). Nonetheless, no benefit over placebo has been found for secretin; media attention and the sensory experience of injections may have increased positive expectations (i.e., the placebo effect) for this treatment option (Sandler, 2005). Secretin as a treatment for autism has been thoroughly studied, resulting in lack of support for its use (Akins et al., 2010).

**Non-biomedical treatments.** Non-biomedical treatments are those that target non-biological causes of disorders. For autism, the focus is on behavioral, emotional, and cognitive developmental deficits (Bodfish, 2004). This includes mind and body practices that generally are administered or taught by a trained practitioner and guided by non-peer-reviewed sources (Levy & Hyman, 2015). Given the general lack of side effects of non-biomedical treatments, these CAM options are considered by some families and professionals as more acceptable (Brondino et al., 2015). Nonetheless, safe but not efficacious treatments redirect limited time and finances, at times resulting in strife and stress among families attempting to navigate challenging treatment decisions (Brondino et al., 2015).

**Massage.** At present, massage is categorized as an emerging treatment for autism in the National Standards Project, Phase 2 (National Autism Center, 2015). Between 11 and 16% of individuals with autism have reported using massage (Hanson et al., 2007). Massage is a means of manipulating soft tissues to affect both physiological (e.g., lowers blood pressure) and psychological states (e.g., improvement in mood) (Aourell, Skoog, & Carleson, 2005; Ernst, 2009). There has been an increase in interest in massage as a treatment option for

ASD since the inclusion of sensory abnormalities in diagnostic criteria (Silva & Schalock, 2013).

Therapeutic touch is widely known for stress reduction, but there is some evidence to support its use to improve sensory impairment in children with ASD (Akins et al., 2010). For persons with ASD, touch may be aversive and result in abnormal responses (e.g., avoidance) (Silva & Schalock, 2013). Massage therapy aims to normalize tactile response in this population (Silva & Schalock, 2013). In one study of a massage therapy based on Chinese medicine, the authors reported improvement in tactile abnormalities, better child self-regulation, and decreased parenting stress (Silva & Schalock, 2013). Nonetheless, limited evidence exists to support massage as a treatment of ASD symptoms, thus massage needs further study before becoming considered EBP (M. S. Lee, Lee, Park, & Shin, 2014).

**Acupuncture.** Estimates of acupuncture use for ASD range widely, from 1 to 43% (M. S. Lee, Choi, Shin, & Ernst, 2012). Acupuncture is the application of needles or pressure to specific points on the body and is generally used to treat pain (Akins et al., 2010; Cheuk, Wong, & Chen, 2011). Side effects reported include crying due to fear or pain, irritability, bleeding, sleep disturbance, and increased hyperactivity (Cheuk et al., 2011). The current evidence base is fraught with issues, including high risk of bias, inconsistent and imprecise result reporting, and lack of heterogeneity in methodology (Cheuk et al., 2011). There are no published randomized studies supporting acupuncture as a treatment for ASD (Akins et al., 2010).

**Chiropractic care.** Chiropractic care includes manual manipulation of the body, particularly the spine, to correct alignment and subsequently relieve pain and improve functioning (Harvard Health, n.d.). The rationale for using chiropractic manipulation for

autism is unknown, and there are no published randomized studies that support its use for this purpose (Akins et al., 2010). Three case reports, one cohort study, and one randomized comparison trial have been conducted but did not provide positive results based on methodologically sound procedures (e.g., lack of control groups, small sample sizes; Alcantara, Alcantara, & Alcantara, 2011; Brondino et al., 2015). Published cases of serious adverse effects related to chiropractic treatment in the pediatric population are rare, although soreness, headaches, irritability, and other mild symptoms have been reported (Todd, Carroll, Robinson, & Mitchell, 2014). At this time, there is no support for chiropractic manipulation as a treatment for ASD.

***Music therapy.*** Of the non-biological interventions, music therapy has been studied most frequently and is sometimes considered part of behavioral intervention rather than a CAM treatment (Brondino et al., 2015). Music therapy involves developing relationships through music with aims to improve communication and expression (Geretsegger, Elefant, Mössler, & Gold, 2014). Music therapists, generally trained and credentialed professionals, use instruments and voices to engage participants in singing and movement activities to build skills in rhythm, listening, turn-taking, matching, and sharing (Sandberg & Spritz, 2012). Basis for its use includes reports that children with ASD respond better to music than spoken words (Sharda, Midha, Malik, Mukerji, & Singh, 2015). Although music therapy for ASD is considered safe, long-term effects remain unknown (Akins et al., 2010; Geretsegger et al., 2014).

According to a 2006 Cochrane review, music therapy for ASD was shown to be superior to placebo in terms of verbal and gestural communicative skills, but effects on behavior were not significant and of limited applicability to clinical practice (Gold, Wigram, &

Elefant, 2006). A more recent Cochrane review included 10 RCTs on music therapy, published between 1995 and 2012, that included a total of 93 participants (Geretsegger et al., 2014). Researchers suggested that music therapy may improve social interaction, verbal communication, social-emotional reciprocity, and nonverbal communication skills (Brondino et al., 2015). However, included studies had small sample sizes and were not consistent in terminology or methodology, making replication difficult. Music therapy may be promising in terms of changes in communication and social reciprocity, but further scientifically rigorous studies that allow for replication are needed. As such, music therapy is currently considered an emerging treatment for autism by the National Standards Project, Phase 2 (National Autism Center, 2015).

***Auditory integration training.*** In auditory integration training (AIT), an individual listens to music that has been modified, reportedly allowing the person to re-train their brain to eliminate hyper- or hyposensitivity to certain frequencies of sound (Brondino et al., 2015). In their review of auditory integration therapy and sound therapies for ASD, Sinha, Silove, Hayen, and Williams (2011) identified six RCTs involving a total of 182 individuals. Only two studies, both from the same research team, reported statistically significant improvements. The largest studies did not report significant differences between treatment and control groups or evidence for long-term benefits. Sufficient evidence to support AIT as treatment for ASD currently does not exist (Brondino et al., 2015).

***Sensory integration training.*** Sensory integration training (SIT) involves exposure to lights, sounds, smells, tastes, or textures, commonly introduced through play activities, that reportedly modulate how the brain responds to these modalities (Brondino et al., 2015). This goal is accomplished through the use of weighted vests, brushing or rubbing with instruments,

swinging, tactile pressure, and other similar techniques (Lang et al., 2012). Supporters of SIT for ASD suggest that sensory stimulation in the appropriate method and dosage may improve the sensory processing ability of nervous system (Lang et al., 2012). In their review of 25 studies investigating SIT for ASD, Lang et al. (2012) found that only three of the studies suggested SIT was effective, and all three of these studies had significant methodological flaws. There is not sufficient evidence to support SIT as treatment for ASD (Brondino et al., 2015).

### **Medication**

At this time, there are no pharmacological treatments for the core symptoms of autism (Hsia et al., 2014; Weitlauf et al., 2014). In this population, psychotropic medication use may aim to increase focus, decrease hyperactivity, aggression, or irritability, and/or address co-occurring symptoms (e.g., anxiety, mood problems, tics; Mire et al., 2015). The only FDA-approved medications for ASD are risperidone (Risperdal) and aripiprazole (Abilify), which are indicated for treatment of irritability in 5 to 16 year olds (Hsia et al., 2014; Lofthouse, Hendren, Hurt, Arnold, & Butter, 2012). These drugs have demonstrated improvement in challenging behavior (e.g., emotional distress, aggression, hyperactivity, self-injury), but both have high incidence of harm (Weitlauf et al., 2014).

Families report concerns about side effects and safety of prescription medication (Hanson et al., 2007). Nonetheless, between 30 and 70% of persons with ASD have received treatment in the form of medication (Frazier et al., 2011). In a recent study, Mire et al. (2015) found that 40% of families endorsed administration of psychotropic medication, with ADHD drugs (i.e., psychostimulants) as the most commonly prescribed. Further, endorsement of medication usage increased for older children. These authors suggested several potential



reasons for this trend: caregivers may be more comfortable with administering pharmaceuticals as children age, non- pharmaceutical treatment options have been exhausted without desired outcomes, treatment needs may have changed due to shifting symptoms, and/or caregivers have difficulty managing aggressive behaviors that may increase as children grow (Mire et al., 2015).

## Treatment Selection

Internet surveys of caregivers of individuals with ASD have provided insight into treatment usage, perceived efficacy, and parental perceptions (Bowker et al., 2011). Thus far, most studies of treatment choices made by caregivers of individuals with ASD have focused on rates of use, whereas fewer studies of treatment selection assess influential factors that affect intervention decisions (Call, Delfs, Reavis, & Mevers, 2015). For both EBP and CAM, usage statistics vary widely, with hypothesized reasons including differing methods of obtaining rates (e.g., caregiver survey, review of records) and categorization (Christon et al., 2010). Nevertheless, as studies of this nature continue, data can be aggregated into an eventual meaningful average. For now, varying estimates are available and are provided below.

### Rates of Use

**Number of treatments.** Parents of children with ASD use an average of four to seven treatments at once (Bowker et al., 2011; Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006), and they have tried an average of seven to nine treatments total (Goin-Kochel et al., 2007; Green et al., 2006). A more recent study of a small convenience sample indicated that caregivers used an average of 11.4 treatments but would use an average of 53.7 if there were fewer constraints (e.g., cost, availability) (Call et al., 2015). Number of treatments increases with symptom severity and presence of challenging behavior (Goin-Kochel et al., 2007; Green et al., 2006; Hanson et al., 2007). Use of numerous treatments at once means resources are spread more thinly instead of maximizing finances and time on options that are most likely to be efficacious (Call et al., 2015). Additionally, this strategy makes evaluating outcomes of a specific treatment selection difficult (Green et al., 2006).

**Rates of EBP.** Despite empirical support for ABA continuing to grow, only a little more than half of caregivers of children with ASD reported use of ABA-based therapies in an Internet survey conducted in 2006 (Green et al., 2006). Goin-Kochel et al. (2007) reported that 47.4% of parents reported current use of ABA for their 1.7 to 5.9 year olds, 31.9% of parents for their 6 to 11.9 year olds, and 23.3% for their 12 to 21.9 year olds. In the same survey, 60.5% of parents reported current use of early intervention for their 1.7 to 5.9 year olds, whereas an encouraging 87.7% of parents reported having ever used early intervention services for their 1.7 to 5.9 year olds. The statistics reported by Mire et al. (2015) are less encouraging with only 37.5% of families having endorsed ever using intensive behavioral intervention. The greatest proportion of usage was in 4-year-olds (24.4%) (Mire et al., 2015). Because social and communication skill deficits are a core symptom in autism, the high rates of use of social-focused interventions is not particularly surprising. For social skills training, current use was highest for adolescents (63%), with about 74% of parents reporting having ever tried social skills training for their adolescents (Goin-Kochel et al., 2007). For social stories, current use was highest for middle childhood (44%), with 59% of parents reporting having ever tried social stories for their 6 to 11.9 year olds (Goin-Kochel et al., 2007).

**Rates of CAM.** CAM is used by individuals with ASD at higher rates than persons with chronic illnesses, genetic disorders, and cerebral palsy, with estimates ranging between 28 and 95% (Akins et al., 2010; Christon et al., 2010; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Perrin et al., 2012). In a recent study, 47% of caregivers reported having used at least one type of CAM in the previous 6 months (Salomone, Charman, McConachie, & Warreyn, 2015). Unfortunately, Levy et al. (2003) found that 9% of their sample of children recently diagnosed with ASD were using potentially harmful treatments. To illustrate, 7 to 8%

of families reported using chelation for autism despite the associated risks (Green et al., 2006). A more recent study reported 2% of respondents endorsed use of any invasive, disproven, or potentially unsafe CAM (Salomone et al., 2015).

Concurrent use of multiple CAM options is not uncommon (Levy & Hyman, 2015; Levy et al., 2003); in one study, for those parents who used any CAM approaches, the total number ranged from 1 to 12 with a mean of 2.15 approaches (Salomone et al., 2015). The most commonly used CAM treatments for ASD are natural products, special diets, and mind and body practices (Levy & Hyman, 2015). In the aforementioned study (Salomone et al., 2015), the most common CAM were diets and supplements (24% of sample reported use). This included use of vitamins by 15% of the sample and gluten- or casein-free diets by 13%. Next were mind and body practices with 23% of the sample having reported use, sensory integration therapy reported by 14%, and massage reported by 7%. Other unconventional approaches included pet therapy (14%) and homeopathy (10%). Similarly, in their sample of primarily Caucasian (87%) caregivers of higher SES (62% within \$70-100 K family income), Hanson et al. (2007) found the most frequently reported CAM treatments were modified diets (38%; e.g., gluten-free, casein-free, wheat-free, sugar-free, dairy-free), vitamins/minerals (30%; primarily Vitamin B6), and food supplements (23%; e.g., omega 3 fatty acids, fish oil, DMG). These methods were followed by prayer/shaman, biofeedback, massage/body-work, herbal remedies, and chiropractic/osteopathic manipulation at 10-16% endorsement each.

### **Influential Factors**

**Sources of information.** The rates of use statistics suggest the need for professionals in the field to better translate research findings to their practice and to put forth additional effort to transmit research findings to programs and families (Mire et al., 2015). Parents

necessitate continuously updated information about treatments and their efficacy from health care providers. Besides health practitioners, many families turn to other caregivers of children with ASD for this information because they share the difficult and confusing task of intervention choice and subsequent implementation (Goin-Kochel et al., 2007).

In fact, H. H. Wong and Smith (2006) investigated frequency of sources of information about CAM, with results indicating family and community members endorsed as the most frequent source (35%). Physicians and the Internet were consulted about one fourth of the time (23% each), followed by other nonmedical professionals (4 to 27%) and books (15%) as less common sources. In a similar study, Miller, Schreck, Mulick, and Butter (2012) reported that 85.6% of their sample used recommendations from autism books, 85.4% from professionals other than medical doctors, and 75.2% from parents.

In their survey, Deyro, Simon, and Guay (2014) found that a professional referral (e.g., pediatrician, other doctor, therapists) was the most influential source of information regarding treatment choices, with general media (e.g., Internet, television, newspaper) as the least influential source. The grouping of all professionals in this survey may be problematic, however. Therapists have varying degrees of experience and education. As such, some professionals are more likely to suggest evidence-based treatments than others. Indeed, in a study by Miller et al. (2012), the authors reported that psychologists and behavior analysts were the professionals most likely to endorse empirically based treatments, whereas medical and allied medical professionals were the least likely to do so.

Although family members and friends, doctors, teachers, the media, and businesses all influence treatment choices made by caregivers of persons with autism (Schreck, 2014), the Internet is a first outlet for medical information for a majority of families (Levy & Hyman,

2015). This trend is worrisome given the current available information about autism treatments on the web. An online search for autism treatments yields accurate information interspersed with numerous sponsored advertisements for CAM options (e.g., chelation, HBOT [Schreck, 2014]). Blogs and other websites may be deceitful in their presentation of information, falsely making it seem as though certain unsupported interventions have empirical bases (Sandberg & Spritz, 2012).

Additionally, the Internet is changing the experience of autism, and illness in general, for affected individuals and their families. Websites, bulletin boards, chat rooms, and social media sites have allowed Internet users to interact with others about ASD. There are certainly benefits to online support groups (e.g., increased understanding of ASD, identification of high-quality service providers), but these sources of information and interaction represent users with varying experiences and perspectives about autism (Conrad & Tan, 2014). Faulty science and misinformation can spread easily in such channels. Websites and groups promoting untested treatments introduce exposure to information about intervention with potentially harmful effects (Levy & Hyman, 2015).

Further, advocacy and awareness websites vary in their discussion of evidence behind the information they present. For instance, some autism websites list interventions that have little empirical basis for use or are considered potentially harmful (Conrad & Tan, 2014). Without a source of accurate, data-supported information, caregivers hopeful for something that works can easily be led astray. In their examination of information provided by web sites of national autism associations, Stephenson et al. (2012) found that many presented positive descriptions and proponent claims for interventions that have been determined to be unsuccessful for ASD, with little reference to research. Further, some sites presented

conflicting descriptions and scientific evidence (e.g., one site presented negative science evidence but a neutral description for auditory integration), as well as providing links for interventions considered to have weak evidence and for which the site provided negative or no scientific support (Stephenson et al., 2012). With incompatible and inconsistent information provided by sites that may seem reputable to the untrained eye, intervention decision-making becomes even more difficult for caregivers to navigate.

### **Child characteristics that influence choice.**

**Autism severity.** Based on extant research, severity of autism may affect treatment usage rates and selections. However, most studies have used diagnosis as a proxy for autism severity. Not only is this strategy less accurate than actual measures of severity, but also the diagnoses used are now obsolete given *Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup>* edition (DSM-5; American Psychiatric Association, 2014) criteria. Nonetheless, past research on this matter is discussed below.

Autism type, described as “autism severity” in studies, has been shown to affect the number of treatments a child is currently using or has tried. Children with Autistic Disorder and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) were currently using and had tried more treatments than their peers with Asperger’s Disorder (Goin-Kochel et al., 2007). Further, “autism severity” has been shown to influence use of EBP and CAM. Multiple studies have indicated that children and adolescents with a diagnosis of Autistic Disorder had higher rates of CAM use than peers with Asperger’s or PDD-NOS (Christon et al., 2010; Hanson et al., 2007; Perrin et al., 2012). To illustrate, CAM use was associated with more severe parent-reported diagnosis, with 90% of children with Autistic Disorder or PDD-NOS and comorbid Intellectual Disability (ID)/Global Developmental Delay (GDD) were

reported to have used CAM (Hanson et al., 2007). Rates were lower for PDD-NOS without comorbid ID/GDD and Asperger's Disorder or ASD-symptoms groups (69 and 42%, respectively) (Hanson et al., 2007). Hebert (2014) found that parents of children with a more severe diagnosis were more likely to consider biological interventions. Further, presence of comorbid symptoms, such as gastrointestinal issues, seizure disorder, and challenging behavior, increases likelihood of CAM use (Perrin et al., 2012).

Unlike the majority of studies that have used autism diagnosis to measure symptom severity, Siller, Reyes, Hotez, Hutman, and Sigman (2013) used Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2002) scores to look at social affect and restricted and repetitive behaviors. The authors reported that severity of symptoms did not independently predict children's intervention programs. As such, there is a lack of consensus at this time about whether or not symptom severity affects treatment choice.

*Age.* There have been minimal studies of changes in intervention use across the lifespan or of age as a factor in treatment decisions. One research group suggests that use of CAM is relatively stable across age span, perhaps because lack of research means these treatments are not specifically indicated for certain ages (Mire et al., 2015). Conversely, younger children have been shown to use more diet, behavioral, educational, or alternative treatments than older children, whereas the opposite is true of psychotropic medication treatments (Goin-Kochel et al., 2007; Mire et al., 2015). This result may be due to the finding that puberty can cause additional challenging behavior not well managed using behavioral techniques (Goin-Kochel et al., 2007). Alternatively, this finding may reflect changing needs; caregivers may decrease the number and/or intensity of treatment options as core ASD symptoms improve over time (Mire et al., 2015). Overall, few studies have investigated age as a predictor of CAM or EBP use.



### **Caregiver characteristics that influence choice.**

***Socioeconomic Status (SES).*** Caregivers of lower socioeconomic status (SES) may have difficulty locating or affording empirically based treatments. Poor access to treatment has been proposed as a reason caregivers implement CAM treatments for their children with ASD (Hanson et al., 2007). Additionally, cost of high intensity interventions (e.g., ABA) has been reported by parents as a reason these options are not used (Valentine, Rajkovic, Dinning, & Thompson, 2011). Interestingly, CAM usage also has been reported as more common among families with high SES (Brondino et al., 2015). At present, research is inconsistent regarding the effect of SES on EBP or CAM use.

Nevertheless, treatments that are available through state programs and/or school settings (e.g., speech, occupational therapies) may be used more frequently due to their wider and free availability, regardless of family SES. In their sample, Mire et al. (2015) found that 80.2% endorsed using school-based speech therapy (compared to 53.2% for private speech therapy), and 67.6% endorsed using school-based occupational therapy. Further, the mandate for autism services for Medicaid beneficiaries that was passed in 2014 may help remedy financial issues associated with autism treatments, potentially decreasing differences in treatment use based on SES (Mire et al., 2015).

***Education.*** As with SES, researchers have not reached a consensus regarding the effect of parental education on CAM vs. EBP use. In a study by Miller et al. (2012), the authors reported that neither education level nor college major significantly contributed to parental choice of ASD treatments. They concluded that parents from a variety of financial and educational backgrounds use CAM options. Similarly, researchers indicate that parents' comprehension and conceptualization of illness differs significantly from biomedical evidence

regardless of parental education (Shyu, Tsai, & Tsai, 2010). In a study of parents of children with autism in Chinese culture, education level did not affect cause attribution or intervention choice. Rather, cause attribution, accessibility, and affordability all influenced the treatments parents selected (Shyu et al., 2010).

In contrast to results suggesting that education does not play a part in selection, some researchers have found that level of education does make a difference. In Siller et al. (2013), the authors reported family characteristics as significant predictors of service utilization, including “indicators of SES,” which included annual household income and parental education. In several studies, parents with a high education level were found to be more likely to report use of CAM (e.g., diets, supplements) than parents with a lower education level (Hanson et al., 2007; Salomone et al., 2015). Salomone and colleagues (2015) have suggested this finding might be moderated by SES; for instance, mind and body practices cost on average twice the amount of self-care therapies such as supplements, which may be why they were used less in the lower SES group, which was indexed by education level. In contrast, Howard, Sparkman, Cohen, Green, and Stanislaw (2005) reported that parents of children enrolled in intensive behavior analytic intervention, an EBP, averaged one to two more years of education than the parents of children participating in intensive “eclectic” intervention or non-intensive public early intervention programs. At present, more research is needed to determine the effect of SES on treatment selection.

## Purpose

The current study aimed to replicate surveys of caregiver treatment choices and expand on previous findings by incorporating a parent-report measure of autism symptom severity. In order to best effect change in caregiver choice, psychologists must know what factors influence families during this process. The author aimed to answer a variety of questions that could help clinicians and other providers guide families affected by ASD toward more evidence-based selections. As such, the current study aims to examine the sources of information, child characteristics, and caregiver characteristics that predict EBP versus CAM use. Results may help professionals target certain client populations for increased psychoeducation about the use of empirically-based treatments for autism. Future projects based on results may include online resources or pilot groups that could provide psychoeducation in an accessible format. Additionally, further effort could be made to educate health professionals who may be providing incorrect or outdated information.

First, the author wanted to know what EBP and CAM treatments caregivers choose for their children and adolescents with ASD (*Q1*). Based on extant research regarding treatment selections, the author predicted that behavioral interventions would receive the greatest percentage of endorsement, likely by about half of caregivers. Further, the author suspected respondents would indicate use of multiple treatments, both CAM and EBP, at once. Finally, the author predicted relatively high rates of Speech Therapy, Occupational Therapy, and Physical Therapy across diverse respondents due to availability of such treatments through early intervention and school programs.

Next, the author wanted to examine the most frequently consulted and most trusted sources of information about treatments for ASD (*Q2a* and *Q2b*). Consistent with extant

research, the author predicted that most common sources of information would be medical professionals, websites/online searches, and other caregivers of individuals with ASD. Further, the author hypothesized that CAM Hours and EBP Hours would vary based on the most trusted source of information. Caregivers who indicated their most trusted source of information was the Internet or other individuals caring for persons with ASD were predicted to endorse higher levels of CAM due to the prevalence of misleading and incorrect information present among these sources.

Finally, the author wanted to determine what factors (i.e., information source, child characteristics, caregiver characteristics) predict hours of CAM versus hours of EBP (*Q3*). The author hypothesized that most trusted source of information, child age, child symptom severity of ASD, respondent education, and respondent income would all contribute to treatment hours. The author predicted that consulting healthcare providers, as opposed to non-healthcare providers (e.g., websites, social media, other caregivers), would result in greater use of EBP treatments. Based on prior research, the author anticipated that greater severity of ASD symptomatology would result in greater endorsement of CAM usage. Following extant data, the author hypothesized that younger children would engage in greater EBP hours (behavioral treatment in particular), and older children or adolescents would engage in less non-pharmaceutical treatment overall. Further, the author suspected that higher respondent education and income would predict higher EBP Hours and lower CAM Hours. Caregivers with higher levels of education may be more likely to consult scientific evidence and base intervention decisions in part on empirical support, resulting in greater endorsement of EBP. Additionally, caregivers with higher incomes may have fewer financial barriers to obtaining treatment and may have better insurance coverage of empirically-based interventions.

## Method

### Participants

For the present study, data was collected between January 11, 2016 and May 1, 2016. Within these dates, 129 people completed the consent to participate page and began the survey. Of total respondents (N=129), 80 participants (62%) completed the survey in its entirety. Respondents who did not finish the survey were not excluded from analyses, as data was included as available. The software program that the survey authors used to run the survey allowed any individual with a link to the survey to complete it. As such, the author used responses to certain survey questions as inclusion and exclusion criteria for analyses.

The author of the current study aims to examine treatment selections made by caregivers for children and adolescents. For this purpose, responses of caregivers were included if they indicated they are a biological or adoptive parent or primary guardian who provides the majority of care for an individual with ASD. Inclusion and exclusion criteria are enumerated following and represented visually in Figure 1. Respondent numbers are provided specifically for each statistical analysis.

Among total respondents (N=129), ages of children (i.e., person with ASD) ranged from 1 year 6 months to 32 years. For the current study, inclusion criterion #1 was age range of child between 1 year 0 months and 17 years 11 months. Only 90 participants answered the question regarding child age. Approximately 15 respondents stopped when they read this question (“How old is your child?”), which was the first question about the *child*. Based on responses regarding relationship to the individual with ASD (“What is your relationship to the individual with ASD?”), it seems these respondents may not have understood that only caregivers serving a parental role (i.e., parents, grandparents; not spouses, therapists) were intended to serve as

respondents. Of the 90, 19 responses were eliminated based on age outside of inclusion criteria; 71 respondents remained.

Next, inclusion criterion #2 was relationship to the child. Only those respondents serving a parental caregiver role were included. Of the 71 respondents included, 54 were biological mothers, 4 were biological fathers, 1 was an adoptive mother, 1 was an adoptive father, and 11 indicated “other.” Most of the “other” category indicated that the respondent was the child’s grandparent. However, one “other” respondent was removed due to indicating s/he was the child’s therapist; 70 respondents remained.

Next, inclusion criterion #3 was child’s diagnosis. Only children with an ASD were included; as such, only respondents that indicated their child had Autistic Disorder, PDD-NOS, Asperger’s Disorder/Syndrome, Autism Spectrum Disorder, or “other” responses that fit into one of these categories was included. This criteria resulted in two further eliminations, for responses of “Sensory Processing Disorder” and “Not sure.” These overall inclusion criteria left a sample of 68 respondents remaining. Data of these 68 respondents is provided following.

## **Measures**

**Survey.** The final version of the survey available on Qualtrics for participants to complete can be found in the Appendix (pg. 91). The survey included questions about demographics, treatment options with which the caregiver is familiar, treatment options which the individual has used and is currently using, sources of information about treatment options, influences on treatment decisions, etc. An additional measure was included with the original survey, as described below. Although this increased the survey length, gathering information about ASD symptom severity allowed for analysis of the influence of this factor on intervention selections.

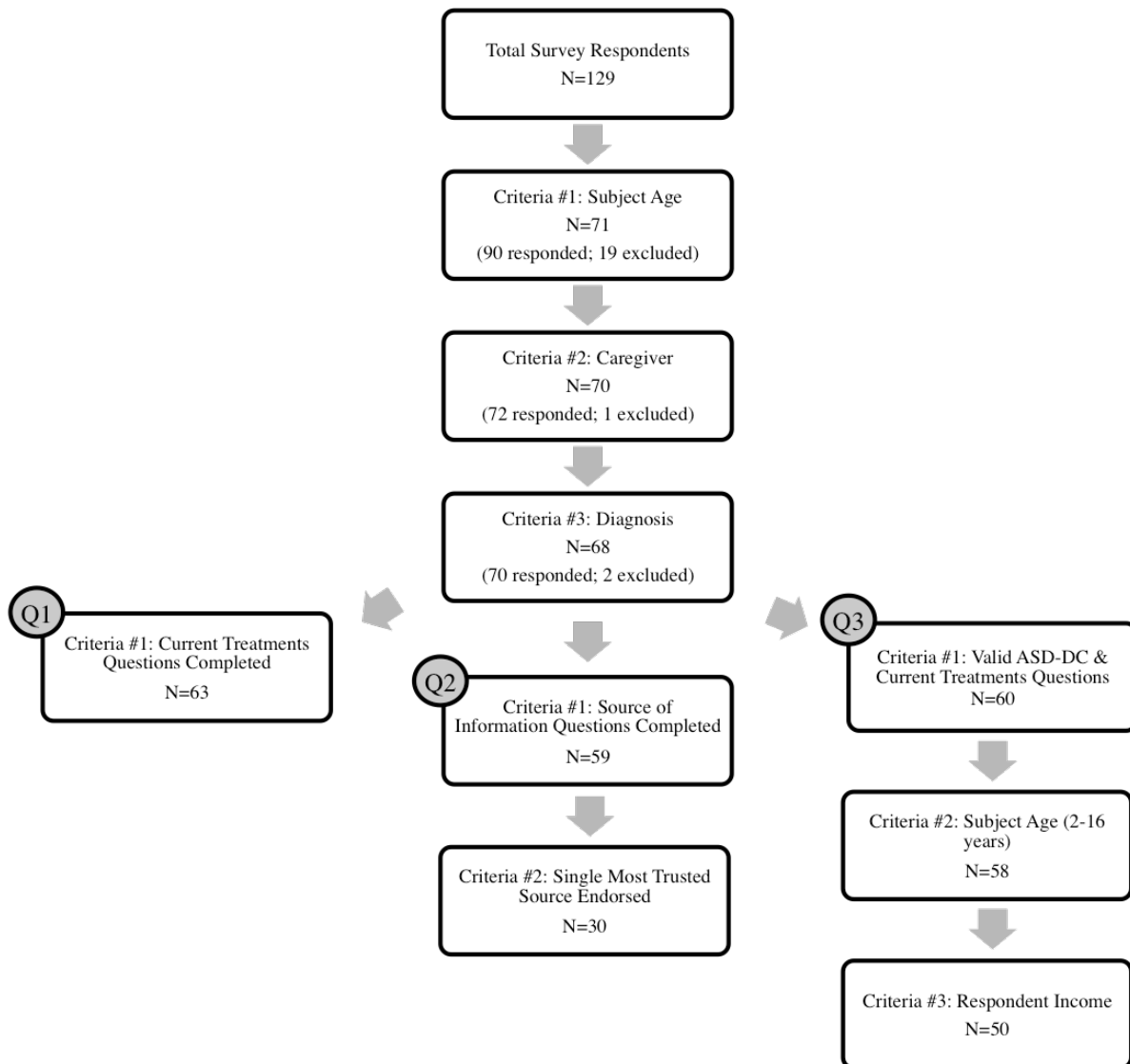


Figure 1. Flowchart Representing Inclusion and Exclusion Process

During preliminary development of the original survey, each treatment included (N=39) was asked about individually for endorsement of use. Preliminary survey completion testing by the authors concluded that this took too significant an amount of time and would be extremely burdensome for respondents. The authors predicted that keeping the survey in this original format would cause significant drop-out when the respondents reached this section (particularly given the lack of monetary incentive for participating). The authors concluded that the survey would be more feasible for respondents if the treatments were grouped into categories,

decreasing the number of questions substantially. Treatments were separated into groups of either EBP or CAM interventions and presented in a random order. Categorization was based on loose themes (e.g., cognitive interventions, social skills interventions, vitamins/supplements and diets, harmful treatments).

**Autism Spectrum Disorder – Diagnostic, Child Version (ASD-DC).** The ASD-DC (Matson & González, 2007) is a caregiver report measure of autism symptoms among individuals ages 2 to 16 years. It is a 40-item scale within the Autism Spectrum Disorder Battery, Child Version. Internal consistency of the measure is excellent at .99, and test-retest and inter-rater reliability are both good, at  $\kappa = .77$  and  $\kappa = .67$  respectively (Matson, Gonzales, Wilkins, & Rivet, 2008). Chronbach's alpha for the present sample indicated a high degree of internal consistency (40 items,  $\alpha = 0.94$ ). Symptoms to be rated include those spanning domains of diagnostic criteria; there are questions regarding communication skills, social abilities, restricted interests, repetitive behavior, sensory issues, etc. Caregiver respondents rate the symptoms compared to the child's peers as *ever* being a problem on a scale of 0 to 2, with 0 implying not different/no impairment, 1 implying somewhat different/mild impairment, and 2 implying very different/severe impairment. The purpose in including the ASD-DC was to obtain a caregiver report of autism symptom severity, thus the endorsements were summed for a total score.

### **Procedure**

The authors of the survey received approval from the Louisiana State University Institutional Review Board prior to initiation of the study. The authors advertised the survey via posts on social media sites (e.g., Facebook, Twitter, NextDoor, MeetUp), via emails on listservs for a variety of groups (e.g., autism groups for each state), and via approved flyers posted in providers' offices (e.g., LSU Psychological Services Center, The Emerge Center). Although



these sources spanned the country, the resulting sample was less demographically diverse than expected. Homogeneity of the sample may be due in part to the manner in which the survey was advertised and the format in which the data was collected (i.e., on the Internet), which is discussed in the Limitations section (pg. 76).

The survey was created using Qualtrics Research Suite, provided by Louisiana State University. This program allows survey authors to send an anonymous link for completion. Additionally, we enabled the Anonymizing Responses feature, which removes data about which response came from which participant, including removing IP addresses from results. As such, all responses were anonymous.

When potential participants clicked the link for the survey, they were directed to a webpage to complete an informed consent process. In the event that an individual reached the consent form and chose not to complete the informed consent process, the program sent them to the end of the survey, and they were not able to participate or access any survey questions. Once the caregiver completed informed consent, he or she was redirected to the first questions of the survey. The ASD-DC was included in full within the survey, between blocks of author-created questions. The survey closed when the respondent pressed a button to indicate he or she had completed the survey.

### **Statistical Analyses**

All statistical analyses were performed in SPSS 21. Demographics were calculated for the sample to provide an overview of the characteristics of the participants. Descriptive statistics were run for all variables. For the predictor variable of child symptom severity of ASD, the endorsements for each item of the ASD-DC were summed. For the primary outcome variables, respondents endorsed current use of a certain treatment group for their children with

ASD and subsequently provided number of hours per week of use for each treatment group. Endorsed hours for each respondent were then divided into CAM Hours and EBP Hours based on the categorization by the National Standards Project.

For hours per week, values can be greater than the actual number of clock hours in a week. Each treatment group was considered on an individual basis, and multiple treatments could be used simultaneously (e.g., receiving 40 hours per week of ABA at the same time as 3 hours of Social Stories and 3 hours of Picture Exchange). However, upon visual inspection of the data, it was noted that multiple caregivers (N=5, almost 10% of the sample who completed these questions) endorsed hours per week of CAM Group 3 (vitamins and supplements, special or restricted diets, and oxytocin) between 40 and 75 hours (i.e., the maximum number of hours permitted). The authors of the survey determined that this question was likely misinterpreted by respondents; specifying that hours endorsed should be time the child and/or family was involved in actual administration of treatment (e.g., purchasing ingredients and preparing specific diet; taking vitamins) would have been helpful in acquiring the data desired. The authors assume that caregivers endorsed the maximum number of hours because their children were receiving this type of treatment all hours of the day (e.g., constant adherence to specialized diet). It was clear that these hour values were not representative of hours involved in treatment and thus did not fulfill the purpose of these analyses. Due to the lack of validity of endorsements on this category, it was excluded from Total Hours, Hours of EBP, and Hours of CAM for all participants. These unrepresentative values altered the CAM data significantly; the mean hours of CAM per week was about 12 prior to removal of this value and about 8 after removal of the value. All other values were added for each participant to create a Total Hours value and separated by CAM and EBP for Hours CAM and Hours EBP values.

What EBP and CAM treatments do caregivers choose for their children and adolescents with ASD (*Q1*)? As discussed, treatments were grouped in order to decrease likelihood of respondent fatigue and subsequent discontinuation, resulting in an inability to pinpoint endorsements for particular treatments (e.g., could not determine percentage of respondents who endorsed use of ABA in particular). Additionally, number of treatments in current use could not be determined. Instead, current treatment selection results are presented in percentages and thus could still be compared with previous research on intervention choice. These percentages represent the proportion of the sample that uses each intervention. Percentages are compared within and between their categorization as either CAM or EBP interventions.

What are the most frequently endorsed sources of information about treatments for ASD (*Q2a*)? What is the most trusted source of information about treatments for ASD (*Q2b*)? Similar to *Q1*, both endorsed sources of information and most trusted source of information results are presented in percentages. Further discussion is provided in the Results section regarding an error related to the results of *Q2b*.

What factors (i.e., information source, child characteristics, caregiver characteristics) predict hours of CAM versus hours of EBP (*Q3*)? For this question, two separate independent samples t-tests and two separate multiple regression analyses were conducted. For each pair of analyses, either CAM Hours or EBP Hours was the dependent or outcome variable.

First, the researcher wanted to examine information source. Due to an error in survey construction, respondents were able to pick more than one source to answer the question, “Of the sources of information about autism treatments you use, which is your **most trusted** source?” (formatted as in survey). Of the 59 respondents who completed this section of questions, 29 misinterpreted this question and chose multiple sources as “most trusted.” Due

to this limitation, information source was examined apart from the other potential predictors of CAM versus EBP use. The author assessed differences in CAM versus EBP use between the group of respondents that endorsed their most trusted source as a healthcare provider (e.g., doctors, psychologists, therapists) and the group of respondents that endorsed their most trusted source as a non-healthcare provider (e.g., other caregivers, media, teachers).

The independent samples t-test can be used to assess for statistically significant differences between means of independent groups on a continuous dependent variable (Laerd Statistics, 2015). Before the t-tests were run, assumptions for using independent sample t-tests were checked (i.e., testing for outliers, normality, homogeneity of variances). The data must meet these assumptions before analyses can take place; as such, transformations of the data were made as needed. If an independent samples t-test is statistically significant, the researcher can conclude that the means of the groups differ significantly. Effect sizes were calculated to provide a measure of the practical significance of the results whether the tests reached significance or not. Cohen's *d* values can be interpreted as .2 as a small effect size, .5 as a medium effect size, and .8 as a large effect size (Cohen, 1988).

Multiple regression can be used to understand whether each independent variable added to the model is important in explaining the variance of the dependent variable (Lund & Lund, 2013). Before the multiple regression analyses were run, assumptions for using multiple regression were checked (i.e., independence of observations, linear relationship between dependent variable and each predictor and the dependent variable and the predictors collectively, homoscedasticity, multicollinearity, presence of significant outliers, residuals approximately normally distributed). The data must meet these assumptions before analyses can take place; as such, transformations of the data were made as needed. There is not yet

conclusive research regarding the separate influence of each predictor being analyzed in the present study and no comparisons of the contributions of these predictors together. As such, this analysis was considered exploratory, and all predictors were entered into the model at once.

For these analyses,  $R^2$  was the first statistic to be examined.  $R^2$  represents the proportion of variation in the outcome variable explained by the predictor variables above and beyond the mean model. Adjusted  $R^2$  was reported as it corrects for positive bias present in  $R^2$ , making it a more representative value expected in the population, and is also an estimate of effect size (Laerd Statistics, 2015). Next, statistical significance of the model was examined. If a model has a significance of  $p < .05$ , insertion of the predictors results in a model that is statistically significantly better at predicting the outcome variable than the mean model (Laerd Statistics, 2015). Further, individual predictors were assessed using the t-statistic, which tests the null hypothesis that the value of regression coefficients is significantly different from zero (Field, 2009). If the test is significant, the researcher can conclude the predictor variable significantly contributes to the prediction of the outcome. Subsequently, the regression coefficients for each predictor were examined for direction and considered in the context of the entire model. If the CAM and EBP models each had the same predictors significantly contributing to the outcome variable, the statistical test indicated by Paternoster, Brame, Mazerolle, and Piquero (1998) could have been employed to see if the coefficients were significantly different. If the coefficients differed significantly for a predictor, the researcher could conclude that the predictor was more or less important in predicting CAM or EBP hours. However, as discussed in the Results section, the predictors that reached significance were different for each of the models, thus this comparison was not indicated.

## Results

### Respondent Demographics

All percentages are rounded. Of the 68 respondents included in the overall sample, 59 were Caucasian (87%), 3 were African American (4%), 2 were East Asian (3%), and 4 identified as “other” (i.e., Colombian/Italian, Caucasian/Hispanic, Hispanic/Asian, Eurasian; 6%). Caregiver respondents (N=68) were primarily female (N=62; 91%), with 6 respondents indicating they were male (9%). In terms of highest level of education completed (N=68), 2 indicated they had completed some high school (3%); 2 were high school graduates (3%); 6 had technical, associate, or professional degree (9%); 11 had some college (16%); 24 were college graduates (35%); 2 had some graduate school (3%); and 21 had a graduate degree (31%). In terms of annual household income (N=68), 6 indicated income less than \$10k (9%); 4 indicated income between \$10k and \$25k (6%); 5 indicated income between \$25k and \$40k (7%); 8 indicated income between \$40k and \$55k (12%); 7 indicated income between \$55k and \$70k (10%); 17 indicated income between \$70k and \$100k (25%); 13 indicated income over \$100k (19%); and 8 indicated they preferred not to answer (12%). In terms of current marital status (N=68), 6 indicated they were single and had never been married (9%); 52 indicated they were married or in a long-term relationship (76%); 8 indicated they were separated or divorced (12%); and 2 indicated they were widowed (3%). In terms of location of respondents (N=67), 17 different states were represented (Arizona, California, Colorado, Florida, Georgia, Idaho, Indiana, Iowa, Louisiana, Massachusetts, Michigan, Minnesota, Missouri, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, South Carolina, Texas, Utah, Wisconsin). There were three states that represented more than 10% of respondents each: Louisiana (10%), Texas (10%), and South Carolina (24%). Most respondents (N=68) characterized the city/town where

they currently live as suburban (56%), followed by urban (34%), then rural (10%). The above statistics can be found in Table 1.

Table 1. Respondent Demographics

<b>Ethnicity</b>		<b>N</b>	<b>%</b>
	Caucasian	59	87
	AA	3	4
	East Asian	2	3
	Other	4	6
<b>Gender</b>		<b>N</b>	<b>%</b>
	Female	62	91
	Male	6	9
<b>Highest Level of Education</b>		<b>N</b>	<b>%</b>
	Some HS	2	3
	Graduated HS	2	3
	Technical, Associate, Prof	6	9
	Some College	11	16
	Graduated College	24	35
	Some Graduate School	2	3
	Graduated Graduate School	21	31
	Prefer Not to Answer	0	0
<b>Annual Household Income (\$k)</b>		<b>N</b>	<b>%</b>
	< 10	6	9
	10-25	4	6
	25-40	5	7
	40-55	8	12
	55-70	7	10
	70-100	17	25
	100+	13	19
	Prefer Not to Answer	8	12
<b>Current Marital Status</b>		<b>N</b>	<b>%</b>
	Single/Never Married	6	9
	Married/Long-Term	52	76
	Separated/Divorced	8	12
	Widowed	2	3

N=68

### Child Demographics

All percentages are rounded. Of the 68 respondents, the children or adolescents for which respondents provided care were primarily Caucasian (78%), followed by a combination of ethnicities (15%); African American (4%); South Asian (2%); and East Asian (2%). In terms of gender (N=68), children were primarily male (82%). In terms of diagnosis (N=68), the most prevalent was ASD (66%); followed by PDD-NOS (16%); Autistic Disorder (12%); Asperger's

Disorder/Syndrome (4%); and finally “other” (2%; High Functioning Autism). In terms of children’s current ages (N=68), age ranged from 18 months to 214 months (17.8 years), with a mean of 105.1 months (8.8 years) and a standard deviation of 45.86 months (3.8 years). In terms of children’s ages at diagnosis (N=66), age ranged from 12 months to 187 months (15.6 years), with a mean of 49.2 months (4.1 years) and a standard deviation of 33.5 months (2.8 years). In terms of children’s ages at initiation of treatment (N=59), age ranged from 7 months to 187 months (15.6 years), with a mean of 44.6 (3.7 years) and a standard deviation of 32.7 months (2.7 years). In terms of children’s comorbid problems, 16% of respondents endorsed child’s diagnosis of intellectual disability; 22% endorsed child exhibits physical aggression; 24% endorsed child exhibits SIB; 54% endorsed child’s presence of sleep problems; and 6% endorsed child’s comorbid diagnosis of epilepsy or seizure disorder. The above statistics can be found in Tables 2 and 3.

Table 2. Child Demographics

<b>Ethnicity</b>		<b>Percentage</b>
	Caucasian	78
	Other	16
	AA	4
	South Asian	2
	East Asian	2
<b>Gender</b>		
	Male	82
	Female	18
<b>Diagnosis</b>		
	ASD	66
	PDD-NOS	16
	Autistic D/O	12
	Asperger's	4
	HFA	2
<b>Age</b>	<b>Mean (Years)</b>	<b>SD (Years)</b>
Present	8.8	3.8
Diagnosis <sup>^</sup>	4.1	2.8
Treatment Initiation <sup>^^</sup>	3.7	2.7

N=68; <sup>^</sup>N=66; <sup>^^</sup>N=59



Table 3. Child Comorbidity

Comorbid Problems	Endorsed by (%)
Intellectual Disability	16
Physical Aggression	22
Self-Injurious Behavior	24
Sleep Problems	54
Epilepsy/Seizure Disorder	6

N=68

## Q1

What EBP and CAM treatments do caregivers choose for their children and adolescents with ASD? From the sample of 68 respondents, 63 completed the current treatment questions and were eligible for inclusion in the Q1 analyses. Treatment groups are provided for reference in Table 4, and percentages of respondents who endorsed each treatment group are provided in Table 5. The treatment group endorsed by the greatest percentage of respondents overall was EBP Group 4 (74.6% of respondents), which included Language Training (Production) and Speech Therapy. The CAM treatment group endorsed by the greatest percentage of respondents was CAM Group 5 (66.1% of respondents), which included Occupational Therapy and Physical Therapy. The only treatment included in the current treatment questions that was not endorsed by any survey respondents was CAM Group 4, which included Chelation, HBOT, and Packing.

Table 4. Treatment Groups

Group	Interventions Included
<b>EBP</b>	
1	EIBI
2	ABA, Modeling, PRT, Natural Teaching Strategies
3	Cognitive Behavioral Intervention, CBT
4	Language Training (Production), Speech Therapy
5	Parent Training, Peer Training Package, Self-Management Training, Schedules
6	Scripting, Social Skills Package, Story-Based Intervention
<b>CAM</b>	
1	Alternative Communication Devices, FCT, PECS, Sign Instruction, Facilitated Communication, Music Therapy, Animal-assisted Therapy, Floor Time, Play Therapy
2	Exercise, Massage Therapy/Deep Pressure, Auditory/Sensory Integration, Chiropractic, Art Therapy, Acupuncture
3	Vitamins and Supplements, Special/Restricted Diets, Oxytocin
4	Chelation, HBOT, Packing
5	OT, PT

Table 5.  
Current Intervention Use  
Endorsed by Respondents

	Group	Percentage
EBP	1	18.6
	2	57.6
	3	19
	4	74.6
	5	53.4
	6	56.1
CAM	1	44.8
	2	28.8
	3	35.6
	4	0
	5	66.1

N=63

## Q2

What are the most frequently endorsed sources of information about treatments for ASD (*Q2a*)? What is the most trusted source of information about treatments for ASD (*Q2b*)? From the sample of 68 respondents, 59 completed the source of information questions and were eligible for inclusion in the Q2 analyses. Websites were the most frequently endorsed source of information (79.7% of respondents), followed by caregivers of children with ASD (69.5%), doctors (57.6%), Internet groups (52.5%), and ABA therapists (50.8%). Least endorsed source of information was newspapers (6.8%) and TV (10.2%). “Other” sources were endorsed by 10.2% of respondents; write-ins of “other” sources included “PCIT (Parent Child Interaction Therapy) therapist,” “work colleagues,” “[Medicaid] service coordinator,” “behavioral therapy agency,” and “RBT (Registered Behavior Technician) training.” See Table 6 for complete list of sources included and their endorsements.

Due to an error in survey construction, respondents were able to pick more than one source to answer the question, “Of the sources of information about autism treatments you use, which is your **most trusted** source?” (formatted as in survey). Of the 59 respondents who

Table 6. Information Sources

Source	Percentage
Websites	79.7
Caregiver of ASD	69.5
Doctor	57.6
Online Group	52.5
ABA Therapist	50.8
OT Therapist	49.2
Books	45.8
Teacher	35.6
Psychologist	23.7
Support Group	22
Magazines	18.6
Caregiver of non-ASD	16.9
PT Therapist	13.6
TV	10.2
Other	10.2
Newspaper	6.8

N=58

completed this section of questions, 29 misinterpreted this question and chose multiple sources as “most trusted.” Table 7 includes percentages of most trusted source including all participants, including respondents who selected multiple sources as most trusted (e.g., one respondent wrote, “They are about equal.”). Table 8 includes percentages of most trusted source including only the 30 respondents who selected a single most trusted source, separated by healthcare provider and non-healthcare provider. The 30 respondents who answered as the authors intended were included in further analyses, as described in the Q3 section following. For this group, caregivers of children with ASD was the most frequently endorsed most trusted source of information (23.3%), followed by ABA therapists (16.7%). For the following analyses (Q3), most trusted sources were divided into two groups, healthcare providers and non-healthcare providers. Of these 30 respondents, 13 (43.4%) indicated their most trusted source was a healthcare provider, whereas 17 (56.7%) indicated their most trusted source was a non-healthcare provider.

Table 7. Most Trusted Source

Source	Percentage
Caregiver of ASD	27.1
Doctor	23.7
ABA Therapist	23.7
OT Therapist	15.3
Books	11.9
Online Group	8.5
Teacher	8.5
Psychologist	8.5
Support Group	6.8
Websites	5.1
Other	5.1
PT	3.4
Caregiver of non-ASD	1.7
Magazines	0
TV	0
Newspaper	0

N=59

### Q3

What factors (i.e., sources of information, child characteristics, caregiver characteristics) predict hours of CAM versus hours of EBP? From the sample of 68 respondents, 50 respondents were eligible for inclusion in the following analyses of treatment hours. Respondents were removed if they did not complete the ASD-DC (N=4), if the children's ages were outside of the range for which the ASD-DC is validated (i.e., 2 to 16 years; N=2), if they did not complete the current treatments section (N=1), and if they answered "Prefer not to answer" for respondent income (N=8). Further, one case was removed due to clear lack of understanding of the hour-selecting process (i.e., selected 40 hours for most interventions, including ones that cannot be used simultaneously), one case was removed due to endorsement that she does not use any therapy and works with her child without any formal training (i.e., endorsed 75 hours of "other"), and one case was removed due to complaint that she was "unsure how to respond" because she does everything herself via "homeschool" (N=3).

Table 8. Most Trusted Source by Group

	Source	N	Percentage	Mean CAM Hours	Mean EBP Hours
<b>Non-provider Source</b>	Caregiver of ASD	7	23.3		
	Support Group	3	10		
	Websites	2	6.7		
	Online Group	2	6.7		
	Books	2	6.7		
	Teacher	1	3.3		
	TV	0	0		
	Newspaper	0	0		
	Caregiver of non-ASD	0	0		
	Magazines	0	0		
Total		17	56.7	7	20.53
<b>Provider Source</b>	ABA Therapist	5	16.7		
	OT Therapist	3	10		
	Doctor	2	6.7		
	Psychologist	2	6.7		
	Other: PCIT Therapist	1	3.3		
	PT Therapist	0	0		
	Total		13		

N=30

Results regarding sources of information were provided in the above section. In terms of total symptom endorsement (ASD-DC Total, summation of all endorsements) for the sample (N=50), the range was 59 to 118; mean score = 92.38; SD = 15.21. Both respondent income and respondent education were measured using scales. For both of these variables, the categorical coding actually represents continuous values. Respondent income and respondent education were entered as continuous variables in the following analyses (Carifio & Perla, 2008; Murray, 2013; Norman, 2010). For respondent income, 1 = less than \$10k; 2 = \$10k-\$25k; 3 = \$25k-\$40k; 4 = \$40k-\$55k; 5 = \$55k-\$70k; 6 = \$70k-\$100k; 7 = more than \$100k. For respondent education, 1 = some high school; 2 = high school graduate; 3 = technical, associate's, or professional degree; 4 = some college; 5 = college graduate; 6 = some graduate school; 7 = graduate school graduate. In terms of respondent income for the sample (N=50), the range was less than \$10k (coded as 1) to more than \$100k (coded as 7); mean score = 5.02 (\$55k-\$70k coded as 5); SD = 1.85. In terms

of respondent education for the sample (N=50), the range was some high school (coded as 1) to graduate degree (coded as 7); mean score = 5.20 (college graduate coded as 5); SD = 1.67.

Among the 50 eligible respondents, total hours per week of treatment ranged from 0 to 122; mean = 31.94 hours; SD = 31.56 hours. Hours per week of CAM ranged from 0 to 75; mean = 8.7 hours; SD = 14.36 hours. Hours per week of EBP ranged from 0 to 119; mean = 23.24 hours; SD = 24.82 hours. The treatment group with the highest average number of hours per week endorsed was EBP Group 2 (ABA, Modeling, PRT, Natural Teaching Strategies), mean = 9.58 hours. The treatment group with the lowest number of hours per week endorsed was CAM Group 4 (Chelation, HBOT, Packing), mean = 0 hours.

Although respondents endorsed a somewhat wide range of hours of treatment (i.e., 0 to 122 total hours), the data was significantly skewed toward lower endorsements. For total hours, 13 respondents (approximately 25% of the sample) endorsed fewer than 10 hours of overall treatment per week. For CAM hours, 39 respondents (78% of the sample) endorsed fewer than 10 hours of CAM treatment per week. For EBP hours, 18 respondents (36% of the sample) endorsed fewer than 10 hours of EBP treatment per week. Histograms are provided in Figures 2 and 3 that illustrate the overall patterns of fairly low rates of current treatment use and a few endorsements of high rates.

#### **Source of information analyses.**

The author intended to determine if most trusted information source groups differed in their use of CAM versus EBP treatments for ASD. As noted, information source was divided into two groups: healthcare provider and non-healthcare provider. First, a priori statistical analyses were conducted to determine if most trusted source groups differed significantly on demographic variables. Several Chi-square analyses were conducted. No significant difference of

respondent ethnicity between most trusted source groups was found,  $\chi^2 (3) = 4.91, p = .18$ . No significant difference of respondent education was found,  $\chi^2 (6) = 1.95, p = .93$ . No significant difference of respondent income was found,  $\chi^2 (5) = 8.47, p = .13$ . As such, none of the above variables necessitated inclusion as covariates, allowing for the use of independent-samples t-tests.

Using G\*Power (Faul, Erdfelder, Lang, & Buchner, 2007), an a priori power analysis was conducted to determine sample sizes required to achieve sufficient power. The standard in the behavioral sciences is to set the significance level at  $\alpha=.05$ , which sets the power at .80 (Field, 2009; Hinkle, Wiersma, & Jurs, 2003). Accordingly, alpha was set to .05, power was set to .80, the effect size was set to .5 (medium), and there were two groups. With these settings, a total sample size of 102 was suggested. As noted prior, only 30 respondents selected a single most trusted source due to misinterpretation of the survey question. The statistical tests were conducted nonetheless, especially give the argument that such parametric tests are robust with respect to violations of sample size, normal distribution, and use of Likert scales (Norman, 2010).

Two separate independent-samples t-tests were conducted to determine if there were differences in Hours CAM and Hours EBP between the group of respondents that endorsed their most trusted source as a healthcare provider (e.g., doctors, psychologists, therapists) and the group of respondents that endorsed their most trusted source as a non-healthcare provider (e.g., other caregivers, media, teachers). Results must be interpreted with caution given the small sample size and resulting power of .039. Future data collection may allow this analysis to be repeated with a larger sample size.

According to numerical tests of normality (i.e., Shapiro-Wilk's test), neither Hours CAM nor Hours EBP were normally distributed for both groups (health provider and non-health

provider as most trusted source). Plotted visually, both variables were positively skewed, with a significant number of responses of 0 hours per week of treatment (see Figures 2 and 3). A squareroot transformation was tested and did not increase normality substantially for either variable. Other transformations (i.e., log10, natural log, inverse) resulted in the elimination of any respondents who endorsed 0 hours of treatment per week. Although these transformations increased normality, eliminating these respondents limited interpretation and was thus not an option. As such, a cuberoot transformation was applied, which allowed inclusion of respondents who endorsed 0 hours but also allowed the data to approach normality. Thus, independent-samples t-tests were conducted using transformed variables of Hours CAM and Hours EBP. Non-transformed means and standard deviations are provided following.

Transformed Hours CAM was normally distributed for the provider and non-provider groups, as assessed by Shapiro-Wilk's test ( $p > .05$ ). There was homogeneity of variances, as assessed by Levene's test for equality of variances ( $p = .66$ ). Respondents who endorsed healthcare providers as their most trusted sources of information (N=13) averaged 7.85 hours of CAM. Respondents who endorsed non-healthcare providers as their most trusted source of information (N=17) averaged 7.00 hours of CAM. The groups did not differ significantly in terms of Hours CAM,  $t(28) = .52$ ,  $p = .61$ , Cohen's  $d = .19$ . Transformed Hours EBP was normally distributed for the provider and non-provider groups, as assessed by Shapiro-Wilk's test ( $p > .05$ ). There was homogeneity of variances, as assessed by Levene's test for equality of variances ( $p = .55$ ). Respondents who endorsed healthcare providers as their most trusted sources of information (N=13) averaged 28.54 hours of EBP. Respondents who endorsed non-healthcare providers as their most trusted source of information (N=17) averaged 20.53 hours of EBP. The groups did not differ significantly in terms of Hours EBP,  $t(28) = 1.08$ ,  $p = .29$ , Cohen's  $d = .40$



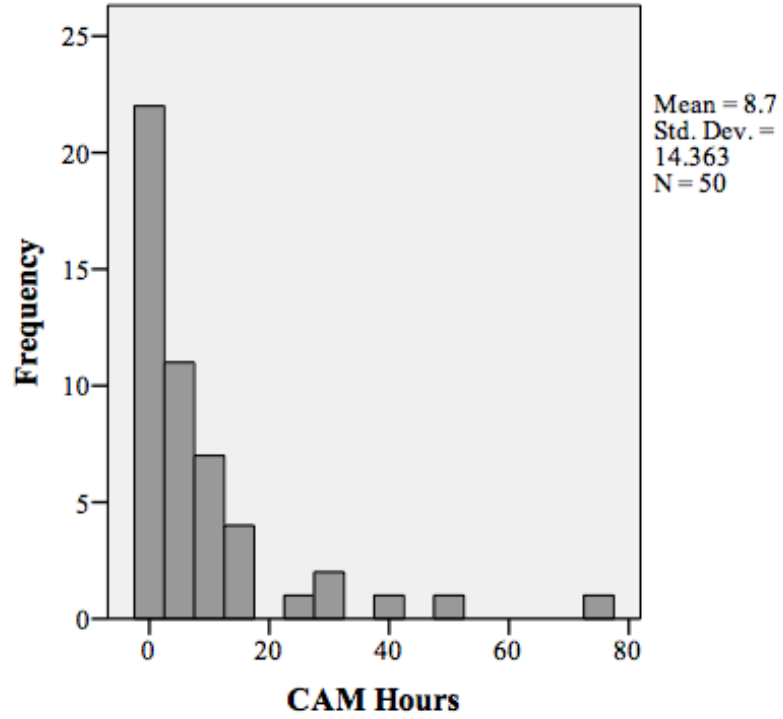


Figure 2. Distribution of CAM Hours

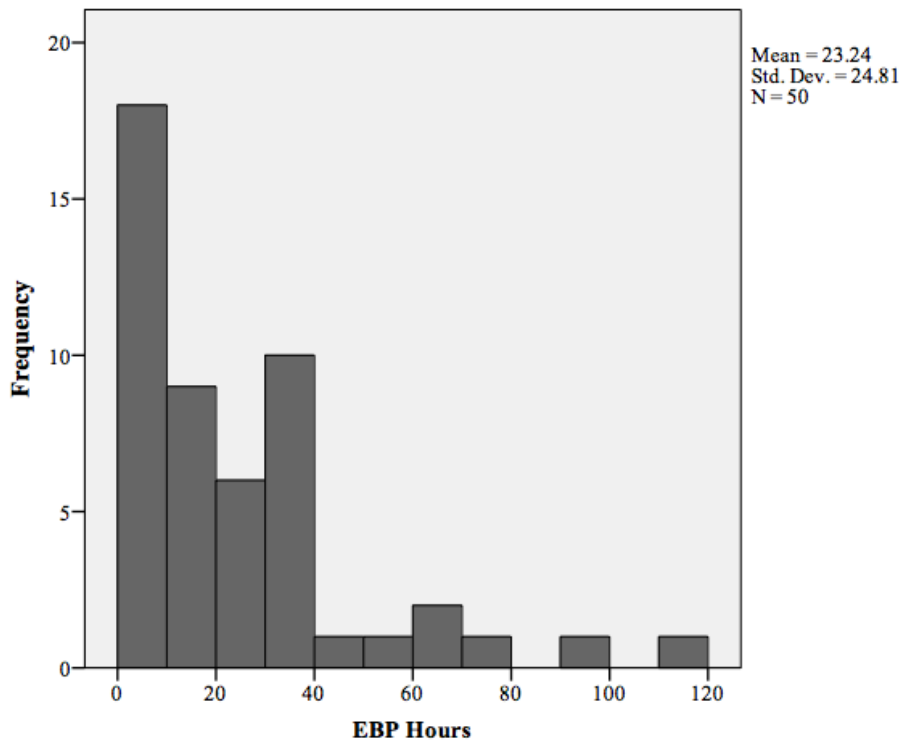


Figure 3. Distribution of EBP Hours

### **Regression analyses.**

Using G\*Power (Faul et al., 2007), an a priori power analysis was conducted to determine sample sizes required to achieve sufficient power. As before, alpha was set to .05, power was set to .80, effect size was set to .25, and there were four predictors. With these settings, a total sample size of 53 was suggested. Similarly, Green (1991) suggested that number of participants should exceed the number of predictors by at least 50, which would necessitate at least 54 participants for this study. As noted prior, 50 respondents met inclusion criteria for these analyses, which approaches the suggested sample size.

Two separate multiple regression analyses were conducted to determine whether characteristics of the respondent (caregiver) and the child/adolescent predict hours of CAM treatment versus hours of EBP treatment differentially. Due to a lack of extant research comparing the included variables' influences on use of evidence- and non-evidence-based treatment, all variables were entered at once as an exploratory analysis. Prior to running analyses, assumptions of multiple regression were checked, as explained in detail next.

Hours of CAM was plotted to check visually for normality. This variable was significantly positively skewed, with a significant number of responses of 0 hours per week of CAM treatment (see Figure 2). A squareroot transformation was tested and did not increase normality substantially. Several other transformations (i.e., log10, natural log, inverse) resulted in the elimination of any respondents who endorsed 0 hours of CAM treatment per week. Although these transformations increased normality, eliminating these respondents limited interpretation and was thus not an option. Thus, a cuberoot transformation was applied, which allowed inclusion of the respondents who endorsed 0 hours but also allowed the data to approach normality. Based on plots of residuals, the independent variables collectively appear to be

linearly related to the transformed dependent variable (i.e., Hours CAM), and each independent variable (i.e., Child Age, ASD-DC Total, Respondent Income, Respondent Education) appeared to be linearly related to the transformed dependent variable (i.e., Hours CAM). Additionally, the plot of residuals suggested they are evenly spread over predicted values of the dependent variable, thus the assumption of homoscedasticity was not violated. None of the independent variables were strongly correlated with each other; the greatest correlation between independent variables was between respondent education and respondent income, with a correlation of  $r=.642$ , which is less than the suggested problematic correlation of  $r=.7$  (Dewberry, 2004); Laerd Statistics, 2015). Additionally, collinearity statistics suggested no presence of problems with multicollinearity (i.e., all Tolerance statistics were greater than .1). There were no problematic outliers, leverage points, or highly influential points.

Hours of EBP was plotted to check visually for normality. This variable was significantly positively skewed, with a significant number of responses of 0 hours per week of EBP treatment (see Figure 3). A squareroot transformation was tested and did not increase normality substantially. Several other transformations (i.e., log10, natural log, inverse) resulted in the elimination of any respondents who endorsed 0 hours of EBP treatment per week. Although these transformations increased normality, eliminating these respondents limited interpretation and was thus not an option. Thus, a cuberoot transformation was applied, which allowed inclusion of the respondents who endorsed 0 hours but also allowed the data to approach normality. Based on plots of residuals, the independent variables collectively appear to be linearly related to the transformed dependent variable (i.e., Hours EBP), and each independent variable (i.e., Child Age, ASD-DC Total, Respondent Income, Respondent Education) appeared to be linearly related to the transformed dependent variable (i.e., Hours EBP). Additionally, the

plot of residuals suggested they are evenly spread over predicted values of the dependent variable, thus the assumption of homoscedasticity was not violated. None of the independent variables were strongly correlated with each other (i.e., greatest correlation between independent variables was between respondent education and respondent income, with a correlation of  $r=.642$ , which is less than the suggested problematic correlation of  $r=.7$  (Dewberry, 2004); Laerd Statistics, 2015). Additionally, collinearity statistics suggested no presence of problems with multicollinearity (i.e., all Tolerance statistics were greater than .1). There were no problematic outliers, leverage points, or highly influential points.

A multiple regression was run to predict hours per week of CAM intervention from child age, child symptom severity of autism (as measured by total score on ASD-DC), respondent income, and respondent education. Child age, child symptom severity of autism, respondent income, and respondent education statistically significantly predicted hours per week of CAM,  $F(4,45)=3.40$ ,  $p < .05$ ,  $\text{adj. } R^2 = .16$ . This result indicates that the model accounts for statistically significantly more variance in the outcome variable (i.e., Hours CAM) than would be expected by chance. Based on the adjusted  $R^2$ , the model accounts for 16% of variance. Only one variable, respondent education, added statistically significantly to the prediction,  $p < .05$ . This result indicates that only respondent education is related to Hours CAM after controlling for all of the other predictors in the model, whereas child age, child severity of autism, and respondent income did not contribute significantly to the model. As seen in Table 9, respondent education had a significant negative regression coefficient ( $b = -.32$ ), indicating respondents with higher levels of education had fewer Hours CAM (cuberoot transformed) after controlling for the other variables in the model.

Table 9. Regression Results for Hours CAM

Variable	Mean <sup>^</sup>	SD <sup>^</sup>	Correlation with Hours CAM	Multiple Regression Weights	
				b	β
Hours CAM	8.7	14.36			
Child Age (mo)	99.24	42.31	-0.165	-0.006	-0.233
Child Severity of ASD	92.38	15.21	0.194	0.015	0.216
Respondent Income	5.02	1.85	-0.199	0.115	0.208
Respondent Education	5.20	1.67	-0.374**	-0.317**	-0.516

<sup>^</sup>untransformed values

\*  $p < .05$  \*\*  $p < .01$  \*\*\*  $p < .001$

A multiple regression was run to predict hours per week of EBP intervention from child age, child symptom severity of autism (as measured by total score on ASD-DC), respondent income, and respondent education. Child age, child symptom severity of autism, respondent income, and respondent education statistically significantly predict hours per week of EBP,  $F(4,45)=2.62$ ,  $p < .05$ , adj.  $R^2 = .12$ . This result indicates that the model accounts for statistically significantly more variance in the outcome variable (i.e., Hours EBP) than would be expected by chance. Based on the adjusted  $R^2$ , the model accounts for 12% of variance. Only one variable, child symptom severity of ASD (as measured by total score on ASD-DC), added statistically significantly to the prediction,  $p < .05$ . This result indicates that only child symptom severity of ASD was related to Hours EBP after controlling for all of the other predictors in the model, whereas child age, respondent income, and respondent education did not contribute significantly to the model. As seen in Table 10, child symptom severity of ASD had a significant positive regression coefficient ( $b = .024$ ), indicating respondents with higher scores on the ASD-DC endorsed more Hours EBP (cuberoot transformed) after controlling for the other variables in the model.

Table 10. Regression Results for Hours EBP

Variable	Mean <sup>^</sup>	SD <sup>^</sup>	Correlation with Hours EBP	Multiple Regression Weights	
				b	$\beta$
Hours EBP	23.24	24.82			
Child Age (mo)	99.24	42.31	-0.194	-0.004	-0.133
Child Severity of ASD	92.38	15.21	0.340**	0.024*	0.313
Respondent Income	5.02	1.85	-.241	-0.161	-0.254
Respondent Education	5.20	1.67	-.040*	0.084	0.119

<sup>^</sup>untransformed values

\* p <.05 \*\* p<.01 \*\*\* p <.001

## Discussion

The sample was fairly homogenous in terms of respondent demographics, particularly for ethnicity (Caucasian) and gender (female). Many of the respondents indicated they had a college or graduate degree, and the greatest percentage of respondents indicated they had an annual household income between \$70k and \$100k. Further, the majority of the sample indicated they were married. Thus, the survey respondents can primarily be characterized as well-educated, middle to upper-middle class, married, Caucasian, and female. Discussion of the limitation in diversity of the sample is discussed following (Limitations section, pg. 76).

For the child characteristics, again the majority was Caucasian, but they were primarily male (82%). This finding was expected given the majority of individuals with ASD are male (i.e., approximately 4 to 1 male to female ratio; Fombonne, 2002). Mean age at the time of respondent survey completion was 8.8 years, whereas mean age at diagnosis was 4.1 years, and mean age at treatment initiation was 3.7 years. The finding that age at treatment initiation was earlier than age at diagnosis is somewhat surprising but may be accounted for by initiation of early intervention services (e.g., Speech Therapy, Occupational Therapy, Physical Therapy) for developmental delay (e.g., language delay, motor delay) before recognition of ASD symptoms and/or official diagnosis of ASD.

In terms of comorbid problems, the most endorsed problem was sleep problems (54%), which is consistent with ranges of 40 to 80% suggested in previous research (Cortesi, Giannotti, Ivanenko, & Johnson, 2010). SIB and physical aggression were the next highest endorsed (24% and 22%, respectively). These rates were relatively low compared to previous research findings that suggest that up to 94% of children with ASD exhibit at least one challenging behavior (Matson, Wilkins, & Macken, 2008; Jang, Dixon, Tarbox, &

Granpeesheh, 2011). In this sample, only 16% of respondents indicated that their child with ASD had comorbid ID. Previous research suggests substantially higher rates, 50 to 70% according to a review on the topic (Matson & Shoemaker, 2009). Least endorsed among this sample was comorbid epilepsy/seizure disorder (6%). According to a review on the comorbidity of ASD and epilepsy, the present rate falls into the range of estimated prevalence from 5 to 38% (Tuchman & Rapin, 2002). Thus, rates of sleep problems and epilepsy were within previously reported ranges, but rates of challenging behavior and ID are significantly lower. One proposed explanation could be that the sample is less severe than average in terms of ASD symptomatology, which could potentially account for lower levels of challenging behavior and comorbid ID. However, ratings on the ASD-DC for this sample suggest that this was not the case, with even the lowest total score among the sample falling within the “Autistic Disorder” range (Matson & González, 2007). These statistics add to the research on the prevalence of these topics and may be used in future analyses, discussed following.

## Q1

Based on extant research regarding treatment selections, the author predicted that behavioral interventions would be endorsed by about half of caregivers. For the current study, this would encompass EBP Groups 1 and 2 (i.e., EIBI, ABA, Modeling, PRT, Natural Teaching Strategies). Of the respondents who met inclusion criteria for this section of analyses (N=63), 18.6% endorsed current use of Group 1 (i.e., EIBI), and 57.6% endorsed current use of Group 2. The latter result is fairly consistent with extant research suggesting behavioral intervention use among 40 to 50% of samples of children and adolescents with ASD (Green et al., 2006).

Further, the author anticipated that the majority of caregivers would report using numerous treatments, both empirically based and not, simultaneously. This pattern was evident



given the high percentages of endorsements of treatments but could not be quantified specifically due to the need to group interventions. Further information regarding this hypothesis is provided in the treatment hours discussion.

As noted, EBP Group 4, which included Language Training (Production) and Speech Therapy, was the most highly endorsed. High rates of these types of intervention were expected given availability of Speech Therapy through early intervention programs and subsequently through school districts. Further, high rates of endorsement for EBP Groups 5 (i.e., Parent Training, Peer Training Package, Self-Management Training, Schedules) and 6 (i.e., Scripting, Social Skills Package, Story-Based Intervention) are not surprising given that interventions such as Schedules and Story-Based Intervention (e.g., Social Stories) can easily be implemented at home by caregivers or at school by teachers with simple and/or one-time training from a professional (e.g., therapist, psychologist). The least endorsed EBP Groups were Groups 1 (i.e., EIBI) and 3 (i.e., Cognitive Behavioral Intervention, CBT). Lower rates of EIBI may have been due to child ages; the mean age for the sample was 8.8 years, which is above the target age for EIBI (Dawson, 2008). The lower endorsement for CBT interventions may be because this intervention is less widely known despite being considered EBP for ASD, there are fewer quality practitioners, and/or this is most relevant for individuals with comorbid mood or anxiety problems (Wood et al., 2009).

In terms of CAM Groups, the most highly endorsed was Group 5, which included Occupational Therapy and Physical Therapy. Much like Speech Therapy, these are treatment options that are commonly provided in early intervention programs and subsequently by public school districts. Thus, they are much more easily obtained than other treatment options. The next most highly endorsed of CAM treatments were Group 1 (44.8%), Group 3 (35.6%),

and Group 2 (28.8%). Group 1 included a number of communication systems that may be used in other types of therapy (e.g., Alternative Communication Devices, PECS, Sign Instruction), including incorporation within EBP (e.g., use of picture exchange within an ABA center).

Group 3 included Vitamins/Supplements, Special/Restricted Diets, and Oxytocin.

Unfortunately, there is much misleading information being spread about special or restricted diets in particular, including at autism conferences for parents, in books, on websites, and in online support groups (Christison & Ivany, 2006). The abundance of misleading or simply incorrect information available likely drives the popularity of this particular option. Group 2 included several mind-body practices (e.g., Exercise, Massage Therapy), which may prove to be reinforcing and/or beneficial in other ways, have ultimately not been found to have any effect on decreasing symptoms of ASD. The mind-body practices likely take little effort and cost to implement, making them an attractive option.

Group 4, which encompassed harmful treatments including Chelation, HBOT, and Packing, was not endorsed as in current use by any respondents. Lack of current use among this sample was surprising given other reported rates of use of potentially harmful treatments between 2 and 9% (Green et al., 2006; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Salomone, Charman, McConachie, & Warreyn, 2015). Of note, reported rates by these studies were observed to decrease over time, with the lowest endorsements in the most recent study. The current findings follow the same pattern as more recent studies, such as Salomone et al. (2015), which suggests that there is minimal current use of these potentially harmful treatments.

Although many respondents endorsed current use of CAM treatments other than Group 4, they are not currently using treatments that have been found to be dangerous or potentially

harmful in some way. Should psychologists or other healthcare providers discourage parents from CAM use if it is not potentially harmful? Some researchers argue that unsupported treatments should be tolerated but with close monitoring of results (Akins, Angkustsiri, & Hansen, 2010). In contrast, the author suggests that use of CAM treatments that are not dangerous may still be problematic in that they siphon off resources, particularly in terms of finances and time, from EBP that is more likely to benefit the child or adolescent with ASD. In clinical practice, caregivers may or may not be open to receiving information or suggestions regarding other treatments their children are receiving. If good rapport and a level of trust are established between the clinician and the family, encouraging families to devote resources to EBP rather than CAM treatments could be helpful. In these cases, the clinician must be committed to remaining current on the research on this topic to provide the most up-to-date information to families.

## Q2

In the present study, the survey inquired more specifically than previous research about types of professionals that may be providing information to caregivers regarding treatment choices: doctor, psychologist, teacher, therapist (specified by type, including occupational, physical, speech, ABA), etc. The author predicted that medical professionals, websites/online searches, and other caregivers of individuals with ASD would be among the most endorsed sources of information. As predicted, the top three most endorsed sources of information were websites, other caregivers of children with ASD, and doctors. Following closely behind doctors were Internet groups (52.5%), ABA therapists (50.8%), OT therapists (49.2%), and books (45.8%). Psychologists ranked ninth out of 16 options, endorsed by 23.7% of respondents as a source of information. Given the previous discussion of misleading

information available online (both within websites falsely claiming to be evidence-based and within online social media groups), the finding that almost 80% of respondents use websites raises concern.

Although there are websites that have information on EBP, these are not the vast majority, and content on EBP may be interspersed with that on CAM, making information-gathering even more difficult. The authors did not request that the respondents specify websites or online groups, although this may be helpful in the future to pinpoint misleading or reliable sources on the Internet. However, the ability to change poor sources of information is minimal. Thus, given the wide usage of the Internet as a source of information for parents navigating ASD treatment selection, there is a need for a reliable, evidence-based, up-to-date online source that can be easily comprehended by non-professionals. Should such a resource exist, a nationwide effort could be made to have healthcare providers, teachers, and other in-person sources of information distribute the resource website address to the caregivers of children recently diagnosed with ASD.

In terms of most trusted source, as discussed previously, 59 respondents answered this question, but 30 chose a single most trusted source. Both samples were represented in tables (Table 7 and Table 8). Among the larger group, of whom 29 selected more than one most trusted source, caregiver of ASD was the most common endorsement, followed by doctor and ABA therapist. Among the smaller group, caregiver of ASD remained the most common endorsement, followed by ABA therapist, and support group and OT therapist (10% each). Further, when the sources were divided between healthcare provider and non-healthcare provider sources, results indicated that more than half of respondents selected a non-healthcare provider as their most trusted source (56.7%). Most of these selections (40%) were sources

that were composed of caregivers of children with ASD (i.e., caregivers themselves, support groups, online groups).

Why would respondents choose another caregiver of a child or adolescent with ASD as their most trusted source of information regarding treatment selection? Goin-Kochel, Myers, and Mackintosh (2007) have suggested that caregivers ask other parents of children with ASD because they have experienced a similar journey of selecting and implementing treatments for ASD. However, an additional facet to consider, discussed in depth in Chivers, Yochim, and Silva (2013), is the subgroup of caregivers who mistrust professionals and experts, then spread their rhetoric and conspiracy theories through easily accessible channels online. These researchers discuss how there is a movement in the autism field, in part attributable to Jenny McCarthy, of caregivers who argue that their voices have been ignored by “big business.” Such caregivers may posit conspiracy theories about causes of autism and talk about their mistrust of the “evidence” provided by government health agencies. Members of this subgroup may argue that they will not take advice, even from professionals, that is in opposition to their parental intuition. Thus, such individuals primarily gather information from other caregivers, spreading misinformation exponentially on blogs, on social media, and in online support groups.

Although having a group with whom to share this journey is useful for emotional support, caregivers should be cautioned that information gathered through such avenues represents varying opinions and reference to empirical evidence. Further, given the heterogeneous nature of presentation of ASD, what works anecdotally for one child with ASD is not necessarily going to prove successful for another. Thus, healthcare providers who have knowledge of the empirical bases of supported treatments, which have proven effective for

large samples of children, can guide the family to options that have evidence to support their use among individuals with ASD.

### Q3

As noted in the Results section, many respondents endorsed relatively low levels of current treatment use. The data indicating what percentage of the sample received fewer than 10 hours of treatment per week in each category was included to help illustrate this pattern. The use of 10 hours was an arbitrary number and is not intended to indicate the importance of 10 hours (or any certain number of hours) as an ideal treatment dose. The endorsement of fewer than 10 hours of CAM by slightly more than 3/4 of the sample can be perceived as a positive trend. However, the endorsement of fewer than 10 hours of EBP by slightly more than 1/3 of the sample is somewhat worrisome because studies delivering low-intensity behavioral interventions have not resulted in the substantial gains that more intensive behavioral options have (Weitlauf et al., 2014). For instance, in their study of children receiving either behavioral treatment or eclectic treatment for an average of 12 hours per week, Eldevik, Eikeseth, Jahr, and Smith (2006) found that the behavioral treatment group made only modestly greater gains that may not have been clinically significant. Thus, it may be valid to argue that these low levels of EBP endorsed by respondents may not be significantly more beneficial than similar amounts of certain emerging treatments. As a result, psychoeducation regarding treatment should include discussion about intensity. Unfortunately, there are likely additional barriers to receiving this more intensive EBP treatment beyond what caregivers typically face acquiring intervention services.

The author hypothesized that there would be differences in CAM and EBP use based on most trusted source of information. Sources were divided into healthcare providers and non-healthcare providers, with the specific hypothesis that those respondents who endorsed a

healthcare provider as their most trusted source would endorse greater hours of EBP interventions and fewer hours of CAM interventions than their counterparts who endorsed a non-healthcare provider as their most trusted source. Caregivers who endorsed non-healthcare providers, such as the Internet or other individuals caring for persons with ASD, as their main sources of information were predicted to endorse higher levels of CAM due to the prevalence of misleading and incorrect information present among these sources.

Due to a small sample size (N=30), the author was unable to analyze this relationship with confidence. The under-powered independent-sample t-tests that were run indicated there was not a significant difference between groups in terms of mean CAM Hours or EBP Hours. However, examining the means on their own reveals interesting patterns that may have reached significance if the sample size had been larger. Contrary to the author's hypothesis, mean CAM Hours was actually greater for the healthcare provider source group (mean = 7.85 hours) than the non-healthcare provider source group (mean = 7.0 hours), with a small effect size. As expected, EBP Hours were greater for the healthcare provider source group (mean = 28.54 hours) than the non-healthcare provider source group (mean = 20.53), with a small to medium effect size.

Despite the lack of valid statistical analyses, the finding that CAM Hours endorsed by the healthcare provider source group were even marginally greater than the non-healthcare provider source group is somewhat surprising. Perhaps having a healthcare provider as a most trusted information source makes treatment-seeking in general, whether CAM or EBP, more likely. Those respondents who felt comfortable seeking information from a healthcare provider may also feel more comfortable with the process of obtaining intervention for their child (i.e., navigating a healthcare system), whether the treatment is evidence-based or not.

Health professionals presumably encourage consideration of research, but depth of knowledge of current empirical support may vary by field. For instance, Miller, Schreck, Mulick, and Butter (2012) found that psychologists and behavior analysts were more likely to recommend EBP than were medical or allied health professionals. Although healthcare providers (e.g., pediatricians) may have years of training and expertise, they still may not be providing to families the most accurate or up to date information regarding interventions for ASD. Healthcare providers who work primarily with persons with ASD, engage in research, and/or attend professional conferences or other learning events may better maintain an updated knowledge base regarding most recent evidence. Thus, these professionals are more likely to provide accurate information that would lead to engagement in EBP.

Further, the grouping of sources into healthcare providers and non-healthcare providers may have been problematic in that some of the healthcare providers are those that provide treatment that are evidence based but not for ASD (i.e., OT and PT therapists). Thus, although these providers could be more scientifically-minded due to their training experience and the nature of their profession, they may encourage use of their services by persons with ASD. Encouraging use of their services would not be problematic so long as these therapists conceptualize their services as not treating ASD symptoms but rather as treating persons with ASD who have co-occurring deficits (e.g., motor) that the therapists can target given their expertise. If the sample size had been greater, analyses may have permitted further separation of information sources, which may have revealed more meaningful findings.

Regarding the regression analyses, the author hypothesized that each of the predictors (child age, child symptom severity of ASD, respondent education, respondent income) would contribute significantly to the models. Although this analysis was exploratory in nature due to a



lack of research on comparisons of these specific predictors, the author had hypotheses for individual predictors that were added to the model. The author suspected that higher respondent education and income would predict higher EBP Hours and lower CAM Hours. The author's theory was that caregivers with higher levels of education may be more likely to consult scientific evidence and base intervention decisions in part on empirical support, resulting in greater endorsement of EBP. Further, the author suspected that caregivers with higher incomes may have fewer financial barriers to obtaining treatment of any type and may have better insurance coverage of supported interventions.

Additionally, the author predicted that child symptom severity of ASD would predict higher CAM Hours and that greater child age would predict fewer EBP Hours and CAM Hours due to greater medication use as a main intervention. Research on child characteristics that influence treatment choice has indicated that age and "severity" of autism diagnosis significantly influence number and type of interventions used in the past and currently in use. Specifically, more "severe" autism diagnosis (e.g., PDD-NOS versus Autistic Disorder) has been associated with greater CAM use. Further, research has suggested that medication use increases as persons with ASD age for a variety of reasons, including exhaustion of non-pharmaceutical options and shifting treatment needs.

In the first regression analysis, CAM Hours was the outcome variable. Results showed the model with predictors of child age, child severity of ASD (based on ASD-DC total score), respondent income, and respondent education statistically significantly predicted CAM Hours, although the model accounted for only 16% of variance. More notable was the result that only respondent education contributed to the model in a statistically significant way.

As predicted, higher respondent education predicted lower CAM hours, as evinced by the negative regression coefficient. However, there was no significant contribution by respondent income as was hypothesized, despite these variables being related ( $r=.642$ ). This pattern of findings indicates that, when education is controlled within the model, income does not influence engagement in CAM treatments. The interpretation of these findings suggests that educated caregivers are less likely to use CAM treatments regardless of whether they have the resources. Why might this be the case? The author proposes that there may be various explanations: more highly educated individuals may be more likely to understand the importance of scientific inquiry and of an empirical basis for intervention use; such individuals may be more easily able to distinguish between valid and misleading information (e.g., on websites); and such individuals may have better knowledge of how and where to locate and implement evidence-based interventions, making use of EBP more likely than use of CAM.

Pickard and Ingersoll (2015) reported that lower SES parents more frequently endorsed the need for information regarding services, their benefit, and insurance coverage than did higher SES parents. Further, the authors indicated that higher parent SES was associated with greater overall intervention use, mediated by knowledge of treatment options. Current results and those reported by Pickard and Ingersoll (2015) raise the question, could psychoeducation about the importance of research and its application in the field of ASD intervention alone be sufficient in decreasing use of non-evidence-based practice? Or is more general education and greater number of years of advanced schooling necessary? If there were a way to parse this apart in future studies, researchers could determine whether a psychoeducation intervention targeted at caregivers of children, implemented at first diagnosis of ASD, would be effective in reducing the use of dangerous treatments and/or treatments without evidence of benefit.

Further, the results indicated that child symptom severity of ASD did not significantly predict Hours CAM, which was predicted based on extant research suggesting this relationship (Christon, Mackintosh, & Myers, 2010; Hanson et al., 2007; Perrin et al., 2012). However, these studies used diagnosis as a proxy for severity. In contrast, when Siller, Reyes, Hotez, Hutman, and Sigman (2013) used ADOS scales as a measure of symptom severity of ASD, this measure did not predict intervention group. The relationship between ASD severity and use of CAM remains unclear, with the present study suggesting symptom severity does not have strong predictive power of use of CAM. Notably, this finding is consistent with the other study that used a validated measure of ASD severity rather than caregiver-reported diagnoses. This precision may be key in the difference in findings amongst studies of this relationship. Future examination of this relationship is needed and is likely to be more meaningful using a quantitative measure of severity, preferably based on both caregiver report and behavioral observations.

In the second regression analysis, EBP Hours was the outcome variable. Results showed the model with predictors of child age, child symptom severity of ASD (based on ASD-DC total score), respondent income, and respondent education statistically significantly predicted EBP Hours, although the model accounted for only 12% of variance. Although there was a significant negative correlation between Hours EBP and respondent education, respondent education did not significantly contribute to prediction of Hours EBP when the other predictors were controlled for in the regression model. Rather, only child symptom severity of ASD contributed to the model in a statistically significant way. A positive regression coefficient indicated that as caregiver-reported symptoms increased, EBP Hours increased.

Arguably the most meaningful finding within the regression analyses was that significant predictors differed between CAM Hours and EBP Hours. The author suspected that education would predict less CAM use but more EBP use. The finding that respondent education predicted CAM Hours but not EBP Hours suggests that more highly educated respondents endorsed fewer hours of CAM, but did not endorse more hours of EBP. The author proposes that perhaps there is a ceiling effect in terms of EBP hours available. Certain CAM treatments may require no or less training than EBP treatments to provide to families, making them more widely available. In contrast, extant research suggests that lack of providers is a major barrier for families seeking interventions for ASD. For instance, Pickard and Ingersoll (2015) reported that 15% of parents in their sample indicated waitlists as a major barrier.

Additionally, why would child symptom severity of ASD only predict EBP Hours and not CAM Hours? One possibility could be that as ASD severity increases, insurance companies approve higher levels of EBP intervention provision. That is, a child with greater language impairment or with challenging behavior, both of which would be rated higher on the ASD-DC, may receive greater insurance coverage of EBP treatments (e.g., Speech Therapy, ABA). As lack of financial resources is frequently a barrier to children with ASD receiving treatment (Pickard & Ingersoll, 2015), insurance approval of EBP treatments is likely to increase access these services and thus increase endorsement. Further, despite ASD severity, insurance providers may be more hesitant to approve coverage of CAM treatments, increasing the likelihood these interventions be paid out of pocket.

Given these regression models contributed to relatively small amounts of variance in CAM and EBP treatment hours (16% and 12%, respectively), what other factors beyond the predictors included could be contributing to these decisions? Because of small sample sizes, the

current study could not determine if source of information contributes to choice of CAM versus EBP, but extant research suggests it may (Deyro, Simon, & Guay, 2014; Miller et al., 2012). Another potential predictor could be comorbid problems and behaviors, particularly given the finding that CAM treatments are used for core symptoms of ASD as well as comorbid problems (Wong & Smith, 2006). Further analyses can be conducted to determine if problems such as ID, SIB, or physical aggression reported in the survey influence CAM Hours or EBP Hours when added to the model with the current predictors. Additionally, information regarding barriers to treatment was collected in the survey but is not included in the current study; however, barriers such as availability of providers, transportation to treatment, insurance coverage, etc. could all influence CAM Hours or EBP Hours. Based on results regarding these variables, such potential predictors could be entered into a larger model, given additional survey data is collected.

### **Limitations**

The current survey had several limitations that would need to be remedied should the survey be administered again in the future. An online survey was selected for this study. The primary way the research project was advertised (i.e., social networks, email) and the way the survey was delivered inherently biases against respondents without reliable or consistent Internet access. This sampling bias could potentially be eliminated in the future by providing the survey in written form via mail-outs or in written form or via tablet or computer in health provider offices that serve more diverse populations (e.g., pediatrician offices that accept private insurance and Medicaid). Further, respondents “self-selected,” which likely means the respondents were highly motivated to participate in scientific research. Such individuals may be more highly educated or have better understanding of empirical evidence, which could bias the results.

Nonetheless, online surveys have numerous advantages, including access to a large population, feasibility, lack of time constraints (i.e., 24 hour access), and completely voluntary participation (Riva, Teruzzi, & Anolli, 2003). Fortunately, researchers suggest good equivalence between online surveys and paper-and-pencil surveys (Riva et al., 2003; Weigold, Weigold, & Russell, 2013). Nonetheless, survey questions could have been misinterpreted, such as the question about hours spent on CAM Group 3. Caregiver interviews would certainly be preferable over online or paper-and-pencil surveys for numerous reasons, primarily in terms of preventing problematic misinterpretation of questions. A research coordinator serving as an interviewer could clarify any confusion during administration and provide consistent definitions of treatments as needed. Such a project would likely require additional resources that were not available when the survey was created.

Additionally, burden of time and lack of availability of any incentive may have prevented caregivers from beginning or completing the survey. There is a strong likelihood that this influenced the respondent demographics in that people who value research and who have more time to engage in research activities likely participated. The survey had a high drop-out rate (60% completed), which was likely due to the length of the survey and lack of incentive for completion. Researchers have suggested that, in studies of university students, 10% drop out of online surveys instantaneously, with 2% additional dropout per 100 survey items (Hoerger, 2010). Comparing these percentages, there was significantly greater dropout in the current study than has been reported in extant research. However, the Hoerger (2010) surveys consisted of simple questions on easy topics (e.g., personality, mood), whereas the current study likely involved greater participant burden to complete. Of the 126 respondents who completed consent, 102 answered the first question (81%). As noted previously, there

was another significant dropout point at the first survey question that was about the child; only 87 respondents answered the question about child age. Surprisingly, few respondents ceased answering questions when presented with the ASD-DC questions or the current treatment questions, which were time-consuming and potentially more burdensome than demographic questions and simple endorsements. Finally, a last significant dropout point was between the question regarding if there were any treatments the respondent wished the child received (75 respondents) and the question addressing the barriers to obtaining these treatments (53 respondents), despite the option of “I just have not gotten around to it yet, no real barriers.”

Providing a small monetary reward may have enhanced motivation to begin and complete the survey. One drawback of providing a reward is the likelihood of duplicate responses; as such, IP addresses would need to be collected to prohibit respondents from completing the survey multiple times in order to receive the reward. Collection of IP addresses was not conducted during the current survey, and doing so would limit anonymity of respondents.

### **Future Directions**

Despite these limitations, the survey provided preliminary data that suggests future research on these topics is worthwhile. Source of information and its ability to predict CAM versus EBP use needs further examination. Should information from certain individuals or groups be more predictive of unsupported treatment use, these sources could be targeted for further education. Caregivers who seek information from other caregivers of children with ASD may be doing so because they do not perceive themselves as having better sources. In this case, the author would not suggest the caregivers discontinue communication with other caregivers, as the emotional support and sense of belonging in such a group is important. Instead, the

caregivers could be educated about the myriad sources of misinformation regarding treatments and be directed to more reliable sources. Professionals assigning the initial ASD diagnosis or those who provide ongoing services and have established rapport could facilitate this discussion.

Further studies are needed to confirm that caregiver education is inversely related to CAM use. Should this finding continue to be replicated, there may be various manners in which to intervene. The author would prioritize the establishment of a comprehensive online resource that provides evidence on ASD treatments and potential negative outcomes of CAM treatments in an easily navigable and comprehended manner. Such a resource does not seem to be available at this time. For instance, the CDC website offers information about treatment classified as “Behavior and Communication Approaches,” “Dietary Approaches,” “Medication,” and “Complementary and Alternative Medicine.” As a government agency, the CDC presumably would be a relatively reliable and trustworthy source, yet it groups together EBP (e.g., ABA) with unsupported treatments (e.g., Floortime, Sensory Integration Therapy). Notably, the CDC’s examples of CAM include special diets, chelation, secretin, and deep pressure but do not mention that some of the treatments listed within the “Behavior and Communication Approaches” category are not supported treatments for ASD at this time. An ideal website would discuss the importance of scientific research and empirical evidence, provide categories of evidence base like the National Standards Project, and facilitate acquisition of empirically supported interventions (e.g., listing of service providers and their contact information, perhaps sorted by zip code). As noted, all of this information would need to be presented in an easily navigable format with a low reading level.



Additionally, the resources available on this website could be provided within a support group setting. A pilot program could be initiated that provides weekly meetings for caregivers of newly diagnosed children with ASD. Program coordinators, ideally psychologists in the field of developmental disabilities, could meet with a small group of caregivers to provide psychoeducation about the diagnosis, level of support that may be needed, realistic expectations in terms of prognosis, evidence for treatments, etc., as well as field the numerous questions caregivers have in the first few months after initial diagnosis. The program coordinator could work closely with a care coordinator, perhaps a social worker with good awareness of treatment options available locally, to help families obtain the EBP services recommended by the psychologist. Such a program could be potentially valuable for caregivers with less advanced education who need more hands-on assistance in selecting and acquiring EBP treatment. Success of such pilot programs could be measured in terms of EBP Hours, ASD treatment outcomes (e.g., social gains, decreases in challenging behavior), and parental stress and acceptance. Should the programs prove successful, the psychologists working on the project could standardize the program to allow psychologists to provide such groups throughout the country.

These two potential program ideas could certainly intervene against the barrier of lack of education or information that some caregivers face. However, further work needs to determine other predictors of CAM versus EBP use. Obviously there is a confluence of factors that affect treatment selection, and targeting each of these variables will be important to best assist families in choosing interventions that are most likely to result in improved outcomes for ASD.

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## Appendix 1. IRB Exemption Approval



### ACTION ON EXEMPTION APPROVAL REQUEST

**TO:** Lindsey Williams  
Psychology

**FROM:** Dennis Landin  
Chair, Institutional Review Board

**DATE:** January 8, 2016

**RE:** IRB# E9711

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

Institutional Review Board  
Dr. Dennis Landin, Chair  
130 David Boyd Hall  
Baton Rouge, LA 70803  
P: 225.578.8692  
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**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 2. Survey

### Treatments for Autism

**CONSENT TO PARTICIPATE:** Thank you for your interest in the Autism Spectrum Disorders Caregiver Survey of Experiences, Interventions, and Resource Availability. The experience of getting an Autism Spectrum Disorder (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 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 20-30 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 (contact any of the investigators via email, below). 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. 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](mailto:lwil175@lsu.edu), Hilary Adams at [hadam15@lsu.edu](mailto:hadam15@lsu.edu), or Dr. Johnny Matson at [psmats@lsu.edu](mailto:psmats@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 Dennis Landin, PhD, Chairman, Institutional Review Board, (225) 578-8692, [irb@lsu.edu](mailto:irb@lsu.edu), or via [www.lsu.edu/irb](http://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.

Please select one option below.

I AGREE (1)

I DISAGREE (2)

If I DISAGREE Is Selected, Then Skip To End of Survey

Autism Spectrum Disorder Caregiver Survey of Experiences, Interventions, and Resource Availability  
By Hilary Adams, MA and Lindsey Williams, MA

Q1 How did you learn about this survey?

Q2 What is your relationship to the individual with Autism Spectrum Disorder (ASD)?

- Biological mother (1)
- Biological father (2)
- Adoptive mother (3)
- Adoptive father (4)
- Other (Please type below.) (5) \_\_\_\_\_

Q3 What is your ethnicity?

- Caucasian (1)
- Latino (2)
- Middle Eastern (3)
- African American (4)
- Caribbean (5)
- South Asian (6)
- East Asian (7)
- Combination (Please type below.) (8) \_\_\_\_\_
- Other (Please type below.) (9) \_\_\_\_\_
- Prefer not to answer (10)

Q4 What is your gender?

- Identify as male (1)
- Identify as female (2)
- Prefer not to answer (3)

Q5 What is the highest level of education you have completed?

- Some high school (1)
- High school graduate (2)
- Technical, associate, or professional degree (3)
- Some college (4)
- College graduate (5)
- Some graduate school (6)
- Graduate degree (e.g., Masters or above) (7)
- Prefer not to answer (8)

Q6 What is your annual household income (US \$)?

- Less than 10,000 (1)
- 10k-25k (2)
- 25k-40k (3)
- 40k-55k (4)
- 55k-70k (5)
- 70k-100k (6)
- More than 100k (7)
- Prefer not to answer (8)

Q7 What is your current marital status?

- Single, never married (1)
- Married or in long-term relationship (2)
- Separated or divorced (3)
- Widowed (4)
- Other (Please type below.) (5) \_\_\_\_\_
- Prefer not to answer (6)

Q8 What state do you live in currently?

- Alabama (1)
- Alaska (2)
- Arizona (3)
- Arkansas (4)
- California (5)
- Colorado (6)
- Connecticut (7)
- Delaware (8)
- Florida (9)
- Georgia (10)
- Hawaii (11)
- Idaho (12)
- Illinois (13)
- Indiana (14)
- Iowa (15)
- Kansas (16)
- Kentucky (17)
- Louisiana (18)
- Maine (19)
- Maryland (20)
- Massachusetts (21)
- Michigan (22)
- Minnesota (23)
- Mississippi (24)
- Missouri (25)
- Montana (26)
- Nebraska (27)



- Nevada (28)
- New Hampshire (29)
- New Jersey (30)
- New Mexico (31)
- New York (32)
- North Carolina (33)
- North Dakota (34)
- Ohio (35)
- Oklahoma (36)
- Oregon (37)
- Pennsylvania (38)
- Rhode Island (39)
- South Carolina (40)
- South Dakota (41)
- Tennessee (42)
- Texas (43)
- Utah (44)
- Vermont (45)
- Virginia (46)
- Washington (47)
- West Virginia (48)
- Wisconsin (49)
- Wyoming (50)

Q10 How would you describe the city/town where you currently live?

- Urban (50,000+ people) (1)
- Suburban (2,500 to 49,000 people) (2)
- Rural (less than 2,500 people) (3)

Q37 How old is your child? (e.g., if your child turned 6 years old this month, put 6 years, 0 months; if your child turned 6 years old 2 months ago, put 6 years, 2 months)

Years (1)  
Months (2)

Q38 What is your child's ethnicity?

- Caucasian (1)
- Latino (2)
- Middle Eastern (3)
- African American (4)
- Caribbean (5)
- South Asian (6)
- East Asian (7)
- Combination (Please type below.) (8) \_\_\_\_\_
- Other (Please type below.) (9) \_\_\_\_\_
- Prefer not to answer (10)

Q39 What is your child's gender?

- Identify as male (1)
- Identify as female (2)
- Prefer not to answer (3)

Q40 What is your child's current autism diagnosis?

- Autistic Disorder (1)
- PDD-NOS (Pervasive Developmental Disorder, Not Otherwise Specified) (2)
- Asperger's Disorder/Syndrome (3)
- Autism Spectrum Disorder (4)
- Other (Please type below.) (5) \_\_\_\_\_
- Not sure (6)

Q41 How old was your child when s/he received the autism diagnosis you indicated above?

Years (1)

Months (2)

Q42 Which, if any, difficulties did you experience when you were trying to get a diagnosis? (Select all that apply.)

- Long wait list for assessment (longer than 1 month) (1)
- Transportation problems (too far to drive, no easy access to transportation, etc.) (2)
- Scheduling problems (hard to get time off work, hard to arrange childcare for other children, etc.) (3)
- Insurance would not cover assessment (4)
- Insurance would cover part of assessment but out of pocket cost still too high (5)
- Caregivers were unsure or disagreed with one another about whether to get assessment (6)
- Professionals said assessment was not needed (said there was no problem, said child would "grow out of it") (7)
- Other (Please type below.) (8) \_\_\_\_\_

Q43 How old was your child when s/he began receiving ANY treatment for the autism diagnosis you indicated above?

Years (1)

Months (2)

Q44 Is your child currently taking prescribed medication meant to address symptoms related to autism, mood/anxiety, or Attention-Deficit/Hyperactivity Disorder? (Select all that apply.)

- Yes, currently taking medication for autism symptoms. (Please type below.) (1)  
\_\_\_\_\_
- Yes, currently taking medication for mood or anxiety symptoms. (Please type below.) (2)  
\_\_\_\_\_
- Yes, currently taking medication for Attention-Deficit/Hyperactivity Disorder. (Please type below.) (3)  
(3) \_\_\_\_\_
- No, not currently taking medication for any of these reasons. (4)

Q45 My child... (Select all that apply.)

- Has received a diagnosis of Intellectual Disability (may be referred to as Mental Retardation in older reports) (1)
- Currently exhibits aggressive behavior toward other people (hitting, pinching, biting, etc.) (2)
- Currently exhibits self-injurious behavior (hurting self by head banging, biting self, etc.) (3)
- Has sleep problems on a regular basis (more nights than not; takes more than 30 minutes to go to sleep, wakes up frequently during the night, etc.) (4)
- Has received a diagnosis of seizure disorder or epilepsy (5)

Q80 Rate each item for the extent that it is or 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

Q81 1. Communication skills.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q83 2. Age appropriate self-help and adaptive skills (i.e., able to take care of self).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q84 3. Engages in repetitive motor movements for no reason (e.g., hand waving, body rocking, head banging, hand flapping).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q85 4. Verbal communication.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q86 5. Prefers foods of a certain texture or smell.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q87 6. Ability to recognize the emotions of others.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q88 7. Maintains eye contact.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q89 8. Social interactions with others his/her age.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q90 9. Response to others' social cues.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q91 10. Use of language in conversations with others.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q128 Rate each item for the extent that it is or was ever a problem. Compare the child to other children his/her age.

Q92 11. Shares enjoyment, interests, or achievement with others (e.g., parents, friends, caregivers).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q93 12. Ability to make and keep friends.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q94 13. Interest in participating in social games, sports, and activities.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q95 14. Interest in another person's side of the conversation (e.g., talks to people with intention of hearing what others have to say).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q96 15. Able to understand the subtle cues or gestures of others (e.g., sarcasm, crossing arms to show anger).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q97 16. Use of too few or too many social gestures.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q98 17. Body posture and/or gestures.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q99 18. Communicates effectively (e.g., using words, gestures or sign language).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q100 19. Displays a range of socially appropriate facial expressions.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q101 20. Restricted interests and activities.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q129 Rate each item for the extent that it is or was ever a problem. Compare the child to other children his/her age.

Q102 21. Eye-to-eye gaze.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q103 22. Reaction to sounds and sights.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q104 23. Walks or runs on toes/balls of feet (If unable to walk/run, rate "0").

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q105 24. Reads nonverbal cues (body language) of other people. (If blind, rate "0")

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q106 25. Expects others to know their thoughts, experiences, and opinions without communicating them (e.g., expects others to "read his/her mind").

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q107 26. Use of facial expressions.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q108 27. Saying words and phrases repetitively (If nonverbal, rate "0").

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q109 28. Make-believe or pretend play.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q110 29. Understanding of age appropriate jokes, figures of speech, or sayings.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q111 30. Gives subtle cues or gestures when communicating with others (e.g., hinting).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q130 Rate each item for the extent that it is or was ever a problem. Compare the child to other children his/her age.

Q115 31. Becomes upset if there is a change in routine.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q116 32. Needs reassurance, especially if events don't go as planned.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q117 33. Language development.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q118 34. Responds to others' distress.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q119 35. Socializes with other children.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q120 36. Use of nonverbal communication.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q121 37. Limited number of interests.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q122 38. Development of social relationships.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)



Q123 39. Isolates self (i.e., wants to be by him/her self).

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q124 40. Participation in games or other social activities.

- 0 = Not different; no impairment (1)
- 1 = Somewhat different; mild impairment (2)
- 2 = Very different; severe impairment (3)

Q71 What type of insurance coverage does your child have?

- Private insurance only (such as through a caregiver's employer) (1)
- Medicaid or other public insurance (2)
- Both private insurance and Medicaid / public insurance (3)
- None (4)
- Not sure or prefer not to answer (5)

If None Is Selected, Then Skip To End of Block

Q72 Does the insurance you indicated 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. (1)
- 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. (2)
- No (3)
- Not sure (4)

Q81 For the next few questions, we will be asking about types of treatments your child CURRENTLY receives. If you are unsure if your child receives a treatment, please do not select it.

Q82 Does your child CURRENTLY use any of the following treatment(s)? · Early Intensive Behavioral Intervention

- Yes (1)
- No (2)

Q83 Does your child CURRENTLY use any of the following treatment(s)? · Applied Behavior Analysis (ABA) · Modeling · Pivotal Response Training · Natural Teaching Strategies

- Yes (1)
- No (2)

Q84 Does your child CURRENTLY use any of the following treatment(s)? · Cognitive Behavioral Intervention Package · Cognitive Behavioral Therapy

Yes(1)

No(2)

Q49 Does your child CURRENTLY use any of the following treatment(s)? · Language Training (Production) · Speech therapy

Yes(1)

No(2)

Q50 Does your child CURRENTLY use any of the following treatment(s)? · Parent Training · Peer Training Package · Self-Management Training · Schedules

Yes(1)

No(2)

Q51 Does your child CURRENTLY use any of the following treatment(s)? · Scripting · Social Skills Package · Story-Based Intervention (e.g., Social Stories)

Yes(1)

No(2)

Q52 Does your child CURRENTLY use any of the following treatment(s)? · Alternative Communication Devices · Functional Communication Training · Picture Exchange Communication System · Sign Instruction · Facilitated Communication · Music Therapy · Animal-assisted Therapy · Floor Time · Play Therapy

Yes(1)

No(2)

Q53 Does your child CURRENTLY use any of the following treatment(s)? · Exercise · Massage Therapy/Deep Pressure · Auditory and/or Sensory Integration · Chiropractic · Art Therapy · Acupuncture

Yes(1)

No(2)

Q54 Does your child CURRENTLY use any of the following treatment(s)? · Vitamins and supplements · Special or restricted diets (e.g., gluten-free, casein-free, yeast-free) · Oxytocin

Yes(1)

No(2)

Q55 Does your child CURRENTLY use any of the following treatment(s)? · Chelation · Hyperbaric oxygen therapy (HBOT) · Packing

Yes(1)

No(2)

Q56 Does your child CURRENTLY use any of the following treatment(s)? · Occupational therapy  
· Physical therapy  
 Yes(1)  
 No(2)

Q57 Does your child CURRENTLY use any other treatment that you did not see above?  
 Yes (Please type below.) (1) \_\_\_\_\_  
 No(2)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Early Intensive Behavioral... Yes Is Selected

Q97 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Early Intensive Behavioral Intervention  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Applied Behavior Analyti... Yes Is Selected

Q51 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Applied Behavior Analysis (ABA) · Modeling · Pivotal Response Training · Natural Teaching Strategies  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Cognitive Behavioral Int... Yes Is Selected

Q52 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Cognitive Behavioral Intervention Package · Cognitive Behavioral Therapy  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Language Training (Produ... Yes Is Selected

Q53 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Language Training (Production) · Speech therapy  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Parent Training ... Yes Is Selected

Q54 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Parent Training · Peer Training Package · Self-Management Training · Schedules  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Scripting  
· Social... Yes Is Selected

Q55 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Scripting · Social Skills Package · Story-Based Intervention (e.g., Social Stories)  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Alternative  
Communicatio... Yes Is Selected

Q56 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Alternative Communication Devices · Functional Communication Training · Picture Exchange Communication System · Sign Instruction · Facilitated Communication · Music Therapy · Animal-assisted Therapy · Floor Time · Play Therapy  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Exercise  
· Massage... Yes Is Selected

Q57 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Exercise · Massage Therapy/Deep Pressure · Auditory and/or Sensory Integration · Chiropractic · Art Therapy · Acupuncture  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Vitamins and  
supplements... Yes Is Selected

Q58 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Vitamins and supplements · Special or restricted diets (e.g., gluten-free, casein-free, yeast-free) · Oxytocin  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Chelation  
· Hyperb... Yes Is Selected

Q59 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Chelation · Hyperbaric oxygen therapy (HBOT) · Packing  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any of the following treatment(s)? · Occupational  
therapy · ... Yes Is Selected

Q60 How many HOURS PER WEEK does your child spend receiving and/or using any of these treatments? · Occupational therapy · Physical therapy  
\_\_\_\_\_ Hours Per Week (1)

Answer If Does your child CURRENTLY use any other treatment that you did not see above? Yes  
(Please type below.) Is Selected

Q61 How many HOURS PER WEEK does your child spend receiving and/or using the OTHER treatment you indicated?

\_\_\_\_\_ Hours Per Week (1)

Q153 Where do you get information about autism treatments? (Select all that apply.)

- Websites(1)
- Internet forum or online support group (2)
- Word of mouth from someone who is a caregiver of individual with ASD (3)
- Word of mouth from someone who is NOT a caregiver of individual with ASD (4)
- Doctor (pediatrician or primary care physician) (5)
- Magazines (6)
- Books (7)
- School/classroom teacher (8)
- ABA therapist (9)
- Occupational therapist (10)
- Physical therapist (11)
- Psychologist (12)
- Parent support group that meets in person (13)
- TV (14)
- Newspaper (15)
- Other (Please type below.) (16) \_\_\_\_\_

Q154 Of the sources of information about autism treatments you use, which is your most trusted source?

Q175 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 any that your child used to use, but then quit using for some reason. There are 6 lists; some lists will be different than the lists you saw previously.

Q176 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select “none of the above.”)

- Applied Behavior Analysis (ABA) (1)
- Cognitive Behavioral Intervention Package (2)
- Cognitive Behavioral Therapy (3)
- Modeling (4)
- Pivotal Response Training (5)
- None of the above (6)

Answer If For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select none of the above. None of the above Is Not Selected

Q177 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q178 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select "none of the above.")

- Early Intensive Behavioral Intervention (1)
- None of the above (2)

Answer If None of the above Is Not Selected

Q179 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q180 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select “none of the above.”)

- Language Training (Production) (1)
- Natural Teaching Strategies (2)
- Parent Training (3)
- Peer Training Package (4)
- Schedules (5)
- Scripting (6)
- Self-Management Training (7)
- Social Skills Package (8)
- Speech therapy (9)
- Story-Based Intervention (e.g., Social Stories) (10)
- None of the above (11)

Answer If None of the above Is Not Selected

Q181 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child’s behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q182 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select “none of the above.”)

- Alternative Communication Devices (1)
- Exercise (2)
- Functional Communication Training (3)
- Massage Therapy/Deep Pressure (4)
- Music Therapy (5)
- Occupational Therapy (6)
- Physical Therapy (7)
- Picture Exchange Communication System (8)
- Sign Instruction (9)
- Structured Teaching (10)
- None of the above (11)

**Answer If None of the above Is Not Selected**

Q183 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q184 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select "none of the above.")



- Acupuncture (1)
- Animal-assisted Therapy (2)
- Art Therapy (3)
- Auditory and/or Sensory Integration (4)
- Chiropractic/osteopathy (5)
- Facilitated Communication (6)
- Floor Time (7)
- Oxytocin (8)
- Play Therapy (9)
- Special or restricted diets (e.g., gluten-free, casein-free, yeast-free) (10)
- Vitamins and supplements (11)
- None of the above (12)

Answer If None of the above Is Not Selected

Q185 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q186 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select "none of the above.")

- Chelation (1)
- Hyperbaric Oxygen Therapy (HBOT) (2)
- Packing / Holding Therapy (3)
- None of the above (4)

Answer If None of the above Is Not Selected

Q187 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q188 For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select "none of the above.")

- Other (Please type below.) (1) \_\_\_\_\_
- None of the above (2)

Answer If For the following list please select any treatments your child used to use but then quit. You can select as many as apply in each list. (If none of these apply, select "none of the above.") Other (Please type below.) Is Selected

Q189 You said your child used to use but quit using the intervention(s) you selected. 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 selected.

- Not seeing enough benefit from the treatment (1)
- Financial- out of pocket expense too great (2)
- My child was no longer eligible due to age or change in diagnosis (3)
- Change in insurance coverage (4)
- Took too much time or the scheduling was too inconvenient with other family obligations (5)
- Dissatisfied with the relationship with direct care providers (e.g., felt they were untrained, unprofessional, or inconsistent) (6)
- Did not like having service providers in my home (7)
- Proximity to my area- distance was too far to travel (8)
- My child's behavior interfered with treatment at that time (for example, aggression, self-injury, refusal to get out of car) (9)
- Other (Please type below.) (10) \_\_\_\_\_

Q190 Is there any treatment you wish your child were currently receiving? If you select "yes", please tell us which treatment(s).

No (1)

Yes (2) \_\_\_\_\_

Answer If Is there any treatment you wish your child were currently receiving? If you select "yes", please tell us which treatment(s).<o:p></o:p> Yes Is Selected

Q191 Think about the treatments you wish your child could receive right now. Which of the following problems are you facing right now? Select all that apply.

Waitlists are too long (1)

Distance- I have reliable transportation but the distance is just too far (2)

Lack of Transportation- lack of reliable access to a vehicle and/or driver (3)

Financial- out of pocket expense too great (4)

Scheduling is too inconvenient for me / family (e.g., therapy time interferes with employment or other family obligations) (5)

My child's current treatments take so much time that I don't want to add another at this time (6)

I have tried or am trying to access this treatment, but the enrollment process is confusing/difficult (7)

My child has challenging behaviors need to be addressed first (e.g., is aggressive, destructive, or runs away) (8)

I just have not gotten around to it yet, no real barriers (9)

Other (Please type below.) (10) \_\_\_\_\_

Q192 Now rank these problems in order, with 1 being the MOST frustrating or problematic. (Drag and drop items to put them in order.)

End of Survey

## Vita

Hilary Adams is originally from Houston, Texas. She earned a B.S. with a major in Psychology and a minor in Spanish from Tulane University in 2010. After one year serving as a research assistant following her undergraduate studies, she enrolled at Louisiana State University, where she earned her M.A. in Clinical Psychology in 2014 and anticipates graduating with her Ph.D. in Clinical Psychology in 2016. She completed her predoctoral internship at Indiana University School of Medicine in August 2016. Intending to continue her clinical and research work in the area of ASD and intellectual and developmental disabilities, Hilary accepted a postdoctoral position at Children's Hospital of New Orleans in their autism clinic.