# FACTORS RELATED TO TREATMENT CHOICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS: THE ROLE OF CHILD- AND FAMILY-CHARACTERISTICS AND OF PARENT PERCEPTIONS

A Dissertation Presented to the
Faculty of the College of Education
University of Houston

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Philosophy

by

Sarah S. Mire

April 2012

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## Abstract

The rates of autism spectrum disorder (ASD) diagnoses continue to increase, and the impact of ASD on children and their families is significant. Children with ASD often are served by various professionals, but parents are ultimately the decision-makers for what types of treatments to pursue. Numerous approaches to and types of ASD treatments have been proposed, many of which are not evidence-based. In addition, parents of children with ASD often choose to pursue multiple treatments simultaneously. Studies indicate that some child-specific (e.g., age, cognitive functioning, severity of ASD symptomatology) and contextual (e.g., parent education level, family income, race/ethnicity) factors are related to the types of ASD treatments parents pursue, though more research in this area is needed. In addition, some research suggests that parent perceptions about the nature and course of their child's ASD are related to what types of treatments are chosen. In the current study, data from well-characterized samples of children (ages 4-17) who were diagnosed with an ASD were examined to address these issues. Samples were drawn from the Simons Simplex Collection ($n$ = 2,115), and a small subset ($n$ = 68) provided additional data on parent perceptions of ASD. Results demonstrated that parents typically tried several different treatment types over their children's lifetimes. School-based treatments were most-often used, but other widely used treatments included psychotropic medication. A series of binary logistic regression analyses indicated that several different child- and contextual-factors, including child age,

age of ASD onset, verbal cognitive ability, annual household income, and parental educational level were found to predict whether parents had ever used particular treatments with their children. Moreover, parent perceptions about the course and nature of their child's ASD—especially how much control parents believed they had over treatment, how many symptoms they ascribed to their child's ASD diagnosis, and how chronic they viewed their child's ASD to be— also contributed to having ever chosen some treatment types. Results are discussed in the context of implications as well as limitations. Many additional questions were generated as a result of this study and are discussed as directions for future research.

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# Chapter I

## Review of Literature

Pervasive Developmental Disorders (PDDs) include DSM-IV-TR (American Psychiatric Association [APA], 2000) diagnoses of Autistic Disorder (AD), Asperger's Syndrome (AS), and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS), as well as the rare diagnoses of Childhood Disintegrative Disorder (CDD) and Rett's Disorder (RD). Autistic Disorder, Asperger's Syndrome, and PDD NOS are often collectively called autism spectrum disorders (ASD); these diagnoses represent subtypes of the early-emerging neurodevelopmental PDDs (Klin, 2009). Childhood Disintegrative Disorder and Rett's Disorder are rare and often excluded from ASD clinical research studies (Posey, Stigler, Erickson, & McDougle, 2008). While the three primary DSM-IV-TR (APA, 2000) diagnoses for ASD (e.g., AD, AS, PDD NOS) differ in terms of specific symptom presentation, core features are currently conceptualized as including qualitative impairments in the areas of communication, socialization, and restricted interests/ repetitive behaviors (APA, 2000).

Persons diagnosed with Asperger's Syndrome do not have delays in language, cognitive, or adaptive behavior development; unusual patterns of communication and impairments with nonverbal communication are typically present (Paul & Wilson, 2009). PDD NOS diagnoses are made when patterns of social, communicative, and restricted interests/ repetitive behaviors are present but do not follow the presentation patterns consistent with other ASD diagnoses. Diagnoses of PDD NOS are often made in one of the following cases: a) presentation resembles that of persons with Asperger's but a mild cognitive or language delay is apparent; b) presentation is like that of Autistic Disorder

but age of onset is later than age three years; or c) presentation is autistic-like but criteria for stereotyped and repetitive behaviors is subthreshold (Walker et al., 2004). For any ASD diagnosis, early development is distinctly deviant from the development expected for a child's chronological or mental age (in cases of comorbid Intellectual Disability [ID]/ Mental Retardation [MR]), and these patterns are usually present prior to age 3 years (APA, 2000; Centers for Disease Control and Prevention [CDC], 2009).

Although seemingly categorical based on the DSM-IV TR (APA, 2000) nosology, these diagnoses are currently conceptualized as existing on a spectrum (National Institute of Mental Health [NIMH], 2008). The proposed DSM-5 criteria for ASD diagnoses collapse the three areas of core deficit (e.g., reciprocal social interaction, communication, restricted interests/repetitive behavior) into two areas (e.g., social communication and interaction, and restricted, repetitive behavior) (APA, 2011). This combination of categorical (i.e., has ASD or does not have ASD) and dimensional (i.e., severity of symptoms) representations of ASD symptoms has demonstrated validity as a model for ASD diagnoses (Frazier et al., 2012), though these authors and others (e.g., McPartland, Reichow, & Volkmar, 2012) have raised concerns regarding the sensitivity of this new diagnostic model.

Though discussion and research regarding diagnostic criteria are ongoing at this time, experts agree that regardless of the subtype (i.e., specific diagnosis) assigned, the clinical presentations of persons with ASD vary greatly (Klin, 2009). For example, some children with Autistic Disorder are non-verbal, while others with the same diagnosis speak articulately but exhibited a language delay early in their development (e.g., first words spoken after 24 months and/or first phrases spoken after 36 months). Children

with Asperger's Syndrome may have extensive vocabularies but struggle with pragmatic use of language. In social domains, some children with ASD may actively avoid interactions with others, while others may exhibit a desire to interact with their peers but do so in intrusive, odd, or rigid ways. Some children with ASD exhibit stereotyped hand mannerisms (i.e., hand flapping or posturing) or self-injurious behaviors (i.e., head banging, hitting self, biting self); in most cases, repetitive/nonfunctional behaviors and/or a restricted pattern of interests is present.

Over the past decade, diagnoses of ASD in the United States have become increasingly prevalent (Baird et al., 2006; Wing & Potter, 2009). Various hypotheses regarding reasons for the increased prevalence in ASD diagnoses have been offered, including expanded diagnostic criteria (Barbaresi, Katusic, Colligan, Weaver, & Jacobsen, 2005; Powell et al., 2000), change in diagnostic practices, younger age at diagnosis (Wazana, Bresnahan, & Kline, 2007), enhanced public awareness of signs and symptoms associated with ASD (Barbaresi et al., 2005; Powell et al., 2000), increased availability of services (Barbaresi et al., 2005; Powell et al., 2000), "diagnostic switching" (i.e., previous diagnoses of mental retardation revised to reflect PDD NOS diagnoses; Shattuck, 2006), changes in policies for special education services (Gurney et al., 2003; Shattuck, 2006), differences in methods used to assess diagnostic rates (Fombonne, 2005), environmental factors (Wing & Potter, 2002), and greater recognition of genetic contributions (Committee on Children with Disabilities, 2001; Muhle, Trentacoste, & Rapin, 2004; Shevell et al., 2003). Though much research has focused on identifying causes for ASD, experts continue to disagree on a single factor related to the inarguable increase in diagnostic rates, or even whether the increased rates of diagnosis

represent increased *incidence* (i.e., number of new cases of ASD occurring in a population over a period of time) or increased *prevalence* (i.e., proportion of people in a population likely to be diagnosed with ASD) related to factors cited previously (Fombonne, 2005; 2009; Wing & Potter, 2009).

**Impact of ASD**

Regardless of the reasons why ASD is diagnosed more often now than ever before, the impact of ASD on children and their families is significant. Family stress is associated with parenting a child with ASD (Duarte, Bordin, Yazigi, & Mooney, 2005), especially as severity of the ASD symptomatology increases (LeCavalier, Leone, & Wiltz, 2006; Lyons, Leon, Roecker-Phelps, & Dunleavy, 2010). Behavioral difficulties such as aggression, self-injurious behaviors, repetitive behaviors (i.e., stereotypies), and non-compliance may further exacerbate family stress (Tomanik, Harris, & Hawkins, 2004), and maternal stress, in particular, may be increased by behavior problems that are related to common health problems (Kring, Greenberg, & Seltzer, 2010). Children with Autistic Disorder often have significant sleeping difficulties, as well as co-occurring gastrointenstinal dysfunction, though the relationship between these problems is unknown at this time (Ming, Brimacombe, Chaaban, Zimmerman-Bier, & Wagner, 2008). Language and communication difficulties often further impact these areas. Financial costs associated with raising a child with ASD are considerably greater than those associated with raising neurotypical children (Liptak, Stuart, & Auinger, 2006) and may be another factor associated with the high rates of stress seen in families of children with ASD (Leslie & Martin, 2007).

Children and adolescents with ASD have significant difficulty with peer relationships, including difficulty making and keeping friends (Kelly, Garnett, Attwood, & Peterson, 2008). Problems with peer relationships were reported by parents of children with ASD as the area of greatest difference between their children and those without ASD (CDC, 2006). Related to the social interaction deficits central to diagnosis, children and adolescents with ASD may be at particular risk of being targets of bullying (Humphrey & Symes, 2010). Moreover, young people with ASD commonly misinterpret social situations, including situations of peer victimization (van Roekel, Scholte, & Didden, 2010).

Comorbid psychiatric diagnoses are common among children and adolescents with ASD (Leyfer et al., 2006; Simonoff et al., 2008), including symptoms of anxiety and depression (Kelly et al., 2008), as well as attentional difficulties, impulsivity, and hyperactive behaviors (Semrud-Clikeman, Walkowiak, Wilkinson, & Butcher, 2010). Some children with Autistic Disorder may have comorbid diagnoses, such as Intellectual Disability (ID)/ Mental Retardation (MR), though Edelson (2006) notes that rates of ID are likely to be much lower than previously believed. Experts have highlighted the importance of identifying comorbid disorders occurring with ASD while also doing careful differential diagnosis, as intellectual disability (ID)/ mental retardation (MR), developmental language disorders, Selective Mutism, Obsessive Compulsive Disorder, and Reactive Attachment Disorder can be mistaken for ASD (Deprey & Ozonoff, 2009; Filipek et al., 1999).

School-related difficulties are prevalent for children and adolescents with ASD, and the need for school-based services and/or supports for children with ASD increases

as the prevalence rates of ASD increase (Yeargin-Allsopp et al., 2003). Students with ASD may be classified under the federal Autism (AU) umbrella criteria (i.e., includes all ASD) and determined to meet eligibility requirements for special education services. The Individuals with Disabilities Education Improvement Act (IDEIA; 2004) stipulates that having a disability (i.e., AU) is not sufficient for a student to qualify for special education services but that students must also demonstrate educational need for special education and related services. The range of services for which they may qualify is dependent on their specific needs but may include self-contained placements in severe cases or social skills training for higher-functioning students.

Such an educational need may manifest in various ways for students with ASD. Specifically, approximately 67% of children and adolescents with ASD who have cognitive scores within the average range are likely to have comorbid, diagnosable specific learning disabilities (Mayes & Calhoun, 2006). Difficulties with executive function (i.e., carrying out purposeful, goal directed behavior) may impede a student with ASD in organizing time or materials for successful task completion (Hill, 2004). Social difficulties may impact their functioning within the school environment, especially in a public education culture that emphasizes inclusion for students with ASD (Humphrey, 2008). Finally, behavioral concerns within the school setting may significantly impact educational progress (Lecavalier, 2006).

**Treatments for ASD**

The phenotypic presentation and needs within ASD are complex and very diverse, often requiring coordination of services across settings (Aman, 2005), and many different specialists are frequently involved with treatment of children with developmental

disabilities (Boulet, Boyle, & Schieve, 2009). However, there is a lack of empirically supported treatment outcome research for treating ASD (Siegel, 2003). Nevertheless, a plethora of treatment options have been proposed to address the needs of persons with ASD, making the identification of appropriate treatments difficult for parents especially, who are central figures in making choices on behalf of their children and coordinating their treatments (Heflin & Simpson, 1998; Marcus, Kunce, & Schopler, 1997). In fact, Greene et al. (2006) have identified more than 100 treatments that parents choose to pursue for children with ASD.

Difficulties in identifying appropriate treatments and treatment planning for children with ASD lies both in the wide variation of individual strengths and needs, as well as in the chronic nature of ASD which leads to changing treatment needs over the lifespan (Aman, 2005). A single course of treatment is not recognized for ASD (Siegel, 2003; Stahmer & Aarons, 2009)— indeed treatment planning is controversial and complex even among professionals (Levy & Hyman, 2005)— and parents often choose different treatments depending on the type (i.e., specific subtype/diagnosis) of ASD their children have (Goin-Kochel, Myers, & Mackintosh, 2007). Though treatments and types of ASD vary widely, experts do agree that treatment, in general, for ASD is critical, with research consistently supporting that the greatest treatment gains are observed with early intervention (Committee on Children with Disabilities, 2001; Lovaas, 1987; Makrygianni & Reed, 2010; National Research Council, 2001; Siegel, 2003; Warren et al., 2011).

Not only are most treatments for ASD lacking scientific or empirical support (Aman, 2005; Greene et al., 2006; Siegel, 2003), some proposed treatments are quite controversial and/or fads (Levy & Hyman, 2005; Metz, Mulick, & Butter, 2005). In

addition, some professionals and service providers continue to recommend treatments despite the limited or lack of scientific evidence to support their use, adding to the difficulties parents face when choosing treatments for their children (Green et al., 2006; Heflin & Simpson, 1998). It is notable, however, that the number of proposed treatments for ASD far outstrips the amount of efficacy research conducted in this area (Matson, 2007). The following section will briefly review commonly used approaches to treatment for children and adolescents with ASD.

Interventions based on the principles of Applied Behavior Analysis (ABA), which have foundations in behavioral theory, are the most well-researched forms of treatment (Makrygianni & Reed, 2010) and are considered the treatment of choice for ASD (Stahmer & Aarons, 2009; Vismara & Rogers, 2010). Behaviorally-based treatments are those that focus on a) children's current physical environment rather than etiology; b) behavioral deficits and excesses as measurable and observable discrete events; c) applying well-established principles of learning and behavior; and d) emphasize the individuality of each child within the heterogenous ASD population (Lovaas & Smith, 2004). Behaviorally-based treatments that are highly structured and delivered individually (McEachin, Smith, & Lovaas, 1993), as well as those that are delivered in natural settings (Schriebman & Koegel, 1996) have demonstrated efficacy for children with ASD.

An educative and widely-used (Myers, Johnson, and the Council on Children with Disabilities, 2007; Siegel, 2003) approach to treatment that has demonstrated efficacy in ASD is the **T**reatment and **E**ducation of **A**utistic and **C**ommunication related handicapped **Ch**ildren (TEACCH) curriculum (Mesibov, 1997). TEACCH was

developed for persons of all ages and developmental levels, and is founded on the principles of Structured Teaching (Schopler, Mesibov, & Baker, 1982). Principles of Structured Teaching include individualized treatment planning that includes families and focuses on structuring the physical environment, and utilizes visual aids to support development. Evidence of cognitive, motor, and social skill improvement with home-based intervention (Ozonoff & Cathcart, 1998), with lasting effects on language and cognitive skills when TEACCH-based programming was used (Rickards, Walstab, Wright-Rossi, Simpson, & Reddihough, 2009).

Developmental models of treatment also address core deficits associated with ASD. For example, the Denver model focuses on remediating social, play, and communication difficulties (Harris, Handleman, & Jennett, 2005) but lacks the controlled trials necessary to establish empirically supported efficacy as a treatment for ASD (Rogers & DiLalla, 1991). The developmental, individual-difference, relationship-based (DIR) approach developed by Greenspan and Wieder (1997) focuses on floor-time play sessions for building social relationships and addressing biological processing issues (i.e., auditory, motor planning, sensory modulation, visual-spatial). However, DIR lacks sufficient empirical support to be considered an efficacious treatment at this time (Myers, et al., 2007).

Communication therapies also frequently focus on skill-building. The Picture Exchange Communication System (PECS; Bondy & Frost, 1994) is method of alternative communication for children who are functionally nonverbal in which pictures of items are traded for actual items, and it incorporates behavioral principles (i.e., provision of reinforcement). PECS is often used in school-based and classroom settings (Earles,

Carlson, & Bock, 1998) and is considered an empirically supported method of developing functional communication skills (Heflin & Simpson, 1998), including emergence of verbal speech (Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002). However, facilitated communication (FC; Biklen, 1992), which purports to aid nonverbal persons with ASD to type out their thoughts with hand-over-hand support from others, not only lacks empirical support (Calculator, 1992; Mostert, 2001) but has been directly refuted (Simpson & Myles, 1995). Speech and language interventions most likely to produce positive gains in functional gains in communication for children and adolescents with ASD are those that are delivered in natural settings and in close collaboration with teachers and parents (American Speech-Language-Hearing Association, 2006).

Difficulties with adaptive behavior skills and unusual sensory responses are also commonly associated with ASD. Problems with self-care skills (i.e., utensils, snaps), as well as with academic skills (i.e., writing), are often addressed through occupational therapy (OT), though research regarding efficacy of OT for skill-building in children with ASD is lacking (Myers et al., 2007). Sensory integration (SI) therapy may be employed as a component of OT or alone and is often used in public school special education programs (Hess, Morrier, Hefflin, & Ivey, 2008). SI is not a skill-based therapy but purports to help children take in and make sense of the sensory experiences from their environment more adaptively. However, efficacy of SI has yet to be empirically validated for children with ASD (Baranek, 2002).

The difficult, aggressive behaviors of many children with ASD are commonly treated with medications, particularly psychotropic medications such as first-generation (e.g., haloperidol) and second-generation (e.g., risperidone, olanzapine, ziprasidone)

antipsychotics, selective serotonin re-uptake inhibitor (SSRI) antidepressants, naltrexone, clonidine, and psychostimulants (McDougle, Stigler, & Posey, 2003). Although psychotropic treatments are often used, the safety and efficacy of such medications are largely unknown in typically developing pediatric populations, much less in populations of children and adolescents with ASD (Julien, Advokat, & Comaty, 2008). In addition, at this time, the only medications that are FDA-approved specifically for addressing aggression in children with ASD are the atypical antipsychotics risperidone (Risperdal; October 2006) and aripiprazole (Abilify; November 2009). Nevertheless, research indicates that approximately half of children with ASD may be taking at least one psychotropic medication, and the use of these medications is increasing (Aman, Lam, & Van Bourgondien, 2005; Witwer & Lecavalier, 2005).

Educational or developmental therapies that focus on skill building in areas associated with the core deficits of ASD (i.e., communication, social interaction, play) are considered conventional practice (National Research Council, 2001). When parents are disappointed with the results yielded by traditional or empirically-based treatments, they often turn to complementary and alternative medicine (CAM; Hyman & Levy, 2005). Indeed, a recent study by Christon, Mackintosh, and Myers (2010) indicated that more than 70% of parents of children with ASD had tried at least one CAM treatment. The National Center for Complementary and Alternative Medicine (NCCAM) (2011) defines CAM treatments as "a group of diverse medical and health care systems, practices, and products that are not generally considered part of traditional (i.e., Western or allopathic) medicine" but rather are used either in addition to or in place of traditional medical treatments. The NCCAM (2011) further points out that the definition of CAM is

continually changing and that the boundaries between CAM and traditional medical approaches to treatment are not absolute. Most complementary and alternative practices have not been subject to scientific scrutiny (Levy & Hyman, 2005). Examples of non-biological CAM treatments for ASD that do not have empirical support include auditory integration training (Gillberg, Johansson, Steffenberg, & Berlin, 1997), facilitated communication (Mostert, 2001), craniosacral manipulation (Levy & Hyman, 2005), and holding therapy (Tinbergen & Tinbergen, 1983). Biologically-based CAM treatments include vitamins (e.g., B6/Mg++ and nutritional supplements (e.g., DMG, folate, omega 3 fatty acids), special diets (e.g., gluten free/casein free [GF/CF]), gastrointestinal treatments (e.g., digestive enzymes, secretin), treating theorized oxidative stress (e.g., hyperbaric oxygen therapy [HBOT]), or detoxification of heavy metals (e.g., chelation) (Levy & Hyman, 2005, 2008). At this time, the strength of research-based evidence ranges from randomized controlled trials and/or meta-analytic studies to isolated studies to case reports and/or theories (Levy & Hyman, 2008), and these authors note that, overall, current research does not support effectiveness of most of these approaches to treating symptoms of ASD. Moreover, safety concerns are salient considerations with CAM treatments, ranging from potential calcium and vitamin D deficiencies when using GF/CF diets to potential death with some chelation regimens (Levy & Hyman, 2008).

**Choosing Treatments for ASD**

The previous section provided a brief overview of some of the more common treatments proposed for ASD, but numerous others are available to and used by parents of children with ASD, often simultaneously (Goin-Kochel et al., 2007; Green et al., 2006; Smith & Antolovich, 2000). Though multiple professionals may be involved with

families of children with ASD, it is the parents who are often responsible for coordinating services for their children. Moreover, parents typically drive the treatment process for their children, beginning with choosing which treatments to pursue for their children. Many parents also play a critical role in implementing treatment (National Research Council, 2001), and families of children with ASD may begin pursuing treatments before formal diagnoses are made (Levy & Hyman, 2005).

The task of deciding which treatments to pursue for their children is often overwhelming (Green, 2007), and the treatment recommendations parents obtain from different sources is often conflicting (Mandell, Novak, & Zubritsky, 2005). Evidence-basis for many of the reviewed treatments is lacking (Heflin & Simpson, 1998), and the research supporting the ones that do have empirical support may be difficult to access for some families (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). However, that a treatment is "empirically supported" may not be the most salient factor in parents' decisions about which treatment to use for either diagnosed (Green, 2007) or ASD at-risk children (Regehr & Feldman, 2009). Parents may use a combination of treatments with evidence-basis and those without empirical support simultaneously (Smith & Antolovich, 2000). In fact, parents of children with ASD often report that the treatments they choose— even those with no research support— have demonstrated some degree of effectiveness for their children (Goin-Kochel, Mackintosh, & Myers, 2009).

Parents' beliefs about the cause of their child's ASD may also influence what treatments they choose. For example, parents who attribute cause to environmental factors were much more likely to use nutritional and detoxification treatments while beliefs about a genetic cause were related to a higher use of vitamin supplements (Al

Anbar, Dardennes, Prado-Netto, Kaye, & Contejean, 2010). In a follow-up study, Dardennes et al., 2011) found the following statistically significant connections between parent beliefs about causes of their child's ASD and subsequent treatments used: believing early trauma caused ASD was associated with less likelihood of behavior therapy and PECS; believing illness during pregnancy caused ASD was associated with higher likelihood of psychotropic medication use; and believing food allergies/reactions caused ASD was associated with *more* likely use of detoxification, special diets, and vitamins/supplements and *less* likely use of psychotropic medications. In this study, neither parent-specific (e.g., age, years of education) nor child-specific (e.g., age, observed symptoms) were associated with treatment use (Dardennes et al., 2011).

However, in other studies, parent-specific characteristics have been shown to influence treatment decision-making for children with ASD, including parent education level (Wong & Smith, 2006) and family income (Mandell et al., 2008). Race and ethnicity may also influence parents' ASD treatment choices. Families from non-white backgrounds may be less likely to attribute their children's chronic illnesses or conditions to underlying health-related reasons and subsequently less likely to pursue traditional medical treatments (Bussing, Schoenberg, & Perwien, 1998; Yeh, Hough, McCabe, Lau, & Garland, 2004). For example, children with ASD who are of Latino descent may be significantly more likely than children of other cultural backgrounds to have parents who pursue alternative, non-traditional treatments (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003).

Studies have also indicated that the age of a child with ASD is related to the treatments their parents choose. Parents of young children often use a greater number of

simultaneous treatments than those with older children (Green et al., 2006). Young children are more likely to be treated with special diets (e.g., gluten-free [GF] and/or casein-free [CF]) and behavioral or educational treatments than older ones (Goin-Kochel et al., 2007). As children get older, their parents are much more likely to choose psychopharmacological treatments for them (Aman, Lam, & Collier-Crespin, 2003; Goin-Kochel et al., 2007), although more recent data indicate that drug treatments are now offered to younger and younger children, including preschoolers (Olfson, Crystal, Huang, & Gerhard, 2010).

The cognitive functioning level of a child diagnosed with ASD may also influence the types of treatments chosen by their parents. For example, children with ASD and comorbid ID are more likely to be treated with psychotropic medications (Aman et al., 2003; Witwer & Lacavalier, 2005). Within the Spectrum, performance on verbal reasoning tasks of cognitive measures is significantly better for children with Asperger's Syndrome than for those with PDD NOS, and children with PDD NOS perform significantly better on verbal tasks than those with Autistic Disorder (AD) (Coolican, Bryson, & Zwaigenbaum, 2008). Thus, results of traditional cognitive measures, which are verbally loaded (Sattler, 2008), may be less appropriate for children with AD (Arnold et al., 2000) because scores likely do not represent their true abilities (Lennen, Lamb, Dunagan, & Hall, 2010). It is important to note, though, that social perceptions of overall cognitive ability are often based on verbal ability (Sternberg, Conway, Ketron, & Bernstein, 1981). This may be especially important within the mainstream American culture. Specifically, U.S. parents of children who were eventually diagnosed with ASD were more likely to recognize problems related to their child's lack of expressive

language development as initial indicators of developmental deviance (Coonrod & Stone, 2004), whereas Indian parents first noticed social interaction deficits (Daley, 2004).

As reviewed, some factors related to parent choices for children with ASD have been explored, including research support for treatments, parent beliefs about ASD causes, parent education level, race and ethnicity, child age, and child cognitive functioning. The current research regarding the decision-making process for parents choosing various treatments for their child's ASD, however, is quite limited (Al Anbar et al., 2010; Christon et al., 2010; Mandell & Novak, 2005). Understanding what factors contribute to how many and what types of treatments chosen by parents is critical (Green, 2007; Green et al., 2006), as this knowledge may help professionals better understand ways to equip parent decision-makers with better information about treatment options, including evidence-based treatments (Levy & Hyman, 2008; Regehr & Feldman, 2009).

**Contribution of Perceptions on Treatment Decisions**

The way parents conceptualize the severity of their children's impairments in social, communication, and/or behavioral domains may also influence the treatments they choose. Greater perceived severity of diagnosis is associated with higher rates of special diets (e.g., GF and/or CF) and other CAM use (Christon et al., 2010; Goin-Kochel et al., 2007; Green et al., 2006) but greater severity is also correlated with more skills training based on evidence-based treatments within applied behavior analysis (ABA; Green et al., 2006). Studies regarding the relationship between perceived severity of diagnosis and psychotropic medication use, however, have yielded mixed results. In some research, use of psychotropic medications was comparably endorsed by parents of children with

varying severity of ASD diagnosis (Green et al., 2006) but in other research greater severity was more associated with psychotropic use (Aman et al., 2003).

Perceptions are cognitive processes, and research has demonstrated that cognitive processes are likely to affect the treatments parents choose for their children with ASD (Al Anbar et al., 2010; Mandell & Novak, 2005). Cognitive theory underlies research on cognitive processes that may mediate decision making, as the focus of cognitive theory is on the internal mental processes, including thinking, remembering, learning, perceiving, and understanding, as well as the impact of these cognitions on emotions and behavior. The first psychological researcher to experimentally investigate cognitive structures involved in mental processing was Wilhelm Wundt, and the principles developed by Wundt eventually became the underpinnings of cognitive psychological theory (Bell-Gredler, 1986, as cited in Grider, 1993). From this theoretical perspective, one's perceptions are purported to be more important in human experiences than the actual events within the environment itself, and this concept of structuralism was one of psychology's first major theories (Bell-Gredler, 1986; Blumenthal, 1977, as cited in Grider, 1993).

Parent perceptions and beliefs about children's behavior impact parents' responses to and interactions with their children (Wiener, 1980). Parents utilize their own personal and cultural backgrounds and experiences, as well as their knowledge about development and disability, to make sense of their children's ASD, such that they "construct" the meaning of the diagnosis and interpret how the diagnosis will impact their child and family (Avdi, Griffin, & Brough, 2000). How parents conceptualize their child's ASD diagnosis—particularly their beliefs about cause—impact treatments chosen

for their children (Dardennes et al., 2011), as well as on parents' feelings about their own role in helping their children and their children's integration into their communities (Hebert & Koulouglioti, 2010).

**Models of Illness Representation**

Cognitive theory is the foundation for models that attempt to explain the ways in which people conceptualize issues related to their health (Leventhal, Leventhal, & Cameron, 2001). Models of illness representation have been developed from cognitive theory that outline psychological processes believed to underlie how health problems are conceptualized (Leventhal et al., 2001). One of the most widely known is the Common Sense Model of Illness Representation (Leventhal, Meyer, & Nerenz, 1980), which has become a widely-used model for studying people's responses to health threats (Leventhal, Musumeci, & Contrada, 2007). Leventhal et al.'s (1980) model proposes that a) both cognitive and affective representations of illness contribute to developing and assessing coping strategies, and b) these mechanisms are linked to outcomes that contribute to revised cognitive and affective representations.

This model was later revised to emphasize the role that people play in modulating their own thoughts, emotions, and behaviors to meet goals within their environment, subsequently named the Self-Regulation Model of Illness Representation (Leventhal, Nerenz, & Steele, 1984; Leventhal et al., 1997). The components of Leventhal et al.'s (1984, 1997) model include five components: identity, consequences, timeline, control/cure, and cause. These five dimensions have been demonstrated to predict adherence to treatment (Brewer, Chapman, Brownlee, & Leventhal, 2002; Horne &

Weinman, 2002) and to be associated with coping, well-being, and overall functioning (Hagger & Orbell, 2003).

Though the theory focuses on perceptions related to one's own illness, Leventhal et al. (1984) also recognized the importance of perceptions of persons providing care for others with illnesses. For example, the Leventhal et al. (1984) model was the basis of an exploration of how caregivers for persons with schizophrenia perceive their loved one's illness and cope with distress they experience related to this (Fortune, Smith, & Garvey, 2005). The model was also the basis of a study demonstrating that mothers of adolescents with Type I diabetes perceived greater consequences and emotional impact of the adolescent's chronic condition than did adolescents and suggested that mothers' perceptions influence their children's coping and the family's management of diabetes (Law, 2002).

A recent study conducted by Al Anbar et al. (2010) applied Leventhal et al.'s (1984) illness representation model to parents of children with ASD, and the results indicated that parents' perceptions about the severity of their child's ASD is associated with educative methods of treatment. Further, parental perceptions that the course of their child's ASD is unpredictable was related to use of psychotropic medication treatment, whereas parents who perceived some degree of control over the ASD were less likely to pursue either psychopharmacological or nutritional (i.e., special diets, vitamins/supplements) treatments (Al Anbar et al., 2010). To date, this appears to be the only study that investigates the ways in which parent perceptions about ASD may be similar to caregivers' perceptions about other chronic conditions, and how these perceptions predict treatment choices.

**Measuring Perceptions**

In order to determine the impact that cognitively-based models of illness representation/ conceptualization may have upon behavioral (i.e., treatment decision-making, treatment adherence) and emotional (i.e., coping) outcomes, perceptions related to illnesses must be measured. To address this need, Weinman, Petrie, Moss-Morris, and Horne (1996) developed the Illness Perception Questionnaire (IPQ) based on Leventhal et al.'s (1984, 1997) five dimensions of illness representation. This instrument was later revised by Moss-Morris et al. (2002), which a) strengthened the psychometric properties by improving the reliability of the subscales, and b) extended the cognitive model to include emotional or affective components that contribute to cognitive representations of illness, which was more aligned with Leventhal et al.'s (1984, 1997) theory. The resulting instrument was called the Illness Perception Questionnaire- Revised (IPQ-R; Moss-Morris et al., 2002). Both the original IPQ (Weinman et al., 1996) and the IPQ-R (Moss-Morris et al., 2002) have been used in research that investigates the role of cognitions on how patients make sense of their symptoms, conceptualize their overall health and well-being, and respond behaviorally and emotionally to their chronic illnesses (www.uib.no/ipq, n.d.).

The creators of both the IPQ (Weinman et al., 1996) and the IPQ-R (Moss-Morris et al., 2002) encourage researchers to modify this instrument to best fit particular illnesses and research settings. They note that creating different versions of the instrument for various illnesses and in various languages, as well as using it with other techniques will further contribute to understanding how illness perceptions may be related to treatment choice and adherence outcomes (Moss-Morris et al., 2002). As a

result, this measure has been widely used in studies about the role perceptions play in outcomes related to a variety of chronic illnesses. Specifically, these instruments have been used to assess the influence of perceptions on treatment-adherence as related to conditions such as multiple sclerosis (Jopson & Moss-Morris, 2003); cancer (Buick & Petrie, 2002; Scharloo et al., 2005); heart attack (Cameron, Petrie, Ellis, Buick, & Weinman, 2005); hemodialysis (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004); Diabetes- Type I (Barnes, Moss-Morris, & Kaufusi, 2004); Huntington's disease (Helder et al., 2002); psoriasis (Fortune, Richards, Griffiths, & Main, 2004); Addison's disease (Heijmans, 1999); Chronic Fatigue Syndrome (Moss-Morris & Chalder, 2003); Irritable Bowel Syndrome (Rutter, Barton, & Rutter, 2002); asthma (Main, Moss-Morris, Booth, Kaptein, & Kolbe, 2003); and Rheumatoid Arthritis (Sharpe, Sensky, & Allard, 2001). This instrument has also been used in assessing the perceptions of spouses and caregivers of persons with chronic health-related conditions (Hews, de Ridder, & Bensing, 1999; Helder et al., 2002; McClenahan & Weinman, 1998; Salewski, 2003; Weinman, Petrie, Sharpe, & Walker, 2000).

Though not an "illness," ASD diagnoses represent chronic conditions, and the pervasive impact of these diagnoses requires different approaches to assessment and subsequent treatment across the lifespan (Aman, 2005; Shea & Mesibov, 2009). In the previously discussed Al Anbar et al. (2010) study, the IPQ-R (Moss-Morris et al., 2002) was adapted for use with parents of children diagnosed with ASD. The study was conducted in France, and the instrument was translated into French for use there. The authors reported respectable to very good internal consistency reliability ($\alpha$ ranged from .69-.81) on six of the seven IPQ-R subscales within their ASD caregiver sample, although

internal consistency reliability was lower ($\alpha$ = .62) on one subscale (Treatment Control) (Al Anbar et al., 2010). Further, results of this study indicated that there were relationships between parent perceptions about their children's ASD and subsequent treatment decisions (Al Anbar et al., 2010).

**Current Research Questions**

Considering the prevalence and impact of ASD, treatment for children with these chronic diagnoses is critical. Many treatments approaches are available to families, and treatment choices are made by parents. However, research regarding child- and family-specific factors that may contribute to treatment choices is limited at this time.

The primary purpose of the current study was to enhance understanding of factors that may contribute to the treatment decisions made by parents of children with ASD. Several research questions were central to the study. First, how many treatment types (i.e., categories) are parents of children diagnosed with ASD using? Second, are there characteristics of the children and families that make it more or less likely that parents will choose certain types of treatments? Specifically, when a child's current age, gender, race/ethnicity, parent education level, family income, verbal ability, onset of ASD symptomatology, and severity of currently observed ASD symptomatology are known, what is the likelihood that particular types of treatments (i.e., speech, behavioral, medication, etc.) are chosen by parents?

In addition to child- and family-specific factors, research also suggests that parent perceptions about their children's ASD influence treatment decision-making (Al Anbar et al., 2010; Dardennes et al., 2011; Mandell & Novak, 2005). Perceptions of parents as decision-makers for their children with ASD were further investigated in the third key

research question: when parents' perceptions of ASD are considered in addition to the aforementioned variables (e.g., child age, gender, ethnicity, parent education level, family income, verbal ability, symptom onset, current ASD severity), do the parents' perceptions contribute to the likelihood of pursuing particular types of treatments? It was expected that parent perception about the nature and course of their children's ASD would contribute to understanding the likelihood of treatments chosen by parents, but no specific a priori hypotheses were developed because of the limited literature currently available about the contribution of various factors to the treatment decisions parents make for their children with ASD.

Understanding the relationship between child symptoms and parent perceptions about their child's ASD symptoms is important, as these cognitive processes may have influence treatment choices. Perceptions are amenable to change (Leventhal et al., 2001), and if particular aspects of parent perception are demonstrated to have an effect on the type of treatments parents choose, researchers and practitioners may be able to tailor dissemination of psychoeducational and treatment information to better align parents' treatment choices with evidence-based practice (Al Anbar et al., 2010; Dardennes et al., 2011).

# Chapter II

# Methods

## Participants

Analyses were conducted on data from three samples. Extant data from 2,115 participants in the multi-site Simons Simplex Collection (SSC) were used, as well as a sub-sample of 199 families who participated in the SSC at the Baylor College of Medicine (BCM) site. New data were collected from 68 families from the BCM sub-sample who volunteered their participation. The SSC was a project funded by the Simons Foundation Autism Research Initiative (SFARI) with the goal of developing a permanent repository of genetic samples from families of children with ASD. The purpose of the SSC was to gather genetic data on families with a single child diagnosed with an ASD, and researchers working within the SSC collected phenotypic (i.e., clinical information) data on all families, as well. These phenotypic data were gathered so that researchers can enhance understanding of connections between genes and specific behaviors that are characteristic of ASD.

Data for this project were collected at twelve university-affiliated research clinics throughout the United States and Canada, including: Baylor College of Medicine (Houston, Texas); Children's Hospital Boston (Boston, MA); Columbia University (New York, New York); Emory University (Atlanta, Georgia); McGill University (Montreal, Quebec); University of California, Los Angeles (Los Angeles, California); University of Illinois (Chicago, Illinois); University of Michigan (Ann Arbor, Michigan); University of Missouri (Columbia, Missouri); University of Washington (Seattle, Washington); Vanderbilt University (Nashville, Tennessee); and Yale University (New Haven,

Connecticut). Data collection at each of these sites ended in March 2011, at which time the SSC had gathered data on approximately 2,700 families.

Inclusion criteria for families in the SSC included: (1) one child between the ages of 4:0 years and 17:11 years who met DSM-IV-TR (APA, 2000) criteria for an ASD diagnosis (i.e., AD, AS, or PDD NOS) according to both, a) cut-off scores on select autism diagnostic instruments, and b) clinical opinion; (2) affected child had at least one unaffected sibling[1]; (3) no first- through third-degree relatives had been diagnosed with or strongly suspected of an ASD; (4) affected child had a minimum non-verbal IQ of 24 months (for children 4:0-6:11) or 30 months (for children 7:0-17:11); (5) both biological parents were available for DNA collection; and (6) the affected child did not experience significant medical complications during prenatal development and/or delivery. Because of these inclusion criteria, all participants whose data were utilized to conduct the current analyses were diagnosed with an ASD. Additional details about the development of the genetic repository of the SSC are available in Fischbach and Lord (2010).

A comparison of the demographic data for each dataset can be reviewed in Table 1. The SSC sample included 2,115 children; 199 were in the BCM dataset, and 68 families returned new data and comprised the New Data (ND) sample. Most participants in all three samples were boys (SSC: 86.3%; BCM: 86.9%; ND: 88.1%). The largest proportions were Caucasian (SSC: 78.5%; BCM: 74.2%; ND: 70.8%). Families endorsed their race group (i.e., African American, Asian American, Caucasian, Native American/Alaskan Native, Native Hawaiian/ Other Pacific Islander; More than One

[1] The SSC inclusion criteria were eventually changed to include children with ASD who were the only children in their immediate families or who had only biological half-siblings without ASD or serious psychiatric conditions. Sites were allowed to submit only a limited number (e.g., approximately 15-20%) of these "sib-exception" families each quarter. This resulted in "sib-exception" families in approximately 18% of the larger SSC sample.

Race; Other; Not Specified) and their ethnicity (i.e., Hispanic/Latino, Non-Hispanic/Non-Latino); proportions of children identifying as members of these groups within the respective samples are also provided in Table 1. The majority of families reported income of more than $81,000 (SSC: 59.4%; BCM: 58%; ND: 63.0%), and the majority of father and mother educational levels reported were college graduate or higher (Fathers: SSC- 60.1%; BCM- 57.6; ND- 62.7%; Mothers: SSC- 61.4%; BCM- 58.0%; ND- 59.7%).

Table 1

*Frequency of Demographic Characteristics by Data Set (Percentage in parentheses)*

| Characteristic | | Sample | | |
|---|---|---|---|---|
| | | SSC (*n* = 2,115) | BCM (*n* = 199) | ND (*n* = 68) |
| Female | | 289 (13.7) | 26 (13.1) | 8 (11.9) |
| Race/Ethnicity | | | | |
| | Asian American | 83 (3.9) | 9 (4.5) | 3 (4.5) |
| | Black/African American | 82 (3.9) | 9 (4.5) | 4 (6) |
| | Hispanic/Latino | 230 (10.9) | 52 (26.3) | 16 (23.9) |
| | More than One | 113 (5.3) | 5 (2.5)[a] | 3 (4.5)[a] |
| | Other | 28 (1.3) | | |
| | White | 1,579 (74.7) | 123 (62.1) | 41 (61.2) |
| Income | | | | |
| | less than 20k | 62 (3.1) | 7 (3.7) | 2 (3.1) |
| | 21-35k | 94 (4.7) | 10 (5.2) | 4 (6.2) |
| | 36-50k | 170 (8.6) | 17 (8.9) | 7 (10.8) |
| | 51-65k | 211 (10.6) | 21 (11.0) | 4 (6.2) |
| | 66-80k | 270 (13.6) | 25 (13.1) | 7 (10.8) |
| | 81-100k | 352 (17.7) | 31 (16.2) | 11 (16.9) |
| | 101-130k | 302 (15.2) | 26 (13.6) | 8 (12.3) |
| | 131-160k | 184 (9.3) | 23 (12.0) | 9 (13.8) |
| | more than 161k | 341 (17.2) | 31 (16.2) | 13 (20.0) |
| Father Education | | | | |
| | < 9th grade | 6 (0.3) | 2 (1.0) | 0 (0) |
| | Through 9th grade | 2 (0.1) | 0 (0) | 0 (0) |
| | HS but no diploma | 38 (1.8) | 7 (3.5) | 2 (3.0) |
| | GED/HS equiv. | 32 (1.5) | 2 (1.0) | 1 (1.5) |
| | HS graduate | 217 (10.4) | 18 (9.1) | 6 (9.0) |
| | Some college | 537 (25.8) | 55 (27.8) | 16 (23.9) |
| | Bach./4-year degree | 673 (32.3) | 70 (35.4) | 20 (29.9) |
| | Graduate/Prof. degree | 580 (27.8) | 44 (22.2) | 22 (32.8) |
| Mother Education | | | | |
| | < 9th grade | 3 (0.1) | 0 (0) | 0 (0) |
| | Through 9th grade | 0 (0) | 1 (0.5) | 0 (0) |
| | HS but no diploma | 20 (1.0) | 2 (1.0) | 0 (0) |
| | GED/HS equiv. | 26 (1.2) | 5 (2.5) | 0 (0) |
| | HS graduate | 152 (7.2) | 14 (7.1) | 4 (6.0) |
| | Some college | 610 (29.0) | 61 (30.8) | 23 (34.3) |
| | Bach./4-year degree | 760 (36.2) | 69 (34.8) | 22 (32.8) |
| | Graduate/Prof. degree | 530 (25.2) | 46 (23.2) | 18 (26.9) |

[a] Combination of “More than One” and “Other” categories

Additional child-specific characteristics are included in Table 2. The average chronological age of participants at the time of evaluation was approximately 8.5 years old (SD = approximately 3.5 years). The average age of problem onset reported across the three samples was between approximately 22 and 24 months. Verbal cognitive scores fell in the below average range, overall, though the scores varied within all three samples (SSC: *M* = 79.42, *SD* = 30.48; BCM: *M* = 77.77, *SD* = 31.09; ND: *M* = 76.01, *SD* = 33.29). Severity of ASD symptomatology as observed during administration of the *Autism Diagnostic Observation Schedule* (ADOS; Lord et al., 2000) was captured via the calibrated severity score (CSS) and the average CSS fell in the moderately severe range, overall (SSC: *M* = 7.4, *SD* = 1.7; BCM: *M* = 7.29, *SD* = 1.6; ND: *M* = 7.28, *SD* = 1.7).

Table 2

*Child-Specific Characteristics by Data Set*

| Characteristic | Sample | | | | | |
|---|---|---|---|---|---|---|
| | SSC (*n* = 2,115) | | BCM (*n* = 199) | | ND (*n* = 68) | |
| | *M* (*SD*) | Range | *M* (*SD*) | Range | *M* (*SD*) | Range |
| Child Age (yrs) | 8.49 (3.5) | 4.0-17.11 | 8.29 (3.38) | 4.0-17.11 | 8.74 (3.7) | 4.0-17.11 |
| Age of Problem Onset (months) | 21.93 (13.92) | n/a | 22.82 (14.98) | n/a | 23.9 (16.92) | n/a |
| Verbal Cognitive Score | 79.42 (30.48) | 5-167 | 77.77 (31.09) | 8-167 | 76.01 (33.29) | 8-140 |
| ADOS CSS | 7.40 (1.70) | 4-10 | 7.29 (1.61) | 4-10 | 7.28 (1.66) | 5-10 |

**Measures**

The SFARI outlined a standard research protocol which was used across all twelve SSC data collection sites. Much of the data analyzed were located within the national repository of the SSC database. This included demographic variables, cognitive functioning, and information related to ASD symptomatology. Data regarding parent perceptions about the course and nature of their children's ASD were not collected as part of the original SSC. For this reason, families who participated in the SSC at BCM and agreed to being re-contacted were asked to complete a 4-page perception questionnaire, as well as a 3-page updated treatment history form that was only used to inform future research hypotheses.

**Demographic variables.** Demographic data were collected on families using a 7-page Background History Form that was completed by families prior to inclusion in the SSC. These data were collected over the phone by research coordinators at the respective sites and became part of the SSC repository. The demographic information analyzed included the age of the child at the time of data collection, child gender, child race/ethnicity, parents' education level (e.g., mother and father), and family income.

Child age was measured in months. Gender was indicated as either male or female. With regard to race, the six aforementioned choices were presented to the families (i.e., African American, Asian American, Caucasian, Native American/Alaskan Native, Native Hawaiian/ Other Pacific Islander; More than One Race; Other; Not Specified), and families were instructed to indicate all categories that are applicable to their child. Parents were also asked to respond for ethnicity as either Hispanic/Latino or Non-Hispanic/Non-Latino. For the current project, race and ethnicity were combined to

create a race/ethnicity variable. Further, due to disproportionate representation of the Caucasian race, for analysis purposes categories were collapsed to include Hispanic/Latino, Other, and Caucasian.

Parent education level was recorded for each parent separately, and the categories included were: Completed Less than 9th Grade; Completed School Through the 9th Grade; Some High School without Diploma; GED or High School Equivalency; High School Graduate; Baccalaureate/ 4-year degree; and Graduate or Professional degree. To streamline analyses, the mother and father educational levels were combined into a single variable, "parent education level". This variable was calculated by taking the arithmetic mean of the father and mother education level, and this was used in all regression analyses because correlational analyses conducted prior to main analyses revealed correlations between mother and father level of education within each of the three samples ($r$ = .49 to .66, all $p$s < .001). Annual household income was also presented in categories. Specifically, the categories available as choices to participant families included: Less than $20,000; $21,000-35,000; $36,000-50,000; $51,000-65,000; $66,000-80,000; $81,000-100,000; $101,000-130,000; $131,000-160,000; and More than $161,000.

**Onset of atypical symptomatology.** Parents participating as SSC families were administered an extensive, semi-structured interview relevant to ASD diagnosis: the *Autism Diagnostic Interview-Revised* (ADI-R; Rutter, Le Couteur, & Lord, 2003). The ADI-R is one of the two[2] ASD-specific diagnostic instruments used by National Institutes of Health (NIH) -funded Autism Centers of Excellence (ACE) (National Database for

[2] The other is the Autism Diagnostic Observation Schedule (ADOS), discussed in subsequent paragraphs.

Autism Research, [NDAR], 2011). Within the SSC, all phenotyping clinicians administering this interview must have (a) attended ADI-R training conducted through the University of Michigan's Autism and Communication Center (UMACC), as well as have (b) established inter-rater reliability at .90 or above with SSC clinician consultants who were considered experts on this measure. The second question of the ADI-R (Rutter et al., 2003) asked parents for the age at which they first noticed something was atypical about their child's development. Their response was recorded in months and indicates the parents' perception of when their child began exhibiting symptoms of atypical development. Since it is unlikely that parents would seek any type of treatment prior to perceiving a problem with their child's development, this score was considered to be the age at which parents first had the opportunity to pursue treatment.

**Verbal ability.** Data regarding child verbal cognitive level were collected by the phenotyping clinicians employed within the respective SSC sites. The SSC research protocol allowed for the use of one of several verbal ability measures. For young or low-functioning children, the Mullen Scales of Early Learning (MSEL; Mullen, 1995) was one option. The age range for the Mullen is birth to 5 years, 8 months. This instrument can yield a standard, global score ($M$ = 100; $SD$ = 15) called the Early Learning Composite, which is derived from scales ($T$-scores; $M$ = 50, $SD$ = 10) measuring the following areas: Gross Motor, Visual Reception, Fine Motor, Receptive Language, and Expressive Language.

A second cognitive instrument available to SSC phenotyping clinicians were the Differential Ability Scales- Second Edition (DAS-II; Elliott, 2007). Two batteries are available within the he DAS-II: Early Years (ages 2:6-6:11) and School-Age (ages 7:0-

17:11). Though different subtests are administered based on the battery administered, there is normative overlap between the two batteries. Global scores derived from examinees older than age 7 years who are suspected to have cognitive performance lower than expected can be administered the Early Years battery. Scores yielded for both the Early Years and School-Age batteries include the General Conceptual Ability Composite (GCA), Special Nonverbal Composite (SNC), Verbal Ability Cluster, and Nonverbal Ability Cluster. Standard scores for each of these Composites have a mean of 100 and standard deviation of 15; *T* scores (for subtests) have a mean of 50 and standard deviation of 10.

The Wechsler Intelligence Scales for Children- Fourth Edition (WISC-IV) was also an option for measuring child cognitive functioning. The WISC-IV yields a global score (Full Scale IQ [FSIQ]) and four index scores: (1) verbal composite (VCI); (2) perceptual reasoning (PRI); (3) working memory (WMI); and (4) processing speed (PSI). The FSIQ and all Index scores are reported in standard scores (SS; M = 100, SD =15).

In this study, verbal cognitive ability was the cognitive variable of interest, as verbal ability is often perceived as representative of overall cognitive functioning (Sternberg et al., 1981). This may be related to findings such as higher verbal cognitive ability being predictive of better classroom performance (Klinger, O'Kelley, & Mussey, 2009), or related to better functional outcomes for children with ASD (Black, Wallace, Sokoloff, & Kenworth, 2009). Though no single pattern of verbal-nonverbal cognitive ability is indicative of an ASD diagnosis (Klinger, O'Kelley, & Mussey, 2009), children with ASD often demonstrate uneven cognitive profiles, such that there may be wide discrepancies between their verbal and nonverbal cognitive performance (Black et al.,

2009). When such discrepancies exist, overall (i.e., full scale) cognitive scores which are derived from verbal and nonverbal cognitive functioning considered together may be poor indicators of cognitive functioning (Sattler, 2008).

Both the DAS-II and the WISC-IV yield a verbal composite score ($M$ = 100; $SD$ = 15), and each composite is derived from scores on two or three verbal subtests, depending on the cognitive instrument used. The Verbal Ability Cluster of the DAS-II is measured with the Verbal Comprehension and Naming Vocabulary subtests (Early Years battery) or with the Verbal Similarities and Word Definitions subtests (School Age Battery). On the WISC-IV, the Verbal Comprehension Index (VCI) is measured using the Vocabulary, Similarities, and Comprehension subtests. The verbal composite score for the Mullen is derived from the Expressive and Receptive subtests by adding together the respective $T$ scores and then multiplying their sum by two, per SSC protocol.

Two types of verbal cognitive scores were reported and available for analysis for SSC participants: ratio and deviation scores. Ratio scores were calculated by dividing the mean of subtest age equivalent scores (in months, as detailed in the respective test manuals) and dividing by the chronological age of the child (in months), multiplied by 100. Deviation scores, or norm-referenced scores, are those derived by comparing performance to that of same-age children within the normative group, and these were available for most participants. The percentages of participants with available deviation scores for the verbal composites, respectively, are as follows: SSC- 87.1%; BCM- 81.4%; and ND- 77.2%. Within the SFARI protocol for the SSC, there were two scenarios when deviation (scores were not available: a) when participants' performance on subtests yielded scores at or below the floor (i.e., lowest available score), or b) when participants'

required out-of-age-range cognitive testing, in which case the norm-reference group would not include scores for that age participant. All analyses were conducted using deviation scores when available and ratio scores in the absence of deviation scores. Because not all scores are deviation and not all are derived from the same cognitive instrument, the verbal cognitive scores utilized within this study are most appropriately conceptualized as an estimate of participants' verbal cognitive ability. Though the procedures for collecting verbal cognitive data were clearly outlined and stringently adhered to per the SSC research protocol, use of different instruments for measuring verbal ability does represent a limitation and will be discussed in subsequent sections.

**Severity of currently observed ASD symptomatology.** All child participants within the SSC were administered the *Autism Diagnostic Observation Schedule* (ADOS; Lord et al., 2000). The ADOS is a semi-structured assessment of social, communicative, and play/imaginative use of materials, and it allows examiners to observe occurrence and non-occurrence of behaviors characteristic of ASD. Phenotyping clinicians who administered this instrument were required to have attended ADOS training through UMACC and to have established inter-rater reliability of .80 or above with other SSC phenotyping clinicians in administering and scoring the items. The ADOS can be used with children or adults ranging from having no speech (e.g., Module 1) to speech with flexible three-word phrases (e.g., Module 2) to verbal fluency (e.g., Module 3 or 4) (Lord et al., 2000). Phenotyping clinicians administer 1 of 4 available modules (e.g., versions) of the ADOS, and selection of the module is dependent on the child's expressive language level. For example, Module 1 is administered to persons who are non-verbal or have single word speech, and Module 2 is administered to persons who are using phrase

speech. Examinees who are using expressive speech fluently are administered Module 3, while Module 4 is designed for use with verbally fluent examinees who are over the age of 17.

Key behaviors characteristic of ASD are coded by examiners during the administration and yield scores in the respective domains of the ADOS (e.g., social communication, restricted repetitive behaviors). Scores were calculated using an algorithm specific to each module, and SSC phenotyping clinicians used revised ADOS algorithms, which were developed to improve the sensitivity and specificity of the instrument (Gotham, Risi, Pickles, & Lord, 2007). Ooserterling et al. (2010) point out that these new algorithms do enhance comparability among Modules, reduce effects of age and IQ, and allow for direct comparison with ADI-R scores. Their replication of the Gotham et al. (2007) study yielded results supporting use of the new algorithms, despite some concerns they raised about relatively low sensitivity (Oosterling et al., 2010).

To enhance the utility of ADOS scores in research by addressing the problems with comparing raw scores that are developmentally-graded across modules, Gotham, Pickles, & Lord (2009) have developed a method of standardizing ADOS scores in order to estimate the severity of overall ASD symptoms. Gotham et al. (2009) aimed to reduce the effect of demographic variables on ADOS scores and to produce a standard score that estimates severity of autism characteristics, and the result is a metric called "calibrated severity scores". In the SSC repository, calibrated severity scores (CSS) were available for those children who were administered Modules 1, 2, or 3 and provided an estimate of the relative severity of each child's ASD symptomatology, as observed by the clinician and scored on the ADOS.

**Parent perceptions about child's ASD.** Parent perceptions about their child's ASD were measured using the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002). The IPQ-R extends the work of Weinman, Petrie, Moss-Morris, & Horne (1996), who developed the original Illness Perception Questionnaire (IPQ). This instrument was designed to measure the five components of illness representation (e.g., identity, consequences, timeline, control/cure, and cause), which were identified in Leventhal's Self-Regulatory Model of illness representation (Leventhal et al., 1984; 1997). Development of the IPQ-R (Moss-Morris et al., 2002) included additional items that increased the internal consistency reliability of the subscales and also provided additional support for Leventhal's Self-Regulatory Model (Leventhal et al., 1984; 1997), with particular emphasis on the differentiation that emerged through Principle Components Analysis (PCA) between the emotional and cognitive dimensions of illness representation.

Subscales identified in the IPQ-R are as follows: Timeline- Acute/Chronic; Timeline- Cyclical; Consequences; Personal Control; Treatment Control; Illness Coherence; and Emotional Representations. Two additional subscales—Identity and Cause—are presented separately. All subscales, with the exception of the Identity subscale, were shown to have good internal consistency reliability, with Cronbach's alpha ranging from $\alpha = .79$ to .89. The Identity subscale demonstrated respectable internal consistency reliability ($\alpha = .75$).

The IPQ-R includes a total of 76 items that measure the 8 scales (Identity is not included as a "scale"). The first 14 items present symptoms and ask whether parents have observed these in their children. They are asked to check a box corresponding to

either “yes” they have observed the symptom in their child or “no” they have not observed the symptom in their child. In addition, the symptoms request a check-box “yes” or “no” response to whether parents believe that the symptom is associated with their child’s diagnosis. The next 38 items are statements about parent opinions, perceptions, and affective responses to aspects of their child’s diagnosis. Response format for these items is a 5-point Likert scale ranging from 1 = Strongly Disagree to 5 = Strongly Agree. Parents are asked to check the box corresponding to the extent to which they agree with the statement. The final section provides 21 statements of reasons parents may believe their child has a diagnosis, and response format is also on a 5-point Likert scale (i.e., 1 = Strongly Disagree to 5 = Strongly Agree). High scores on the Identity, Timeline Consequences, and Cyclical dimensions indicate strong beliefs about number of symptoms attributed to the illness, chronic nature of the condition, negative consequences of the illness, and the cyclical nature of the illness. High scores on the personal control, treatment control, and coherence dimensions indicate positive beliefs about how controllable the illness is and how well the illness is understood (Using and Scoring the IPQ-R, no date). Three blanks are provided at the bottom of the page where parents are prompted to write in rank-order their beliefs about the underlying cause of their child’s diagnosis.

The IPQ (Weinman et al., 1996) and IPQ-R (Moss-Morris et al., 2002) authors encourage researchers to adapt language of the causal and identity subscales to enhance applicability to their areas of study. Recently, the IPQ-R was adapted to explore the role of parent perceptions on treatment decision-making within families of children with ASD (IPQ-RA; Al Anbar et al., 2010). Modifications to the IPQ-R (Moss-Morris et al., 2002)

made within the Al Anbar et al., (2010) study included use of the word "disorder" instead of "illness", inclusion of a symptom list with ASD characteristics, and wording appropriate to caregivers (e.g., replaced "my illness" with "his disorder").

For the current study, the language of the IPQ-R was modified, and the modifications differed slightly from those made by Al Anbar et al. (2010). Specifically, the words "his/her illness" were replaced with "your child's ASD". In addition to adhering to person-centered language emphasized by the American Psychological Association (APA, 2010), this wording was used with the goal of not offending parents who may not view their child's ASD diagnosis as either an illness or a "disorder". The wording within the original IPQ-R citing "Hereditary- Runs in my family" as a potential cause for illness was changed to "Genetics", a distinction that seemed important within the current sample as families were included in the SSC specifically *because* their child's ASD is *not* thought to be inherited but is being investigated as having genetic components. Finally, four additional potential causes of ASD were included in the last section, and these include "in utero stress or accident", "my child's brain structure", "toxins found in vaccines/immunizations", and "stress at birth". This is aligned with current research indicating that these causes are sometimes considered by parents of children with ASD (Hebert & Koulouglioti, 2010). In the current study, the version of the IPQ-R mailed to potential participants inadvertently omitted two items. One of these items was from the Treatment Control subscale (e.g., "The negative effects of my child's ASD can be prevented (avoided) by my treatment.") and the other was from the Illness Coherence subscale (e.g., "My child's ASD is a mystery to me.") The survey sent to parents is included in Appendix A.

**Treatments chosen by parents.** Data regarding treatments chosen by parents for their children with ASD were taken from existing data within the SSC repository. This information was gathered during the extensive Medical History Interview (MHI) conducted by site research coordinators with parents via phone prior to the phenotyping appointment, which included completion of the Treatment History Form (TRH). Categories of treatment queried for parents within the TRH were organized by general type of treatment (column) and age in years when treatment took place (row). The categories included: Private Speech/Language Therapy; School-Based Speech/Language Therapy; Private Occupational Therapy; School-Based Occupational Therapy; Intensive Behavioral Therapy (ABA, AVB, VB, Pivotal Response, Discrete Trials, etc.); Other Intensive Therapy (TEACCH, Floortime, etc.); Biomedical Treatment (Special Diet, Chelation, etc.); and Any Other Treatment/Therapy. School Classroom Placement was also queried within the TRH but this was not considered within the current study.

For each age beginning at age 2 years, parents were asked to specify descriptions of any treatments endorsed, including hours per week and weeks per year, and responses were recorded in the appropriate rows to capture the time period (i.e., year) the treatment was conducted. The extant data regarding treatment choices included information about what types of treatment parents were using at the time of data collection (*Current*) and also what types they had chosen *in the past*. For analysis in the current project, an *Ever* variable was created for each treatment type, and this variable included both currently and previously used treatment types. Parents of children with ASD often use multiple treatments simultaneously (Aman, 2005; Bowker, D'Angelo, Hicks, & Wells, 2011; Goin-Kochel et al., 2007; Green et al., 2006) and to initiate or discontinue treatments

suddenly (Bowker et al., 2011). For these reasons, the *Ever* variable was created with the goal of capturing the most information about treatment use as was possible.

In addition to treatment types outlined on the TRH, psychotropic medication use was included as a treatment type, as children and adolescents with ASD often taken psychotropic medications (Aman et al., 2005). Data regarding psychotropic medication use were collected from the MHI itself, wherein parents were presented with different classes of medications (i.e., antidepressants, antihypertensives, etc.) and asked to endorse wither their child was taking that type of medication now (*Current*) or in the past. Medications prescribed for their psychotropic effects include a wide range of formulations. Psychotropic drugs, also referred to as psychoactive drugs, include any chemical substances that influence mood or behavior as a result of alterations in brain functioning (Julien et al., 2008). These include stimulant and non-stimulant drugs to treat ADHD symptoms, antidepressants (tricyclics, selective serotonin reuptake inhibitors or SSRIs, serotonin-norepinephrine reuptake inhibitors or SNRIs, and atypical antidepressants), anxiolytics (benzodiazepines, sedatives), antipsychotics (first generation/typical and second generation/atypical), and anticonvulsants/antiepileptics, lithium, antihypertensives, and naltrexone.

Within the SSC protocol, however, psychotropic drug use was differently characterized. Unlike the TRH, parents were asked only whether they were “currently” using different categories of Psychotropic Medications or had used them in the “past” (e.g., specific ages were not queried). Specific medication categories capturing psychotropic medication use were classified within the SSC repository under the following titles: “Medications for Attention Deficit Disorder”, “Antiepileptics or anti-

seizure medications"; "Antidepressants", "Mood Stabilizers or anti-psychotics", "Sedatives or sleeping pills", and "Tranquilizers or nerve pills". However, for the current study, the use or non-use of *any* type of Psychotropic Medication was of primary interest; because this research is exploratory and focused on factors related to selection of *types* of treatments, all psychotropic medication classes were collapsed into this dichotomous (i.e., use or non-use) variable.

A total of nine treatment types, as well as a "no treatment" option if parents did not endorse use of any category of treatment, were investigated as potential choices for parents: Private Speech Therapy, School-Based Therapy, Private Occupational Therapy, School-Based Occupational Therapy, Intensive Behavioral Therapy, Other Intensive Therapies, Biomedical Treatments, Psychotropic Medications, and Any Other Treatments (e.g., social skills, etc.). There was no limit to the number of treatment types parents could endorse, but if no treatment category was endorsed, this was classified as "no treatment *Ever* endorsed".

Future studies may investigate patterns of treatment choices over time. To facilitate future studies in this vein, additional treatment information was obtained from the ND participants. A total of 124 treatment options, based on the work of Green et al. (2006), were listed on a 3-page form included in the survey packet mailed to potential participants from the BCM group. Parents were first asked to indicate their child's educational placement, and for these and the treatment options, the date(s) of treatment were requested. Finally, an "other" category was provided at the end of the questionnaire to allow parents to provide information about additional, unlisted treatments they have used either now or in the past. This form is included in Appendix B.

**Procedures**

Approval was granted from the University of Houston's Committees for the Protection of Human Subjects (CPHS), the Institutional Review Board at Baylor College of Medicine (BCM), and the SFARI to utilize the SSC data set. Informed consent was sought from all SSC participants prior to study participation that addressed both phenotypic and genotypic data collection, as well as informed that their de-identified data would be made available to researchers who requested and were approved for access to the data set. Details regarding access to the SSC dataset is available via the Internet (http://sfari.org/simons-simplex-collection).

**The three samples (SSC, BCM, ND).** Extant data were requested through the SFARI system after receiving approval from the UH CPHS committee and the BCM IRB. These data were used to answer the first research question (e.g., how many treatments were used by parents of children/adolescents with ASD?) and the second research question (e.g., are there characteristics of children and/or families that impact treatments chosen for their children?). To address the third research question regarding the potential contribution of parent perceptions of ASD on treatment choices, new data were collected in the local (e.g., Baylor College of Medicine) sub-sample of the SSC. Families who participated in data collection at BCM prior to January 2011 (n = 199) completed informed consent that inquired specifically whether the family was willing to be re-contacted for future research studies about ASD. Of the families who had participated at BCM by January 2011, 148 consented to recontacting. All information about these families is kept within a password-protected database at BCM and maintained by an SSC research coordinator. Names, four-digit local identification numbers, and

contact information was obtained from the SSC research coordinator. Each family who provided consent to be re-contacted was mailed a research packet which included a welcome letter (Appendix C), statement of informed consent (Appendix D), in addition to the aforementioned adapted IPQ-R questionnaire (Appendix A), the updated treatment history form (Appendix B), all in a stamped, addressed envelope. Completion of the IPQ-R and updated treatment history form was estimated to take approximately 30 minutes for participants to complete. The packet included the explanation that there was no obligation for study participation but returning a completed packet in the enclosed envelope would serve as their informed consent for participation. This was done with the goal of maintaining their anonymity since no name (e.g., signature) was associated with the returned research packet. Families received no compensation or reward for returning the new data (e.g., IPQ-R and Updated Treatment Form). Parents were also informed that neither participation nor non-participation in the current study would impact their standing as an SSC family.

To ensure that the responses obtained from participants in the new study were correctly linked to extant data in the local database, each form included in the mailed packet included the family's unique four-digit local identification number. These numbers were assigned to participating families when they entered the local SSC sub-sample at BCM and were numbers used in uploading family data gathered during SSC participation into the local database. The identification number was also included on the envelope mailed to the family and the envelope enclosed for returning documents. Family names were utilized in the address but not included on any document within the

packet. Each return envelope was stamped and addressed to the student researcher's local post office box.

***ND sample: Additional considerations.*** Approximately three weeks after the packets were mailed, all families were emailed regarding the packet that was sent and the opportunity to obtain a new packet if needed by responding to the email. The email is included in Appendix E. Fourteen parents requested a second packet be mailed to them. Names from these emails were provided for the SSC research coordinator who obtained the families identification number and resent the requested packets, which were identical to the original survey packets. Within the ND sample (n = 68), three respondents returned their modified IPQ-R survey without completing the last page of the questionnaire (opinions regarding causes of their child's ASD), presumably due to failure to turn over the last page. A blank copy of the missing page along with an addressed and stamped envelope was mailed to each of these participants with a note requesting completion of the page. All three participants returned this page. Overall, 148 families were mailed survey packets and 68 were returned prior to data analysis for a response rate of 46%.

Two questions from the IPQ-R were inadvertently omitted during survey preparation, such that all respondents' questionnaires were missing these items. The first omitted item was from the Treatment Control subscale: "The negative effects of my child's ASD can be prevented (avoided) by my treatment." The second omitted item was from the Illness Coherence scale: "My child's ASD is a mystery to me." To correct for this, mean substitution was conducted such that the missing values were replaced with the mean of the participant's responses on the other items of the same subscale. Both the

Treatment Control and Illness Coherence subscales include five items each. Therefore, the mathematical means of the four existing items on the respective subscale were calculated and entered as best estimate values for the missing item on that subscale. Though not ideal, this popular type of imputation is a conservative method of estimating the value of missing variables (Tabachnick & Fidell, 2001). This imputation was conducted to adhere to the structure of the IPQ-R, an established instrument. The limitations of this approach will be addressed in the Discussion.

**Statistical Analysis**

**Data preparation.** Prior to conducting any statistical analyses, all data were screened in SPSS to a) ensure they were entered correctly, b) look for missing values, and c) check for outliers. Guidelines for data collection and data entry were detailed and stringent across all SSC sites. Two researcher coordinators from each SSC site independently entered and validated each participating family's data. Then, a series of "flight checks" were run in RexDB (the data management software) as an initial cross-examination, which allowed for identification of any missing items, unusual or out-of-range scores, and/or inconsistent patterns in scores across measures. Any "warning" or "fail" messages in the "flight check" report prompted further review of the data in question; corrections were made when warranted, and "flight checks" were conducted until reports came back without errors. The family's data were then submitted electronically to the RexDB portal for viewing by the SSC site's off-site clinical consultant. The consultant performed a serious of additional validation checks and queried the site's research staff about any items needing correction or clarification. The site consultant then determined the family's final acceptance into the collection. Families

who were accepted into the collection had been stripped of all identifying information and were given a new, unique identification number. These procedures increased the likelihood of correct data entry and decreased the likelihood of missing data, and Fischbach and Lord (2010) note that the SFARI (extant) data set is "unusually clean" due to the extensive reliability checks conducted throughout data collection. For newly created variables, raw data were used to correct any out-of-range values were identified.

Although the standard research protocol for the SSC reduced the likelihood of missing values, missing value analyses were conducted as a part of the current study using frequency tables for all variables in the three datasets (e.g., SSC, BCM, ND) to review the three datasets for potential problems. No more than 6% of values were missing on any variable in any dataset. Missing values were identified in the following categories: income (SSC-6%; BCM-4%; ND-4.5%), calibrated severity scores (CSS; SSC-3%; BCM-5%), and parent education level (SSC: 1.4%). These were likely non-random missing errors, in that SSC participants may have chosen to not report their income and/or educational level. CSS were not generated for any participant who received the ADOS Module 4 (SSC: 65; BCM: 1; ND: 0). Within the race/ethnicity category, no missing values were identified in any dataset, though it is important to note that the parent choice of "not specified" was collapsed into the "other" category for purposes of statistical analysis. In addition, missing data were not identified for any treatment category, though the manner in which these data were collected possibly precludes knowledge about truly missing data. Specifically, research coordinators recorded affirmative parent responses regarding whether their children had particular treatments at particular ages but did not consistently record negative responses.

Therefore, absence of data about treatment at a specific age likely represents absence of treatment at that age but also may represent missing data.

Tabchnick and Fidell (2001) note that non-random missing data are problematic because this may limit generalizability of the results. Missing data that do not occur for more than 5% of a large sample are generally considered to be acceptable (Tabachnick & Fidell, 2001) and current data fell close to this guideline.

Identification of outliers is important because they can cause regression models to be biased due to the effect they have on estimated regression coefficients (Fields, 2009). Univariate outliers, or extreme values on a single variable, were first identified by visually inspecting simple histograms for any cases that appeared to fall outside of the range of most other scores. Because of the potential to influence statistical analyses, outliers were identified through examination of diagnostic statistics for each of the three datasets. Standardized residuals (residuals divided by an estimate of their standard deviation; converted to z-scores) of different models were reviewed to determine how well the models represented the actual data. Specifically, Field (2009) suggests that standardized residuals above 3 may be considered outliers. By this criterion, so few outliers were identified within the three datasets (SSC: 1; BCM: 3; ND: 1) that data analyses were unlikely to be influenced. Potentially influential cases were examined by utilizing Cook's distance, a measure of the overall influence of a single case on a regression model as a whole. Values over 1 are considered problematic (Cook & Weisberg, 1982, as cited in Field, 2009), and no Cook's distance values over 1 were found among any of the three datasets.

**Preliminary analyses.** To investigate the research questions, several analyses were conducted in PASW Statistics 18. Descriptive analyses were first conducted for the child- and family-specific variables, and Tables 1 and 2 includes these statistics grouped by sample (e.g., SSC, BCM, ND). To determine whether the BCM and ND samples were representative of the national (SSC) sample independent sample *t*-tests were conducted. In addition, Pearson chi-square analyses were conducted to examine differences among the three groups in terms of (a) gender, and (b) race/ethnicity. Correlational analyses were performed using all potential predictor variables to examine relationships among them that might indicate collinearity or confounding effects. Pearson product-moment correlations were utilized to examine correlations between continuous variables, and Spearman correlations were used to examine relationships between categorical variables; point-biserial correlations (an application of Pearson product-moment correlations) were utilized when one variable was dichotomous.

To address the first research question regarding treatments used by families of children with ASD, descriptive analyses were completed to examine the frequency of different treatment usage across the SSC, BCM, and ND groups. Both *Current* and *Ever* (lifetime) treatment use was examined for each of the three groups.

**Main analyses—binary logistic regressions.** A series of binary logistic regression analyses were conducted to answer the second research question regarding the extent to which child and family-specific characteristics would predict utilization of certain treatment types. Within each sample, one binary logistic regression was performed for each treatment type: several child and family-specific characteristics were entered as potential predictors and a binary dependent variable (0 = no treatment, 1 =

treatment) was the outcome variable. Binary logistic regression analyses were chosen because these allow for the prediction of group membership, as well as determination of the relative contribution that predictors have on the binary outcome/dependent variable (Field, 2009). Stepwise logistic regressions test the fit of the model after each coefficient is added or deleted, and this method is useful and appropriate during the exploratory phase of research (Menard, 1995, as cited in Field, 2009). The current research is exploratory in nature because no a priori assumptions regarding the relationships between the variables were made.

***Correction for multiple comparisons.*** In the current study, multiple binary logistic regression analyses were conducted, as described in detail in the subsequent paragraphs. When multiple analyses are performed, the likelihood of a significant finding due to chance increases (i.e., Type I error/false positive due to random variability), and many researchers suggest that adjusting the *p* value can help reduce such familywise error rates (Field, 2009). However, reducing this type of error increases the likelihood of missing true effects (i.e., Type II error/false negative rates), and the balancing of these different types of error must be considered (Feise, 2002). The current study is considered exploratory, in that little research regarding the contribution of multiple factors to ASD treatment selection is available. As such, no adjustment for multiple comparisons was utilized for the main analyses, since identifying potentially contributory factors is desirable in this study (Rothman, 1990). Instead, interpretation of logistic regression will focus on the odds ratios, as this indicates the magnitude of the effect (Field, 2009).

***SSC and BCM samples— logistic regression.*** Backward stepwise logistic regressions were used for analyses within the SSC (n =2,115) sample. Backward stepwise regression is the preferred method of stepwise regression because there is less risk of excluding predictors that yield suppressor effects, thereby reducing the risk of Type II error (Field, 2009). In the backward stepwise logistic regressions, all predictor variables (e.g., child- and family-specific variables) were initially entered into models for each outcome (e.g., presence or absence of treatment type). These predictors were then removed from the model (by SPSS) if the significance value of the *t*-test for each predictor exceeded $p = .05$, as this suggested predictors did not have a substantial effect on how the model fit the observed data, beginning with the one with the least impact on how the model fit the data (Field, 2009).

For the BCM (n = 199) sample, forward stepwise binary logistic regression analyses were utilized. Though the forward method is more likely to exclude predictors that truly predict the outcome (i.e., increased likelihood of Type II error), forward stepwise logistic regressions were preferable to backwards with the smaller BCM sample size due to the number of predictor variables, which can result in over-fitting the model (i.e., relationships appear to be statistically significant but are not, resulting in the model poorly replicating and poorly predicting future responses) (Field, 2009). In forward stepwise regression, the initial models included only a constant ($b_0$) and as predictors were added to the model, redundant predictors (i.e., not making statistically significant contribution as determined by $p > .05$) were removed (by SPSS), and contributions of remaining predictors were then reassessed.

For both the SSC and BCM datasets, one stepwise binary logistic regression was conducted per treatment type, wherein each model predicted *Ever* having used (1) or not used (0) a different treatment type. Child-specific predictors entered into the backward stepwise binary logistic regression models for the SSC sample included gender, current age, race/ethnicity, severity of ASD symptomatology, and verbal cognitive scores; family-specific predictors entered included family income, parent education level, and parent report of age onset atypical symptomatology. The forward stepwise binary logistic regression models for the BCM sample included the same child- and family-specific predictors, with the exception of child gender, as gender was not retained as a predictor in any of the SSC sample models.

***IPQ-R subscales as predictors for ND sample.*** In preparation for analyses to address the third research question, whether parent perceptions about their children's ASD would be predictive of use or non-use of specific treatment types, descriptive analyses for the IPQ-R subscales, including the two subscales with imputed sums (e.g., Treatment Control, Illness Coherence), were conducted and are included in Table 3.

Table 3

*Descriptive Characteristics of the IPQ-R Subscales within the ND Sample*

| IPQ-R Subscale | M | SE | SD | Range |
|---|---|---|---|---|
| Identity | 8.93 | 0.387 | 3.164 | 2 to 14 |
| Timeline-Acute/Chronic | 23.88 | 0.572 | 4.717 | 6 to 30 |
| Consequences | 22.72 | 0.612 | 5.043 | 9 to 30 |
| Personal Control | 25.1 | 0.375 | 3.096 | 19 to 30 |
| Treatment Control | 19.68 | 0.366 | 2.998 | 10 to 25 |
| Illness Coherence | 16.41 | 0.478 | 3.941 | 6 to 25 |
| Timeline- Cyclical | 11.63 | 0.41 | 3.381 | 4 to 20 |
| Emotional Representations | 20.4 | 0.597 | 4.927 | 9 to 30 |

*NOTE:* High scores on Identity, Timeline- Acute/Chronic, Consequences, Timeline-Cyclical, and Emotional Representations dimensions indicate strongly-held beliefs, respectively, that symptoms observed are attributable to ASD, that ASD is chronic, that there are negative consequences associated with ASD, that ASD is cyclical in nature, and that there are negative feelings associated with ASD. High scores on Personal Control, Treatment Control, and Illness Coherence represent positive beliefs about controllability of ASD and personal understanding of ASD. (Using and Scoring the IPQ, n.d.)

A series of exploratory logistic regressions were conducted with the IPQ-R subscales to make a decision about whether these subscales should be entered as predictors in the ND group's binary logistic regressions for predicting utilization of the respective treatment types. For each treatment type, separate logistic regressions were conducted for the respective treatments, using a subscale of the IPQ-R entered as the single predictor. Due to the relatively small sample size of the ND group, this was done with the goal of including only those subscales most likely to be significant when entered as one of the predictors of the different treatment types in subsequent analyses.

Odds ratios were generated for each subscale per treatment type. The criterion for retaining IPQ-R subscales for entry into subsequent binary logistic regressions for the ND sample was $p \leq .15$. This criterion was chosen to increase the likelihood that subscales that could be important predictors for treatment type use in the ND sample would be

included in the logistic regressions (Hosmer & Lemeshow, 1989, as cited in Tabachnick & Fidell, 2001), although it is recognized that this increases the likelihood of making a Type I error. The odds ratios and p-values for IPQ-R subscales used to determine whether they would be included in the ND logistic regression analyses is included in Table 4.

Table 4

*Odds Ratios and p-values for IPQ-R Subscales by Lifetime Treatment Type, Used to Determine Inclusion/Exclusion in ND Logistic Regression Analyses*

| Treatment / Subscale | PRIVATE ST | | | SCHOOL-BASED ST | | |
|---|---|---|---|---|---|---|
| | Exp(B) | *p* | Used[a] | Exp(B) | *p* | Used[a] |
| Identity | 1.073 | 0.371 | no | 1.25 | 0.037 | yes |
| Timeline- Acute/Chronic | 0.877 | 0.048 | yes | 0.943 | 0.452 | no |
| Consequences | 1.081 | 0.706 | no | 0.95 | 0.439 | no |
| Personal Control | 1.041 | 0.641 | no | 0.866 | 0.177 | no |
| Treatment Control | 1.17 | 0.078 | yes | 1.037 | 0.726 | no |
| Illness Coherence | 0.996 | 0.955 | no | 1.128 | 0.13 | yes |
| Timeline- Cyclical | 1.031 | 0.672 | no | 0.844 | 0.077 | yes |
| Emotional Representations | 1.054 | 0.298 | no | 1.029 | 0.652 | no |

[a] Criterion for inclusion in subsequent logistic regressions for the ND sample was $\alpha \leq .15$.

| Treatment / Subscale | PRIVATE OT | | | SCHOOL-BASED OT | | |
|---|---|---|---|---|---|---|
| | Exp(B) | *p* | Used[a] | Exp(B) | *p* | Used[a] |
| Identity | 1.079 | 0.335 | no | 1.288 | 0.006 | yes |
| Timeline- Acute/Chronic | 0.952 | 0.358 | no | 1.027 | 0.626 | no |
| Consequences | 1.04 | 0.426 | no | 1.048 | 0.357 | no |
| Personal Control | 0.978 | 0.782 | no | 0.988 | 0.88 | no |
| Treatment Control | 1.24 | 0.023 | yes | 0.917 | 0.308 | no |
| Illness Coherence | 1.057 | 0.38 | no | 1.106 | 0.134 | yes |
| Timeline- Cyclical | 1.046 | 0.54 | no | 0.959 | 0.572 | no |
| Emotional Representations | 1.037 | 0.473 | no | 1.047 | 0.37 | no |

[a] Criterion for inclusion in subsequent logistic regressions for the ND sample was $\alpha \leq .15$.

| Treatment / Subscale | INTENSIVE BEHAVIORAL | | | OTHER INTENSIVE | | |
|---|---|---|---|---|---|---|
| | Exp(B) | *p* | Used[a] | Exp(B) | *p* | Used[a] |
| Identity | 1.373 | 0.005 | yes | 1.488 | 0.091 | yes |
| Timeline- Acute/Chronic | 0.955 | 0.408 | no | 0.881 | 0.114 | yes |
| Consequences | 1.157 | 0.037 | yes | 1.048 | 0.673 | no |
| Personal Control | 1.109 | 0.838 | no | 0.961 | 0.813 | no |
| Treatment Control | 1.166 | 0.127 | yes | 1.57 | 0.045 | yes |
| Illness Coherence | 1.03 | 0.681 | no | 1.11 | 0.463 | no |
| Timeline- Cyclical | 1.129 | 0.156 | no | 1.059 | 0.705 | no |
| Emotional Representations | 1.141 | 0.039 | yes | 1.117 | 0.33 | no |

[a] Criterion for inclusion in subsequent logistic regressions for the ND sample was $\alpha \leq .15$.

| Treatment / Subscale | BIOMEDICAL | | | PSYCHOTROPIC MEDICATIONS | | |
|---|---|---|---|---|---|---|
| | Exp(B) | *p* | Used[a] | Exp(B) | *p* | Used[a] |
| Identity | 1.111 | 0.27 | no | 0.885 | 0.129 | yes |
| Timeline- Acute/Chronic | 1.003 | 0.957 | no | 0.994 | 0.908 | no |
| Consequences | 1.043 | 0.478 | no | 0.988 | 0.806 | no |
| Personal Control | 1.021 | 0.827 | no | 1.227 | 0.019 | yes |
| Treatment Control | 1.012 | 0.898 | no | 1.411 | 0.002 | yes |
| Illness Coherence | 1.095 | 0.243 | no | 0.943 | 0.349 | no |
| Timeline- Cyclical | 0.978 | 0.791 | no | 1.031 | 0.677 | no |
| Emotional Representations | 1.067 | 0.28 | no | 1.001 | 0.988 | no |

[a] Criterion for inclusion in subsequent logistic regressions for the ND sample was $\alpha \leq .15$.

| Treatment / Subscale | ANY OTHER | | | NONE | | |
|---|---|---|---|---|---|---|
| | Exp(B) | *p* | Used[a] | Exp(B) | *p* | Used[a] |
| Identity | 0.981 | 0.824 | no | 0.719 | 0.214 | no |
| Timeline- Acute/Chronic | 1.04 | 0.522 | no | 1.884 | 0.17 | yes |
| Consequences | 1.019 | 0.726 | no | 1.202 | 0.367 | no |
| Personal Control | 0.97 | 0.725 | no | 1.045 | 0.853 | no |
| Treatment Control | 0.936 | 0.47 | no | 0.789 | 0.292 | no |
| Illness Coherence | 1.007 | 0.918 | no | 0.745 | 0.129 | yes |
| Timeline- Cyclical | 1.054 | 0.509 | no | 1.233 | 0.323 | no |
| Emotional Representations | 1.049 | 0.384 | no | 1.19 | 0.31 | no |

[a] Criterion for inclusion in subsequent logistic regressions for the ND sample was $\alpha \leq .15$.

***ND sample— binary logistic regression.*** Subsequently, series of forward stepwise binary logistic regressions were conducted for the ND dataset to investigate the third research question, whether parent perceptions about their children's ASD would be predictive of use or non-use of specific treatment types. As in the BCM analyses, separate forward stepwise binary logistic regressions were run for each treatment type, wherein the treatment type (i.e., presence or absence) was the outcome variable. Forward stepwise regression was used with the ND sample in order to reduce the likelihood of overfitting the models with a relatively small sample size (n = 68) compared with the number of potential predictors.

For the ND subsample, independent variables entered as potential predictors included only those found in the BCM subsample to be predictors within the final binary logistic regression models for a specific treatment. For example, within the BCM subsample, the following predictors were found to be predictive of Private Speech Therapy: race/ethnicity, family income, current age, age of onset of atypical symptomatology, and verbal cognitive score. Therefore, these five variables were entered into the ND subsample forward stepwise binary logistic regression for prediction of use or non-use of Private Speech Therapy. In addition, the two IPQ-R subscales retained according to the preparatory analysis (Timeline-Acute/Chronic, Treatment Control) were entered as additional predictors for a total of seven predictors entered for Private Speech Therapy within the ND subsample.

For all stepwise logistic regression models described, correlational analyses did not reveal any bivariate correlations above .60, which is lower than the guideline of $r$ = .70 at which variables may be considered redundant, and it is lower than bivariate correlations of $r$ = .90 at which statistical problems are caused by multicollinearity (Tabachnick & Fidell, 2001).

# Chapter III

## Results

Data from a total 2,115 participant families within the national SSC sample were analyzed, as well as data from 199 families who had participated in the BCM sub-sample, and, finally, from 68 families who participated in the ND sample.

### Differences Between Samples

Because participants of both the BCM and ND groups were drawn from the national sample, characteristics of the local subsamples were anticipated to be representative of the national sample. Table 5 includes the results of independent *t*-tests indicating that the three samples did not differ significantly on any of the child- and family-specific predictor variables utilized. Descriptive statistics on all child- and family-specific variables are presented in Tables 1 and 2.

Table 5

*Results of Independent t-tests Comparing Differences Among the Three Data Sets*

| | SSC v. BCM | | BCM v. ND | | SSC v. ND | |
|---|---|---|---|---|---|---|
| Variable | *t* | Df | *t* | df | *t* | df |
| Child Age | .785 | 2312 | -.922 | 265 | -.570 | 2181 |
| Age of Onset | -.851 | 2275 | -.49 | 262 | -.939 | 68.91 |
| CSS | .869 | 2236 | .057 | 254 | .598 | 2116 |
| Verbal Cognitive Score | 1.95 | 2310 | .220 | 263 | 1.26 | 70.22 |
| Parent Education | 1.667 | 2281 | -1.312 | 263 | -.590 | 2150 |
| Income | .287 | 2175 | -.582 | 254 | -.515 | 2049 |

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

Results of Pearson's chi-square analyses indicated that there was not a significant difference in terms of participants' gender across the three samples, $\chi^2$ (2, 2380) = .200, $p > .05$. However, there was a significant difference with regard to participant's race/ethnicity, $\chi^2$ (4, 2382) = 47.23, $p < .001$. Though most participants identified themselves as "Caucasian" in each sample, there were higher percentages of Hispanic/Latino participants within the BCM (26.1%) and ND (23.5%) samples as compared to those within the SSC sample (10.9%).

**Research Question 1**

**Current treatment use.** The first research question investigated in this study was, "how many treatment types are parents using for their children with ASD?" Identification of whether any of the nine treatment types were being used at the time of data collection (*Current*) was accomplished by examining only the responses for each treatment type for the participant's current age. On average, parents within the SSC sample endorsed using 1.97 (*SD* = 1.53) treatment types at the time of data collection. Within the BCM sample, this average was 1.57 (*SD* = 1.37) treatment types per participant. ND participants were using, on average, 1.62 (*SD* = 1.21) treatment types at the time of data collection. Table 6 shows the percentages and frequencies of treatments parents reported they were using at the time of data collection.

Table 6

*Percentage and Frequency of Endorsement of Number of Treatment Types Used Currently Across Samples*

| Number Treatment Types | Sample | | | | | |
|---|---|---|---|---|---|---|
| | SSC (*n* = 2,115) | | BCM (*n* = 199) | | ND (*n* = 68) | |
| | % | Freq | % | Freq | % | Freq |
| 0 | 20.7 | 437 | 25.3 | 49 | 16.2 | 11 |
| 1 | 21.9 | 464 | 31.4 | 61 | 39.7 | 27 |
| 2 | 21.9 | 463 | 18 | 35 | 19.1 | 13 |
| 3 | 18.6 | 393 | 14.9 | 29 | 17.6 | 12 |
| 4 | 11.1 | 235 | 7.7 | 15 | 5.9 | 4 |
| 5 | 4.3 | 92 | 2.1 | 4 | 1.5 | 1 |
| 6 | 1.3 | 27 | 0.5 | 1 | 0 | 0 |
| 7 | 0.1 | 3 | 0 | 0 | 0 | 0 |
| 8 | 0 | 1 | 0 | 0 | 0 | 0 |
| 9 | 0 | 0 | 0 | 0 | 0 | 0 |
| Missing | 0 | 0 | 2.5 | 5 | 0 | 0 |

Within the SSC sample, the greatest percentage of parents reported using either one or two treatment types *Currently* (21.9% for both 1 and 2 treatment types). In the BCM and ND samples more parents reported using one treatment type currently (BCM =31.4%; ND = 39.7%). There were some children and adolescents across the three samples who were not *Currently* receiving any of the nine treatment types at the time of data collection (SSC: 20.7%, BCM: 25.3%; ND: 16.2%).

Similarities and differences were noted among the specific treatment types parents endorsed *Currently* across the three samples. The percentages of families endorsing each treatment type are presented in Table 7.

Table 7

*Percentage and Frequency of Current Treatment Type Across Samples*

| | Sample | | | | | |
|---|---|---|---|---|---|---|
| | SSC | | BCM | | ND | |
| Treatment Type | (*n* = 2,115) | | (*n* = 199) | | (*n* = 68) | |
| | % | Freq | % | Freq | % | Freq |
| Private Speech Therapy | 17.8 | 376 | 21.1 | 42 | 17.6 | 12 |
| School-Based Speech Therapy | 54.1 | 1145 | 45.2 | 90 | 51.5 | 35 |
| Private Occupational Therapy | 13.5 | 285 | 17.1 | 34 | 19.1 | 13 |
| School-Based Occupational Therapy | 36.2 | 766 | 17.6 | 35 | 17.6 | 12 |
| Intensive Behavior Treatments | 16.4 | 347 | 9.0 | 18 | 11.8 | 8 |
| Other Intensive Treatments | 4.8 | 102 | 4.5 | 9 | 2.9 | 2 |
| Biomedical Treatments | 12.1 | 225 | 8.0 | 16 | 8.8 | 6 |
| Psychotropics- ANY | 31.7 | 668 | 39.2 | 76 | 36.8 | 25 |
| Any Other Type of Treatment | 28.0 | 592 | 13.1 | 26 | 13.2 | 9 |
| No treatment endorsed | 20.1 | 425 | 24.1 | 48 | 16.2 | 11 |

Approximately half of participants within all three samples were currently receiving School-Based Speech Therapy (SSC: 54.1%, BCM: 45.2%; ND: 51.5%), making this the most frequently used treatment type. Another school-based service, School-Based Occupational Therapy was the second-most frequently reported currently-used treatment type in the SSC (36.2%), although it was used about half as often in the

BCM and ND samples (BCM: 17.6%; ND: 17.6%). Although initially intended to be excluded because parents are not solely responsible for the selection of school-based treatments (e.g., must result from school multidisciplinary team's determination of eligibility and educational need for such services), school-based Speech and Occupational therapies were included in analyses because omitting them would have overlooked these very frequently used treatments. The *non-school based* treatment type most widely reported being used at the time of data collection was Psychotropic Medications (SSC: 31.7%; BCM: 39.2%; ND: 36.8%). Across all three samples, Biomedical and Other Intensive Treatments were the two least endorsed treatment types used at the time of data collection. Table 8 presents the most-to-least endorsed *Currently* used treatment types by sample.

Table 8

*Percentages of Most-to-Least Used Treatment Types Across Samples-- Current*

| | SSC | | BCM | | ND | |
|---|---|---|---|---|---|---|
| | Treatment | % | Treatment | % | Treatment | % |
| Most Used | ST-S | 54.1 | ST-S | 45.2 | ST-S | 51.5 |
| | OT-S | 36.2 | Psy Med | 39.2 | Psy Med | 36.8 |
| | Psy Med | 31.7 | None | 24.1 | OT-P | 19.1 |
| | Any Oth | 28.0 | ST-P | 21.1 | ST-P | 17.6 |
| | None | 20.1 | OT-S | 17.6 | OT-S | 17.6 |
| | ST-P | 17.8 | OT-P | 17.1 | None | 16.2 |
| | Int Bx | 16.4 | Any Oth | 13.1 | Any Oth | 13.2 |
| | OT-P | 13.5 | Int Bx | 9.0 | Int Bx | 11.8 |
| | Biomed | 12.1 | Biomed | 8.0 | Biomed | 8.8 |
| Least Used | Oth Int | 4.8 | Oth Int | 4.5 | Oth Int | 2.9 |

*NOTE:* ST-P = Private Speech Therapy; ST-S = School-Based Speech Therapy; OT-P = Private Occupational Therapy; OT-S = School-Based Occupational Therapy; Int Bx = Intensive Behavioral (e.g., ABA, IBI, etc.); Oth Int = Other Intensive Therapies (e.g., TEACCH, etc.); Biomed = Biomedical (e.g., chelation; vitamins/supplements); Psy Med = Psychotropic Medication; Any Oth = Any Other Treatment Not Listed (e.g., social skills training, etc.); None = No treatment endorsed

**Lifetime treatment use.** While completing these descriptive analyses, informal review of the data suggested that focusing only on *Current* treatment type use would eliminate a wealth of relevant data: the treatments parents utilized prior to the data collection. Indeed, the literature supports that parents often use treatment types simultaneously (Bowker et al., 2011; Goin-Kochel et al., 2007; Green et al., 2006). Using the *Current* and *Past* data points for each treatment type at each age, a Lifetime, or *Ever* variable for parents' endorsement of having used the treatment now *or* in the past was created. This allowed data to capture not only what treatment types parents were using *Currently* but what treatments they had *Ever* used.

The average number of treatment types parents had *Ever* used was higher than current treatments across all three samples (SSC $M = 4.09$, BCM $M = 3.43$, ND $M = 3.44$). Table 9 illustrates the percentages of both *Current* and *Ever* used treatment types.

Table 9

*Percentage and Frequency of Number of Treatment Types Used Currently and Lifetime/"Ever" Across Samples*

| Number Tx Types | Sample | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | SSC (*n* = 2,115) | | | | BCM (*n* = 199) | | | | ND (*n* = 68) | | | |
| | Current | | *Ever* | | Current | | *Ever* | | Current | | *Ever* | |
| | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq |
| 0 | 20.7 | 437 | 4.4 | 93 | 25.3 | 49 | 6.9 | 13 | 16.2 | 11 | 2.9 | 2 |
| 1 | 21.9 | 464 | 6.8 | 144 | 31.4 | 61 | 10.1 | 19 | 39.7 | 27 | 11.8 | 8 |
| 2 | 21.9 | 463 | 11.8 | 249 | 18.0 | 35 | 17.0 | 32 | 19.1 | 13 | 20.6 | 14 |
| 3 | 18.6 | 393 | 16.5 | 348 | 14.9 | 29 | 17.6 | 33 | 17.6 | 12 | 17.6 | 12 |
| 4 | 11.1 | 235 | 17.5 | 371 | 7.7 | 15 | 19.7 | 37 | 5.9 | 4 | 19.1 | 13 |
| 5 | 4.3 | 92 | 17.5 | 370 | 2.1 | 4 | 13.3 | 25 | 1.5 | 1 | 13.2 | 9 |
| 6 | 1.3 | 27 | 13.3 | 282 | 0.5 | 1 | 9.0 | 17 | 0.0 | 0 | 8.8 | 6 |
| 7 | 0.1 | 3 | 7.7 | 163 | 0.0 | 0 | 4.8 | 9 | 0.0 | 0 | 4.4 | 3 |
| 8 | 0.0 | 1 | 3.0 | 63 | 0.0 | 0 | 1.1 | 2 | 0.0 | 0 | 1.5 | 1 |
| 9 | 0.0 | 0 | 1.5 | 32 | 0.0 | 0 | 0.5 | 1 | 0.0 | 0 | 0.0 | 0 |
| Missing | 0.0 | 0 | 0.0 | 0 | 2.5 | 5 | 5.5 | 11 | 0.0 | 0 | 0.0 | 0 |

Within the SSC sample, the greatest percentage of parents reported having *Ever* used 4 or 5 treatment types (17.5%). Similarly, in the BCM sample the greatest percentage of parents reported having *Ever* used 4 treatment types (19.7%). For the ND participants, the highest percentage of parents reported having *Ever* used two treatment types (20.6%), though percentages reporting *Ever* having used four treatment types was very close (19.1%).

Most families reported that their child had *Ever* received some type of treatment, and comparison of the percentages of what treatment types that had *Ever* or *Current*ly been used are presented in Table 10.

Table 10

*Percentage and Frequency of Current and Lifetime/"Ever" Treatment Type Usage Across Samples*

| Treatment Type | Sample | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | SSC (*n* = 2,115) | | | | BCM (*n* = 199) | | | | ND (*n* = 68) | | | |
| | Current | | *Ever* | | Current | | *Ever* | | Current | | *Ever* | |
| | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq | % | Freq |
| Speech Therapy-Private | 17.8 | 376 | 52.6 | 1,113 | 21.1 | 42 | 53.5 | 107 | 17.6 | 12 | 51.5 | 35 |
| Speech Therapy-School-based | 54.1 | 1,145 | 80.4 | 1,701 | 45.2 | 90 | 73.0 | 146 | 51.5 | 35 | 80.9 | 55 |
| Occupational Therapy-Private | 13.5 | 285 | 41.4 | 876 | 17.1 | 34 | 41.8 | 79 | 19.1 | 13 | 50.0 | 34 |
| Occupational Therapy-School-based | 36.2 | 766 | 66.4 | 1,406 | 17.6 | 35 | 42.3 | 80 | 17.6 | 12 | 41.2 | 28 |
| Intensive Behavior Treatments | 16.4 | 347 | 36.1 | 761 | 9.0 | 18 | 24.3 | 46 | 11.8 | 8 | 25.0 | 17 |
| Other Intensive Treatments | 4.8 | 102 | 14.4 | 305 | 4.5 | 9 | 8.5 | 16 | 2.9 | 2 | 5.9 | 4 |
| Biomedical Treatments | 12.1 | 225 | 23.8 | 503 | 8.0 | 16 | 21.0 | 42 | 8.8 | 6 | 23.5 | 16 |
| Psychotropics-ANY | 31.7 | 668 | 41.7 | 883 | 39.2 | 76 | 49.0 | 95 | 36.8 | 25 | 47.1 | 32 |
| Any Other Type of Treatment | 28.0 | 592 | 51.9 | 1,098 | 13.1 | 26 | 28.5 | 57 | 13.2 | 9 | 29.4 | 20 |
| No treatment endorsed | 20.1 | 425 | 4.4 | 93 | 24.1 | 48 | 8.5 | 17 | 16.2 | 11 | 2.9 | 2 |

Only small percentages of each group's total participants did not endorse use of any type of treatment either now or in the past (e.g., *Ever;* SSC: 4.4%, BCM: 6.9%, ND: 2.9%). In all groups, School-Based Speech Therapy was reported as having *Ever* been used by more participants than any other treatment type (SSC: 80.4%; BCM: 73.0%; ND: 80.9%). Within all three samples, the most widely *Ever*-used *non-school-based* treatment was Private Speech Therapy (SSC: 52.6%, BCM: 53.5%, ND: 51.5%). Treatments are presented in terms of most-to-least endorsed as *Ever* having been used by participants in each of the groups in Table 11.

Table 11

*Percentages of Most-to-Least Used Treatment Types by Data Set— Lifetime/"Ever"*

| | SSC | | BCM | | ND | |
|---|---|---|---|---|---|---|
| | Treatment | % | Treatment | % | Treatment | % |
| Most Used | ST-S | 80.4 | ST-S | 73.0 | ST-S | 80.9 |
| | OT-S | 66.4 | ST-P | 53.5 | ST-P | 51.5 |
| | ST-P | 52.6 | Psy Med | 49.0 | OT-P | 50.0 |
| | Any Oth | 51.9 | OT-S | 42.3 | Psy Med | 47.1 |
| | Psy Med | 41.7 | OT-P | 41.8 | OT-S | 41.2 |
| | OT-P | 41.4 | Any Oth | 28.5 | Any Oth | 29.4 |
| | Int Bx | 36.1 | Int Bx | 24.3 | Int Bx | 25.0 |
| | Biomed | 23.8 | Biomed | 21.0 | Biomed | 23.5 |
| | Oth Int | 14.4 | Oth Int | 8.5 | Oth Int | 5.9 |
| Least Used | None | 4.4 | None | 8.5 | None | 2.9 |

*NOTE:* ST-P = Private Speech Therapy; ST-S = School-Based Speech Therapy; OT-P = Private Occupational Therapy; OT-S = School-Based Occupational Therapy; Int Bx = Intensive Behavioral (e.g., ABA, IBI, etc.); Oth Int = Other Intensive Therapies (e.g., TEACCH, etc.); Biomed = Biomedical (e.g., chelation; vitamins/supplements); Psy Med = Psychotropic Medication; Any Oth = Any Other Treatment Not Listed (e.g., social skills training, etc.); None = No treatment endorsed

When considering the differences between *Current* use of treatment types compared with *Ever* having used treatment types across all three samples, it became

increasingly clear that focusing exclusively on the *Current* treatments provided a very limited view of what treatment types parents pursued. Utilizing only the *Current* treatments would have been analogous to presenting a photograph when an entire video (e.g., *Ever* treatments) was available. For this reason, the focus of inferential analyses for Research Questions 2 and 3 was on the *Ever* variable for each treatment type.

**Supplemental Analyses.** Pearson's chi square analyses were conducted to investigate differences among the three groups' (e.g., SSC, BCM, ND) frequencies of *Currently* and *Ever* using the respective types of treatment. To minimize experimentwise error within these supplemental analyses, alpha ($\alpha$) level of .001 was used, as multiple analyses were conducted on the same datasets, and the $\alpha$ of .001 is more stringent than the Bonferroni correction (.05/30 = .002).

When considering *Current* treatment use, chi-square analyses ($\alpha \leq .001$) indicated that there were only two significant differences among the SSC, BCM, and ND groups' endorsement of using treatment types at the time of evaluation. These included statistically significant differences in the groups' use of School-Based Occupational Therapy ($\chi^2 = 36.54$, $p < .001$) and use of Any Other Treatments ($\chi^2 = 27.07$, $p < .001$).

Chi-square analyses ($\alpha \leq .001$) examining the three groups' *Ever* having used particular treatments revealed that there were significant differences for lifetime use of the same two treatment types, School-Based Occupational therapy ($\chi^2$ (2, 2372) = 59.38, $p < .001$) and Any Other treatments ($\chi^2$ (2, 2382) = 50.52, $p < .001$). However, there were also significant differences found among the three groups in reports of having had no treatment ($\chi^2 = 1514.59$, $p > .001$) throughout their lifetime.

**Research Question 2**

The second research question for this study was whether there were characteristics of children and families that made it more or less likely that parents would choose certain types of treatments. As discussed in the previous section, the focus of these analyses was on whether parents had *Ever* chosen different treatment types rather than whether they were using them at the time of the evaluation (*Current*). Specifically, the odds of parents *Ever* pursuing specific treatments were analyzed separately with stepwise binary logistic regression analyses. Each treatment type was treated as a separate outcome, or dependent, variable. A series of binary logistic regression analyses were conducted because research indicates that families of children with ASD often pursue multiple types of treatment simultaneously rather than choosing a single treatment type (Bowker et al., 2011; Goin-Kochel et al., 2007; Green et al., 2006).

To facilitate comparison of the magnitude of effect of predictors, Table 12 includes odds ratios for logistic regression analyses for each treatment type across the three samples. Specific findings (regression coefficients, Wald statistics, odds ratios, and confidence intervals) for each of these predictors are included in their respective results sections (SCC, BCM, NSD).

Table 12

*Odds Ratios for Each Predictor Retained in the Final Models for Treatment Types Across SSC, BCM, and ND Samples*

| | Tx Type | Parent Education | Income | CSS | Age | Onset | Verbal Cognitive | Race /eth[a] |
|---|---|---|---|---|---|---|---|---|
| SSC | | | | | | | | |
| | P-ST | 1.233 | 1.109 | 1.073 | 0.961 | 0.975 | 0.990 | - |
| | S-ST | - | 1.107 | | | 0.947 | 0.980 | .631/2.340 |
| | P-OT | 1.100 | 1.107 | 1.089 | - | 0.970 | 0.997 | - |
| | S-OT | - | 1.108 | 1.088 | - | 0.976 | 0.988 | .658/- |
| | Int Bx | 1.241 | 1.211 | - | 0.916 | 0.972 | 0.980 | -/2.038 |
| | Oth Int | 1.198 | 1.170 | - | 0.951 | 0.980 | 0.989 | -/1.495 |
| | Biomed | 1.240 | 1.128 | - | 0.965 | 0.978 | 0.987 | .804/1.360 |
| | Psy Med | - | - | - | 1.313 | 0.993 | - | .633/.616 |
| | Any Oth | 1.200 | 1.124 | - | 1.072 | 0.988 | - | .703/1.489 |
| | None | - | 0.807 | - | 0.881 | 1.037 | 1.009 | 1.908/- |
| BCM | | | | | | | | |
| | P-ST | - | 1.253 | - | 0.899 | 0.957 | 0.985 | - |
| | S-ST | - | - | - | - | - | 0.959 | - |
| | P-OT | - | - | - | - | 0.962 | 0.984 | 3.957/.332 |
| | S-OT | - | - | - | - | - | - | -/.334 |
| | Int Bx | 1.634 | - | - | 0.871 | - | 0.973 | - |
| | Oth Int | - | 1.437 | - | 0.773 | - | 0.970 | - |
| | Biomed | 1.750 | - | - | 0.825 | 0.967 | 0.976 | -/.328 |
| | Psy Med | n/a | n/a | n/a | n/a | n/a | n/a | n/a |
| | Any Oth | - | 1.240 | - | - | - | 1.012 | - |
| | None | - | - | - | - | - | 1.032 | - |
| ND | | | | | | | | |
| | P-ST | - | - | - | - | - | - | - |
| | S-ST | - | - | - | - | - | 0.963 | - |
| | P-OT | - | - | - | - | 0.947 | 0.978 | -/.082 |
| | S-OT | - | - | - | - | - | - | - |
| | Int Bx | - | - | - | - | - | 0.977 | - |
| | Oth Int | - | - | - | - | - | - | - |
| | Biomed | - | - | - | 0.789 | 0.937 | - | - |
| | Psy Med | - | - | - | - | - | - | - |
| | Any Oth | n/a | n/a | n/a | n/a | n/a | n/a | n/a |
| | None | n/a | n/a | n/a | n/a | n/a | n/a | n/a |

a = “other”/”Hispanic/Latino”

*NOTE*: P-ST = Private- Speech Therapy; S-ST = School-based Speech Therapy; P-OT = Private OT; S-OT = School-based OT; Int Bx = Intensive Behavioral; Oth Int = Other Intensive; Biomed = Biomedical Treatment; Psy Med = Psychotropic Medication; Any Oth = Any Other

**SSC Sample.** Eight predictor variables were entered into each backward binary logistic regression for the SSC group: child sex, child race/ethnicity, child current age, child verbal cognitive score, child level of current ASD symptomatology (calibrated severity score; CSS), age in months of onset of atypical symptomatology, parent education level, and family income level. Predictors were removed from each regression if the significance value of the *t*-test was not significant ($p > .05$) by SPSS. Analyses were conducted for all 2,115 participants within this sample, though 259 variables across the total 16,920 variables (e.g., 2,115 in sample x 8 predictors per participant) were missing. The missing variables occurred on parent educational level (n = 30; 1.4%), income (n = 129; 6.1%), CSS (n = 65; 3.1%), age of onset (n = 35; 1.7%). Missing CSS scores can be attributed to these participants being administered the ADOS Module 4, for which CSS were not calculated per the SFARI protocol. Missing age of onset scores can be attributed to parents being unable to identify an exact age of onset for atypical symptomatology. Missing educational level and income levels may be the result of parents choosing not to disclose this information to the research coordinators collecting data for these initial demographic variables.

Within the SSC, for each of the nine treatment types and the "no treatment" category, separate tests of the full models with all eight predictors against the constant-only models were statistically significant ($p < .001$) in all cases, indicating that the set of predictors retained for each were statistically better than intercept-only models. Prediction success, or the percentage of non-users and users correctly predicted by the models, varied widely; these statistics are presented by treatment type in Table 13.

Table 13

*Prediction Success of Backward Stepwise Binary Logistic Regression Models for Each Treatment Type Within the SSC Sample*

| Treatment Type | % Correctly Predicted by the Final Model | | |
|---|---|---|---|
| | Non-Users | Users | Overall |
| Private ST | 49.8 | 72.8 | 62.0 |
| School-Based ST | 7.8 | 99.0 | 81.5 |
| Private OT | 78.9 | 37.1 | 61.4 |
| School-Based OT | 19.0 | 93.4 | 68.6 |
| Intensive Behavioral | 85.4 | 41.4 | 69.2 |
| Other Intensive | 100.0 | 0.0 | 84.9 |
| Biomedical | 98.8 | 4.2 | 76.1 |
| Psychotropic Medication | 83.0 | 46.6 | 68.3 |
| Any Other | 51.8 | 66.6 | 59.5 |
| None | 100.0 | 1.2 | 95.5 |

Tables 14-23 show the regression coefficients (*B*), Wald statistics, odds ratios (*Exp(B)*), and 95% confidence intervals (C.I.) for odds ratios for each of the eight predictors by *Ever* treatment type in the SSC sample.

Table 14

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Private Speech Therapy in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Parent Education | .210 | .061 | 11.986 | 1 | .001 | 1.233 | 1.095 | 1.389 |
| Income | .104 | .026 | 15.946 | 1 | .000 | 1.109 | 1.054 | 1.167 |
| CSS | .071 | .029 | 5.914 | 1 | .015 | 1.073 | 1.014 | 1.137 |
| Child Age | -.040 | .015 | 7.037 | 1 | .008 | .961 | .933 | .990 |
| Age Onset (mos) | -.025 | .004 | 40.089 | 1 | .000 | .975 | .968 | .983 |
| Verbal Cognitive | -.010 | .002 | 33.110 | 1 | .000 | .990 | .987 | .993 |
| Constant | -.753 | .446 | 2.856 | 1 | .091 | .471 | | |

Table 15

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used School-Based Speech Therapy in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 21.336 | 2 | .000 | | | |
| "Other"[a] | -.461 | .168 | 7.537 | 1 | .006 | .631 | .454 | .877 |
| Hispanic/Latino[a] | .850 | .254 | 11.175 | 1 | .001 | 2.340 | 1.421 | 3.852 |
| Income | .102 | .028 | 13.057 | 1 | .000 | 1.107 | 1.048 | 1.170 |
| Age Onset (mos) | -.026 | .004 | 41.098 | 1 | .000 | .974 | .966 | .982 |
| Verbal Cognitive | -.020 | .002 | 67.579 | 1 | .000 | .980 | .976 | .985 |
| Constant | 3.144 | .272 | 133.826 | 1 | .000 | 23.203 | | |

[a] In comparison to "White" participants

Table 16

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Private Occupational Therapy in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Parent Education | .149 | .061 | 5.884 | 1 | .015 | 1.160 | 1.029 | 1.308 |
| Income | .102 | .026 | 15.228 | 1 | .000 | 1.107 | 1.052 | 1.165 |
| CSS | .085 | .029 | 8.401 | 1 | .004 | 1.089 | 1.028 | 1.153 |
| Age of Onset | -.030 | .004 | 53.390 | 1 | .000 | .970 | .962 | .978 |
| Verbal Cognitive | -.003 | .002 | 3.863 | 1 | .049 | .997 | .993 | 1.000 |
| Constant | -1.664 | .434 | 14.737 | 1 | .000 | .189 | | |

Table 17

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used School-Based Occupational Therapy in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 9.905 | 2 | .007 | | | |
| "Other"[a] | -.418 | .143 | 8.535 | 1 | .003 | .658 | .497 | .871 |
| Income | .103 | .023 | 19.401 | 1 | .000 | 1.108 | 1.059 | 1.160 |
| CSS | .084 | .031 | 7.665 | 1 | .006 | 1.088 | 1.025 | 1.155 |
| Age Onset (mos) | -.024 | .004 | 39.908 | 1 | .000 | .976 | .969 | .984 |
| Verbal Cognitive | -.012 | .002 | 39.994 | 1 | .000 | .988 | .985 | .992 |
| Constant | 1.022 | .322 | 10.044 | 1 | .002 | 2.777 | | |

[a] In comparison to "White" participants

Table 18

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Intensive Behavioral Treatment in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 19.373 | 2 | .000 | | | |
| Hispanic/Latino[a] | .712 | .165 | 18.570 | 1 | .000 | 2.038 | 1.474 | 2.818 |
| Parent Education | .216 | .067 | 10.251 | 1 | .001 | 1.241 | 1.087 | 1.416 |
| Income | .191 | .029 | 44.312 | 1 | .000 | 1.211 | 1.144 | 1.281 |
| Child Age | -.088 | .017 | 28.071 | 1 | .000 | .916 | .886 | .946 |
| Age Onset (mos) | -.028 | .005 | 36.019 | 1 | .000 | .972 | .963 | .981 |
| Verbal Cognitive | -.020 | .002 | 118.088 | 1 | .000 | .980 | .976 | .983 |
| Constant | -.361 | .437 | .683 | 1 | .408 | .697 | | |

[a] In comparison to "White" participants

Table 19

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Other Intensive Treatment in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 6.296 | 2 | .043 | | | |
| Hispanic/Latino[a] | .402 | .200 | 4.034 | 1 | .045 | 1.495 | 1.010 | 2.213 |
| Parent Education | .181 | .089 | 4.141 | 1 | .042 | 1.198 | 1.007 | 1.426 |
| Income | .157 | .037 | 17.928 | 1 | .000 | 1.170 | 1.088 | 1.259 |
| Child Age | -.050 | .021 | 5.756 | 1 | .016 | .951 | .913 | .991 |
| Age of Onset (mos) | -.021 | .006 | 11.338 | 1 | .001 | .980 | .968 | .991 |
| Verbal Cognitive | -.011 | .002 | 24.793 | 1 | .000 | .989 | .984 | .993 |

[a] In comparison to "White" participants

Table 20

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Biomedical Treatment in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 5.734 | 2 | .057 | | | |
| "Other"[a] | -.219 | .163 | 1.795 | 1 | .180 | .804 | .584 | 1.106 |
| Hispanic/Latino[a] | .308 | .175 | 3.090 | 1 | .079 | 1.360 | .965 | 1.916 |
| Parent Education | .215 | .074 | 8.448 | 1 | .004 | 1.240 | 1.073 | 1.434 |
| Income | .121 | .031 | 15.408 | 1 | .000 | 1.128 | 1.062 | 1.198 |
| Child Age | -.036 | .018 | 4.160 | 1 | .041 | .965 | .932 | .999 |
| Age Onset (mos) | -.023 | .005 | 19.571 | 1 | .000 | .978 | .968 | .988 |
| Verbal Cognitive | -.014 | .002 | 49.825 | 1 | .000 | .987 | .983 | .990 |

[a] In comparison to "White" participants

Table 21

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Psychotropic Medication in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 15.192 | 2 | .001 | | | |
| "Other"[a] | -.458 | .151 | 9.221 | 1 | .002 | .633 | .471 | .850 |
| Hispanic/Latino[a] | -.484 | .171 | 8.004 | 1 | .005 | .616 | .441 | .862 |
| Child Age | .272 | .017 | 244.420 | 1 | .000 | 1.313 | 1.269 | 1.359 |
| Age Onset (mos) | -.007 | .004 | 3.699 | 1 | .054 | .993 | .985 | 1.000 |
| Constant | -2.389 | .166 | 208.253 | 1 | .000 | .092 | | |

[a] In comparison to "White" participants

Table 22

*Results of Backward Stepwise Binary Logistic Regression for Ever Having Used Any Other Treatments in the SSC Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 15.290 | 2 | .000 | | | |
| "Other"[a] | -.352 | .136 | 6.688 | 1 | .010 | .703 | .539 | .918 |
| Hispanic/Latino[a] | .398 | .156 | 6.529 | 1 | .011 | 1.489 | 1.097 | 2.022 |
| Parent Education | .182 | .060 | 9.354 | 1 | .002 | 1.200 | 1.068 | 1.349 |
| Income | .117 | .025 | 20.999 | 1 | .000 | 1.124 | 1.069 | 1.181 |
| Child Age | .070 | .015 | 21.673 | 1 | .000 | 1.072 | 1.041 | 1.104 |
| Age Onset (mos) | -.012 | .004 | 10.565 | 1 | .001 | .988 | .982 | .995 |
| Constant | -2.145 | .385 | 31.024 | 1 | .000 | .117 | | |

[a] In comparison to "White" participants

Table 23

*Results of Backward Stepwise Binary Regression for Having Endorsed No Treatments in the SSC Sample*

| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | 95% CI for *Exp(B)* Lower | Upper |
|---|---|---|---|---|---|---|---|---|
| Race/Ethnicity | | | 7.603 | 2 | .022 | | | |
| "Other"[a] | .646 | .279 | 5.354 | 1 | .021 | 1.908 | 1.104 | 3.299 |
| Income | -.215 | .051 | 17.658 | 1 | .000 | .807 | .730 | .892 |
| Child Age | -.127 | .043 | 8.940 | 1 | .003 | .881 | .810 | .957 |
| Age Onset (mos) | .036 | .007 | 25.907 | 1 | .000 | 1.037 | 1.022 | 1.051 |
| Verbal Cognitive | .009 | .004 | 4.042 | 1 | .044 | 1.009 | 1.000 | 1.018 |
| Constant | -3.400 | .675 | 25.407 | 1 | .000 | .033 | | |

[a] In comparison to "White" participants

As shown in these tables, the Wald criterion indicated that having *Ever* used specific treatment types was reliably predicted by groups of predictors as follows:

- Private Speech Therapy: parent education, income, CSS, child age, age of onset, and verbal cognitive score
- School-Based Speech Therapy: race/ethnicity, income, age of onset, and verbal cognitive score
- Private Occupational Therapy: parent education, income, CSS, age of onset, and verbal cognitive score
- School-Based Occupational Therapy: race/ethnicity, income, CSS, age of onset, and verbal cognitive score
- Intensive Behavioral Treatment: race/ethnicity, parent education, income, child age, age of onset, and verbal cognitive score

- Other Intensive Treatment: race/ethnicity, parent education, income, child age, age of onset, and verbal cognitive score
- Biomedical Treatment: race/ethnicity, parent education, income, child age, age of onset, and verbal cognitive score
- Psychotropic Medications: race/ethnicity, child age, and age of onset
- Any Other Treatments: race/ethnicity, parent education, income, child age, and age of onset)
- No Treatment: race/ethnicity, income, child age, age of onset, and verbal cognitive score

A significant Wald statistic indicates that the predictor is making a significant contribution to the prediction of *Ever* having used a treatment. Odds ratios (*Exp(B)*) indicate the change in odds that result from a unit change in the predictor. An odds ratio greater than 1 suggests that as the predictor increases, the odds of having *Ever* had a particular treatment *increase*; an odds ratio less than 1 indicates that as the predictor increases, the odds of having *Ever* had that treatment *decreases*. Predictors are more influential as the odds ratio is farther from 1. For example, for Private Speech Therapy the odds ratio (OR; *Exp(B)*) for the CSS is 1.073, which suggests that for every one unit increase in severity of ASD symptoms as captured via this score, the odds of having *Ever* had Private Speech Therapy *increase* by 7%. The OR of 0.961 for age indicates that for every year increase in age, the odds of having *Ever* had Private Speech Therapy *decrease* by 4%. Confidence intervals (CI) are also calculated for each odds ratio. The 95% CI is interpreted in logistic regression similarly to in other statistical analyses, in that these intervals include the actual value of odds ratios in the population in 95 of 100 samples.

Unique to logistic regression is that it is important that both the lower and upper limits of CIs generated for odds ratios are above or below one. If the CI crosses one (e.g., lower limit below one, upper limit above one), confidence about the direction of the relationship between the predictor and outcome is reduced.

Interpretation of the race/ethnicity predictor is similar. A significant Wald statistic indicates only that race/ethnicity is a factor contributing to the prediction of having *Ever* used a treatment type. To understand more about the impact of this factor, interpretation must take into consideration that two comparisons are made: "Other" compared to "White", and "Hispanic/Latino" compared to "White". "White" is used as the comparison group due to the disproportionate representation of this group within all three datasets, as discussed previously. As an example, for School-Based Speech Therapy, results suggested that the odds of having *Ever* used this treatment for those from Hispanic/Latino backgrounds were 134% higher (OR = 2.34, $p < .01$) than the odds for Caucasian participants. Conversely, the odds of having *Ever* had School-Based Speech Therapy for participants whose race/ethnicity was classified as "other" were 37% lower (OR = .631, $p < .01$) than the odds for their Caucasian counterparts.

**BCM sample.** Seven predictor variables were entered into each forward binary logistic regression for the BCM group: child race/ethnicity, child current age, child verbal cognitive score, child level of current ASD symptomatology (calibrated severity score; CSS), age in months of onset of atypical symptomatology, parent education level, and family income level. Child sex was not used as a predictor variable as it was in the SSC group because child sex was not retained as a significant predictor of any treatment type in the larger sample. For the forward regressions, all initial models included only a

constant ($b_0$). Then, predictors were added to the model one at a time by SPSS. Those predictors that did not make a statistically significant contribution ($p > .05$) were removed, and contribution of remaining predictors were then reassessed until all predictors retained made a significant contribution. Analyses were conducted for all 199 participants within this sample. Only 24 cells across the total 1,393 cells (e.g., 199 in sample x 7 predictors per participant) were missing. The missing variables occurred on parent educational level (n = 1; 0.5%), income (n = 8; 4.0%), CSS (n = 11; 5.5%), age of onset (n = 2; 1%), race/ethnicity (n = 1; 0.5%), and verbal cognitive score (n = 1; 0.5%). Missing CSS scores can be attributed to these participants being administered the ADOS Module 4, for which CSS were not calculated per the SFARI protocol. Missing age of onset scores can be attributed to parents being unable to identify an exact age of onset for atypical symptomatology. Missing educational level and income levels may be the result of parents choosing not to disclose this information to the research coordinators collecting data for these initial demographic variables.

Within the BCM sample, separate tests of the full models with all seven predictors against the constant-only models were statistically significant ($p < .001$) for all treatment types (and for "no treatment"), with the exception of the model for Psychotropic Medications. Statistically significant models indicate that the set of predictors retained for these were statistically better than intercept-only models. For Psychotropic Medications, a test of the full model with all seven predictors against a constant-only model was not statistically significant, such that the model did not reliably distinguish between families within the BCM sample who had *Ever* used Psychotropic Medications

and those who had not. For all treatment types, prediction success varied widely; these statistics are presented by treatment type in Table 24.

Table 24

*Prediction Success of Forward Stepwise Binary Logistic Regression Models for Each Treatment Type Within the BCM Sample*

| Treatment Type | % Correctly Predicted by the Final Model | | |
|---|---|---|---|
| | Non-Users | Users | Overall |
| Private ST | 51.3 | 83.3 | 69.7 |
| School-Based ST | 18.4 | 97.1 | 80.3 |
| Private OT | 82.4 | 57.9 | 71.9 |
| School-Based OT | 80.4 | 40.8 | 63.5 |
| Intensive Behavioral | 94.8 | 25.6 | 78.1 |
| Other Intensive | 100.0 | 6.7 | 92.1 |
| Biomedical | 94.2 | 30.0 | 79.8 |
| Psychotropic Medication | - | - | - |
| Any Other | 93.4 | 12.5 | 68.0 |
| None | 100.0 | 0.0 | 95.5 |

Tables 25-33 show regression coefficients (*B)*, Wald statistics, odds ratios (*Exp(B)*), and 95% confidence intervals (C.I.) for odds ratios for each of the seven predictors by treatment type in the BCM sample.

Table 25

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Private Speech Therapy in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Income | .225 | .078 | 8.281 | 1 | .004 | 1.253 | 1.074 | 1.460 |
| Verbal Cognitive | -.015 | .006 | 6.775 | 1 | .009 | .985 | .974 | .996 |
| Child Age | -.106 | .054 | 3.892 | 1 | .049 | .899 | .809 | .999 |
| Age Onset (mos) | -.044 | .013 | 11.073 | 1 | .001 | .957 | .933 | .982 |
| Constant | 2.045 | .720 | 8.073 | 1 | .004 | 7.727 | | |

Table 26

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used School-Based Speech Therapy in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Verbal Cognitive | -.042 | .009 | 19.351 | 1 | .000 | .959 | .941 | .977 |
| Constant | 4.967 | .917 | 29.315 | 1 | .000 | 143.66 | | |

Table 27

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Private Occupational Therapy in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 15.441 | 2 | .000 | | | |
| "Other"[a] | 1.376 | .580 | 5.618 | 1 | .018 | 3.957 | 1.269 | 12.342 |
| Hispanic/Latino[a] | -1.103 | .411 | 7.209 | 1 | .007 | .332 | .148 | .742 |
| Verbal Cognitive | -.016 | .006 | 7.276 | 1 | .007 | .984 | .973 | .996 |
| Age Onset (mos) | -.039 | .013 | 9.090 | 1 | .003 | .962 | .938 | .986 |
| Constant | 1.911 | .566 | 11.393 | 1 | .001 | 6.760 | | |

[a] In comparison to "White" participants

Table 28

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used School-Based Occupational Therapy in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 8.646 | 2 | .013 | | | |
| "Other"[a] | .290 | .405 | .327 | 1 | .567 | 1.336 | .495 | 3.61 |
| Hispanic/Latino[a] | -1.098 | .405 | 7.359 | 1 | .007 | .334 | .151 | .737 |
| Verbal Cognitive | -.020 | .006 | 12.304 | 1 | .000 | .980 | .970 | .991 |
| Constant | 1.484 | .508 | 8.535 | 1 | .003 | 4.411 | | |

[a] In comparison to "White" participants

Table 29

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Intensive Behavioral Treatments in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Parent Education | .491 | .201 | 5.949 | 1 | .015 | 1.634 | 1.101 | 2.424 |
| Verbal Cognitive | -.027 | .006 | 17.679 | 1 | .000 | .973 | .961 | .986 |
| Child Age | -.138 | .063 | 4.803 | 1 | .028 | .871 | .770 | .986 |
| Constant | -1.365 | 1.350 | 1.022 | 1 | .312 | .255 | | |

Table 30

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Other Intensive Treatments in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Income | .363 | .143 | 6.442 | 1 | .011 | 1.437 | 1.086 | 1.902 |
| Verbal Cognitive | -.030 | .010 | 8.989 | 1 | .003 | .970 | .951 | .990 |
| Child Age | -.258 | .115 | 5.026 | 1 | .025 | .773 | .617 | .968 |
| Constant | -.707 | 1.181 | .358 | 1 | .549 | .493 | | |

Table 31

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Biomedical Treatments in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 6.305 | 2 | .043 | | | |
| "Other"[a] | -1.197 | .721 | 2.759 | 1 | .097 | .302 | .074 | 1.240 |
| Hispanic/Latino[a] | -1.116 | .520 | 4.605 | 1 | .032 | .328 | .118 | .908 |
| Parent Education | .560 | .242 | 5.367 | 1 | .021 | 1.750 | 1.090 | 2.811 |
| Verbal Cognitive | -.024 | .007 | 12.013 | 1 | .001 | .976 | .963 | .989 |
| Child Age | -.192 | .069 | 7.721 | 1 | .005 | .825 | .720 | .945 |
| Age Onset (mos) | -.034 | .018 | 3.416 | 1 | .065 | .967 | .933 | 1.002 |
| Constant | -.644 | 1.678 | .147 | 1 | .701 | .525 | | |

[a] In comparison to "White" participants

Table 32

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Any Other Treatments in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Income | .215 | .078 | 7.544 | 1 | .006 | 1.240 | 1.064 | 1.446 |
| Verbal Cognitive | .012 | .006 | 4.184 | 1 | .041 | 1.012 | 1.000 | 1.023 |
| Constant | -3.043 | .702 | 18.781 | 1 | .000 | .048 | | |

Table 33

*Results of Forward Stepwise Binary Logistic Regression for Having Endorsed No Treatments in the BCM Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Verbal Cognitive | .032 | .015 | 4.593 | 1 | .032 | 1.032 | 1.003 | 1.063 |
| Constant | -5.915 | 1.522 | 15.093 | 1 | .000 | .003 | | |

In summary, the Wald criterion indicated that having *Ever* used the different treatment types in the BCM sample were reliably predicted by groups of predictors as follows:

- Private Speech Therapy: income, age, age of onset, and verbal cognitive score
- School-Based Speech Therapy: verbal cognitive score
- Private Occupational Therapy: race/ethnicity, age of onset, and verbal cognitive score

- School-Based Occupational Therapy: race/ethnicity and verbal cognitive score
- Intensive Behavioral Treatment: parent education, child age, and verbal cognitive score
- Other Intensive Treatment: income, child age, and verbal cognitive score
- Biomedical Treatment: race/ethnicity, parent education, age of onset, child age, and verbal cognitive score
- Any Other Treatments: income and verbal cognitive score
- No Treatment: verbal cognitive score

Interpretation of Wald statistics and OR follow the same guidelines as those described previously.

**Research Question 3**

The third research question addressed in this study was whether parent perceptions about their children's ASD would be predictive of *Ever* having used or not used specific treatment types. It was expected that parent perception about the nature and course of their children's ASD would contribute to understanding the likelihood of treatments *Ever* chosen by parents.

As described in detail within the Methods section, prior to the main analyses, descriptive statistics for the IPQ-R subscales, including the two subscales with imputed sums (e.g., Treatment Control, Illness Coherence), were computed (see Table 3). A series of logistic regressions for the IPQ-R subscales to determine which subscales should be entered as predictors in the ND binary logistic regressions were then completed (see Table 4). The odds ratio and *p*-values for the IPQ-R subscales by treatment type are

presented in Table 4. A summary of the IPQ-R subscales that were retained for entry as predictors in the ND binary logistic regressions ($p < .15$) are presented in Table 34.

Table 34

*Odds Ratios for IPQ-R Subscales Retained from Logistic Regressions for Entry into Binary Logistic Regressions for ND Sample ($p < .15$)*

| | Identity | Timeline-Acute/ Chronic | Consequences | Personal Control | Treatment Control | Illness Coherence | Timeline-Cyclical | Emotional Representations |
|---|---|---|---|---|---|---|---|---|
| Private ST | -- | 0.877 | -- | -- | 1.17 | -- | -- | -- |
| School-Based ST | 1.25 | -- | -- | -- | -- | 1.128 | 0.844 | -- |
| Private OT | -- | -- | -- | -- | 1.24 | -- | -- | -- |
| School-Based OT | 1.288 | -- | -- | -- | -- | 1.106 | -- | -- |
| Intensive Behavioral | 1.373 | -- | 1.157 | -- | 1.166 | -- | -- | 1.141 |
| Other Intensive | 1.488 | 0.881 | -- | -- | 1.57 | -- | -- | -- |
| Biomedical | -- | -- | -- | -- | -- | -- | -- | -- |
| Psychotropic Medications | 0.885 | -- | -- | 1.227 | 1.411 | -- | -- | -- |
| Any Other Treatments | -- | -- | -- | -- | -- | -- | -- | -- |
| No Treatments | -- | 1.884 | -- | -- | -- | 0.745 | -- | -- |

**ND Sample.** Predictor variables entered into each forward binary logistic regression for the ND group included, a) those predictors retained in the final models of the BCM forward binary logistic regressions for the same outcome variable, and b) subscales of the IPQ-R that met the $\alpha < .15$ criteria described in the previous section for the respective outcome variables. Table 35 includes an overview of all predictors entered into the respective logistic regressions for each treatment type within the ND sample.

Table 35

*Predictors Entered into Forward Stepwise Binary Logistic Regressions by Treatment Type for the ND Sample*

| | | Treatment Type | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Predictors | P-ST | S-ST | P-OT | S-OT | Int Bx | Oth Int | Bio-med | Psy Med | Any Oth | No Tx |
| Child | Age | yes | - | - | - | yes | yes | yes | - | - | - |
| | Age onset | yes | - | yes | - | - | - | yes | - | - | - |
| | CSS | - | - | - | - | - | - | - | - | - | - |
| | Verbal Cognitive | yes | yes | yes | yes | yes | yes | - | - | - | yes |
| Family | Race/ Ethnicity | - | - | yes | yes | - | - | yes | - | - | - |
| | Parent Education | - | - | - | - | yes | - | yes | - | - | - |
| | Family Income | yes | - | - | - | - | yes | - | - | yes | - |
| IPQ-R Scale | Identity | - | yes | - | yes | yes | yes | - | yes | - | - |
| | Timeline-Acute/Chronic | yes | - | - | - | - | yes | - | - | - | yes |
| | Consequences | - | - | - | - | yes | - | - | - | - | - |
| | Personal Control | - | - | - | - | - | - | - | yes | - | - |
| | Treatment Control | yes | - | yes | - | yes | yes | - | yes | - | - |
| | Illness Coherence | - | yes | - | yes | - | - | - | - | - | yes |
| | Timeline-Cyclical | - | yes | - | - | - | - | - | - | - | - |
| | Emotional Representations | - | - | - | - | yes | - | - | - | - | - |

*NOTE:* ST-P = Private Speech Therapy; ST-S = School-Based Speech Therapy; OT-P = Private Occupational Therapy; OT-S = School-Based Occupational Therapy; Int Bx = Intensive Behavioral (e.g., ABA, IBI, etc.); Oth Int = Other Intensive Therapies (e.g., TEACCH, etc.); Biomed = Biomedical (e.g., chelation; vitamins/supplements); Psy Med = Psychotropic Medication; Any Oth = Any Other Treatment Not Listed (e.g., social skills training, etc.); No Tx = No treatment endorsed

For all the forward regressions, all initial models included only a constant ($b_0$). Then, predictors were added to the model one at a time and those that did not make a statistically significant contribution ($p > .05$) were removed via SPSS, and the contribution of remaining predictors were then reassessed until all predictors retained made a significant contribution.

Analyses were conducted for all 68 participants within this sample. Only 6 cells across the total 476 cells (e.g., 68 in sample x 7 potential predictors per participant) were missing. The missing variables occurred on race/ethnicity (n = 1; 1.5%), income (n = 3; 5.5%), parent educational level (n = 1; 1.5%), and age of onset (n = 1; 1.5). Missing age of onset scores can be attributed to parents being unable to identify an exact age of onset for atypical symptomatology. Missing educational level and income levels may be the result of parents choosing not to disclose this information to the research coordinators collecting data for these initial demographic variables.

Within the ND sample, for eight of the treatment types, separate tests of the full models with predictors against the constant-only models were statistically significant ($p < .001$), indicating that the set of predictors retained for these were statistically better than intercept-only models. For Any Other Treatments and No Treatment, tests of the full models against a constant-only model were not statistically significant, such that the model did not reliably distinguish between families within the ND sample who had *Ever* used Any Other Treatments and those who had not, nor did the model differentiate between families in this sample who had endorsed no treatments used *Ever*. For the eight statistically significant models, the percentage of non-users and users correctly

predicted by the models varied widely; these statistics are presented by treatment type in Table 36.

Table 36

*Prediction Success of Forward Stepwise Binary Logistic Regression Models for Each Treatment Type Within the ND Sample*

| Treatment Type | % Correctly Predicted by the Final Model | | |
|---|---|---|---|
| | Non-Users | Users | Overall |
| Private ST | 60.0 | 57.6 | 57.8 |
| School-Based ST | 80.6 | 7.7 | 98.1 |
| Private OT | 75.0 | 81.8 | 78.5 |
| School-Based OT | 74.4 | 55.6 | 66.7 |
| Intensive Behavioral | 87.5 | 52.9 | 78.5 |
| Other Intensive | 100.0 | 0.0 | 93.7 |
| Biomedical | 94.0 | 25.05 | 77.3 |
| Psychotropic Medication | 74.3 | 64.5 | 69.7 |
| Any Other | - | - | - |
| None | - | - | - |

Tables 37-44 show regression coefficients (*B*), Wald statistics, odds ratios (*Exp(B)*), and 95% confidence intervals (C.I.) for odds ratios for the predictors—including IPQ-R subscales— used within each treatment type in the ND sample.

Table 37

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Private Speech Therapy in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Timeline-Acute/Chronic | -.233 | .088 | 7.019 | 1 | .008 | .792 | .667 | .941 |
| Constant | 5.750 | 2.181 | 6.954 | 1 | .008 | 314.23 | | |

Table 38

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used School-Based Speech Therapy in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Verbal Cognitive | -.037 | .015 | 6.245 | 1 | .012 | .963 | .936 | .992 |
| Constant | 4.651 | 1.448 | 10.317 | 1 | .001 | 104.69 | | |

Table 39

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Private Occupational Therapy in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Race/Ethnicity | | | 8.459 | 2 | .015 | | | |
| Hispanic/Latino[a] | -2.507 | .949 | 6.980 | 1 | .008 | .082 | .013 | .524 |
| Age Onset (mos) | -.054 | .023 | 5.554 | 1 | .018 | .947 | .906 | .991 |
| Verbal cognitive | -.022 | .011 | 4.162 | 1 | .041 | .978 | .957 | .999 |
| Treatment Control | .360 | .123 | 8.613 | 1 | .003 | 1.434 | 1.127 | 1.824 |
| Constant | -3.641 | 2.381 | 2.339 | 1 | .126 | .026 | | |

[a] In comparison to "White" participants

Table 40

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used School-Based Occupational Therapy in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Identity | .246 | .093 | 7.014 | 1 | .008 | 1.279 | 1.066 | 1.534 |
| Constant | -2.631 | .915 | 8.265 | 1 | .004 | .072 | | |

Table 41

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Intensive Behavioral Treatments in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Verbal Cognitive | -.023 | .009 | 6.198 | 1 | .013 | .977 | .960 | .995 |
| Identity | .279 | .126 | 4.892 | 1 | .027 | 1.321 | 1.032 | 1.691 |
| Constant | -2.155 | 1.499 | 2.067 | 1 | .151 | .116 | | |

Table 42

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Other Intensive Treatments in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Treatment Control | .476 | .234 | 4.126 | 1 | .042 | 1.609 | 1.017 | 2.546 |
| Constant | -12.80 | 5.307 | 5.817 | 1 | .016 | .000 | | |

Table 43

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Biomedical Treatments in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Child age | -.237 | .114 | 4.343 | 1 | .037 | .789 | .631 | .986 |
| Age Onset (mos) | -.066 | .029 | 5.106 | 1 | .024 | .937 | .885 | .991 |
| Constant | 1.979 | 1.072 | 3.410 | 1 | .065 | 7.237 | | |

Table 44

*Results of Forward Stepwise Binary Logistic Regression for Having Ever Used Psychotropic Medications in the ND Sample*

| | | | | | | | 95% CI for *Exp(B)* | |
|---|---|---|---|---|---|---|---|---|
| Predictor | *B* | S.E. | Wald | df | *p* | *Exp(B)* | Lower | Upper |
| Identity | -.198 | .095 | 4.328 | 1 | .037 | .820 | .681 | .989 |
| Treatment Control | .401 | .121 | 11.060 | 1 | .001 | 1.494 | 1.179 | 1.893 |
| Constant | -6.305 | 2.299 | 7.520 | 1 | .006 | .002 | | |

In summary, the Wald criterion indicated that the following predictors reliably predicted having *Ever* used each of the treatment types:

- Private Speech Therapy: Timeline-Acute/Chronic subscale
- School-Based Speech Therapy: verbal cognitive score
- Private Occupational Therapy: race/ethnicity, child age, verbal cognitive score, Treatment Control subscale
- School-Based Occupational Therapy: Identity subscale
- Intensive Behavioral Treatment: verbal cognitive score and Identity subscale
- Other Intensive Treatment: Treatment Control subscale
- Biomedical Treatment: child age and age of onset
- Psychotropic Medications: Identity subscale and Treatment Control subscale

As in descriptions of SSC and BCM analyses, interpretation of Wald statistics and OR follow the same guidelines as those described previously.

# Chapter IV

## Discussion

The current study adds to the literature by offering information about treatments received by children and adolescents with ASD in a large, national sample, as well as two subsets of that sample, for which extensive data were rigorously collected as a part of a large-scale study. Though the overwhelmingly white, upper-middle class sample is not representative of the U.S. population, the study results yield initial information about parents' treatment decisions for youths with ASD that were not previously available. Moreover, the stringent data collection procedure ensured that clinical diagnoses of ASD were based on protocol-consistent criteria and data obtained from multiple methods and multiple informants; many previous studies investigating treatments in ASD relied solely on parent report of diagnosis.

Many of the findings related to frequency and types of treatments used by families, either now or in the past, were consistent with previous literature. Most children and adolescents were using one or more treatment types at the time of data collection in all groups (i.e., full SSC sample, full Baylor sample, and Baylor subset who completed the IPQ-R), and almost all of them had received treatment at some time during their lives. That greater than 90% of participants in all groups had had some type of treatment at some point was somewhat higher than other findings (Bowker et al., 2011). However, the average number of treatment types used *Current*ly and *Ever* was lower than expected, considering that previous findings suggest parents of children with ASD often use many treatments simultaneously (Bowker et al., 2011; Goin-Kochel et al., 2007; Smith & Antolovich, 2000). School-based services were very frequently used, and

parents' reliance on schools to provide treatment for their children with ASD has been highlighted previously (Thomas, Morrissey, & McLaurin, 2007). Moreover, the high rates of using speech therapy found in this study were also consistent with previous reports (Bowker et al., 2011; Green et al., 2006). The frequency of using other treatment types, such as Psychotropic Medications and Intensive Behavioral Treatments, were also consistent with the findings of other studies (Aman et al., 2005; Bowker et al., 2011; Green et al., 2006; Mandell et al., 2008; Oswald & Sonenklar, 2007; Witwer & Lecavalier, 2005). It is difficult to ascertain the degree to which endorsement of use of Biomedical Treatments (i.e., vitamins/supplements, special diets, chelation, etc.) is consistent with previous studies because several different treatments were captured in this category. Certainly, the categorization of treatment "types" utilized in this study limits conclusions that can be drawn about specific treatments. Nevertheless, results do indicate similarities among types of treatments used by participants in this study and in other studies.

Importantly, results also contribute to the understanding of *why* families may choose the treatments that they do, an area where literature is only emerging (Al Anbar et al., 2010; Dardennes et al., 2011; Christon et al., 2010; Mandell & Novack, 2005). The current study suggest that several factors, including child- and family-specific characteristics, as well as parent perceptions about the nature, course, and impact of their child's ASD diagnosis, contributed meaningfully to treatment types selected by parents. This supports suggestions from previous studies that there are likely many factors contributing to decisions parents make about what kind of treatments they choose for

their children with ASD (Aman, 2005; Green et al., 2006; Siegel, 2003; Smith & Antolovich, 2000).

**Differences Across the Three Samples**

Many more child- and family-specific characteristics emerged as predictors in the largest group (e.g., SSC) across all treatment types, which is likely attributable to the much larger size (and thus statistical power) of this group compared to the smaller groups. However, the contributions of predictors in the SSC group were fairly small, overall (i.e., odds ratios were close to 1). Even so, the same predictors were found to be contributory for some treatment types, even in the smaller groups (e.g., age of onset was a predictor for use of Biomedical Treatments in SSC, BCM, and ND groups). When this occurred, the influence of the predictor appeared to be somewhat greater as the group size decreased (e.g., odds ratios for age of onset on Biomedical Treatments was .978 [SSC], .967 [BCM], .937 [ND]; odds ratios are stronger when farther from 1), though the difference between the contributions was not examined to determine whether such findings were statistically significant.

**Similarities Across the Three Samples**

Though some differences emerged among the three different-sized samples of participants, several consistent trends with regard to treatment were noted, and these were congruent with extant literature. Across all three samples, youths' families were less likely to report having tried treatment types when children were older at the time of data collection, older at the time of symptom onset, and demonstrated greater verbal cognitive abilities. Age of a child has been previously demonstrated as a factor in what treatments they receive (Aman et al., 2003; Goin-Kochel et al., 2007; Green et al., 2006), as has

cognitive ability (Aman et al., 2005). In the current study, verbal cognitive ability influenced use of various treatment types more often than any other predictor investigated, though the contribution was consistently small. Trends also emerged indicating that treatments, overall, were more likely to be used when parent education and family income level were higher. Previously, Aman et al. (2005) found that parent education contributed to patterns of psychotropic medication use, though Green et al. (2006) pointed out that lack of variability in parent educational level within treatment-related studies may represent a limitation of such works.

**Contributions of Parent Perceptions (ND Sample)**

Parent perceptions about their child's ASD were demonstrated to contribute to choices of some treatment types, consistent with the work of Al Anbar et al. (2010) and Dardennes et al. (2011). For the smaller ND subsample in the current study, data regarding parent perceptions of their child's ASD were available. In these cases, parent perceptions—particularly perceptions about the extent to which they could control their child's treatment (i.e., Treatment Control), the number of symptoms they believed to be directly related to their child's ASD diagnosis (i.e., Identity), and how chronic they viewed the ASD (i.e., Timeline- Acute/Chronic)—also had some influence on choosing particular treatment types. In fact, when these perceptions were influential for certain treatment choices, there often was a relatively greater effect of the perceptions than of other factors (i.e., child and family characteristics).

In the following sections, findings regarding each of the three research questions of the current study will be discussed in detail. Prior to discussion about each of the

research questions individually, characteristics of the sample will help provide context in which the reader should consider the findings of this study.

**Characteristics of the Sample**

Data from three groups were analyzed: the national, multi-site SSC (n = 2,115), the local BCM site (n = 199), and a subsample who participated in new data collection (ND; n = 68). The only significant difference between these groups' demographics was in terms of race/ethnicity, in that there were higher percentages of Hispanic/Latino participants within the BCM (26.1%) and ND (23.5%) samples when compared to those within the SSC sample (10.9%). This may be related to the geographic location of the BCM data collection site (Houston, Texas), from which the ND sample was also drawn, as Texas is a state with a higher representation of Hispanic/Latino persons (37.6%) compared to many other states, as well as and also to the national average of Hispanic/Latino persons (16.3%; U.S. Census Bureau, 2010).

Though the three groups shared common characteristics, these groups may not be representative of the U.S. population in general. Higher-than-average socioeconomic status has been identified as a potential bias in other studies related to ASD treatment (Green et al., 2006; Smith & Antolovich, 2000). Overall, participants from all groups in the current study were overwhelmingly from families having a higher-than-average household income and parent-education level. For example, U.S. Census Bureau (2010) reported that the median household income was $51,914, and in the current samples, the majority of families in each sample had incomes exceeding this national median household income level (SSC: 78.5%; BCM: 78.9%; ND: 76.4%). Families reporting a household income over $100K were also over-represented (SSC: 39.1%; BCM: 40.2%;

ND: 44.1%). U.S. Census Bureau (2010) found that 27.9% of the adult population over 25 years had a bachelor's degree or higher, and the proportion of parents with a college degree or graduate education within all three samples exceeded this national average, as well. For example, most fathers had a bachelor's degree or higher (SSC: 59.2%; BCM: 57.2%; ND: 61.8%), as did most mothers (SSC: 61.0%; BCM: 57.8%; ND: 58.8%).

Participants themselves were similar across the samples. The average age of participants was 8.5 years (SSC: 8.5; BCM: 8.3; ND: 8.7), and the average age of onset of parents noticing something problematic about their child's development was before age 24 months (SSC: 21.9; BCM: 22.8; ND: 23.9), though it is important to note that this does not indicate an age of ASD diagnosis—only the age in months at which parents suspected something was problematic with development. Child participants, overall, had estimates of verbal cognitive scores in the low to low-average range (SSC: 79.4; BCM: 77.8; ND: 76.0), in that the mean of standardized cognitive measures is 100 and standard deviation is 15. In terms of severity of ASD symptoms (relative to age and language level) as observed via clinical evaluation, the average CSS was over 7 on a scale of 1-10 (SSC: 7.4; BCM: 7.3; ND: 7.3), which indicates the presence of moderately severe ASD symptomatology.

**Research Question 1: How Many Treatment Types Are Parents Using for their Children with ASD?**

**Frequency.** At the time of data collection, the majority of children and adolescents in these samples were using one or more treatment types. Specifically, only 20.7% of the SSC sample, 25.3% of the BCM sample, and 16.2% of the ND sample were using no treatment types at the time of data collection. Most parents reported that their

children were using an average of one treatment type. This is consistent with Bowker et al.'s (2011) finding that the majority (72.4%) of children in their large sample (*N* = 1,034) were currently using one or more treatments, as well as that 27.6% were not using any treatment at the time of their data collection. Conversely, other studies have found that parents often use multiple treatments simultaneously (Goin-Kochel et al., 2007, Green et al., 2006; Smith & Antolovich, 2000). It is possible that parents in the current study may have been currently using treatment types from the same category (i.e., multiple Psychotropic Medications, both vitamins/supplements and special diets) which would not have been captured because the use of any treatment within a single category was the focus of the current study.

Parents often have tried many treatments, then abandoned them for various reasons; therefore, treatments being used at the time of data collection may be unrepresentative of treatments children with ASD have tried at some point in the past (Bowker et al., 2011; Goin-Kochel et al., 2007; Smith & Antolovich, 2000). For this reason, the main analyses investigating factors that contributed to treatment choices focused on whether parents had *Ever* used various treatment types (e.g., lifetime use).

In the Bowker et al. (2011) study, 76.7% of responding families reported having *Ever* used some type of treatment. Conversely, almost all of the children/adolescents in the current study had reportedly received at least one type of treatment at some point in their lives (SSC: 95.6%; BCM: 91.5%; ND: 97.1 %). While the Bowker et al. (2011) study and others focused on treatment use have employed the web-based data collection methodology (Goin-Kochel et al., 2007; Green et al.,2006), the unique approach to data collection with the SSC may have influenced the relatively higher frequency of reported

treatment use. Specifically, the SSC families self-initiated participation in the study and necessarily completed their participation in order to be included in the datasets, which took considerable amounts of time.

For example, at the BCM site (which followed the same protocol as the other 12 SSC data collection sites), families typically participated in approximately 4 hours of phone interviews and spent approximately 2 hours completing standardized questionnaires before being seen for in-person data collection. This in-person data collection was completed at a large children's hospital located in a busy medical center in a major city, often requiring families to drive one or more hours for participation. In-person data collection typically lasted 6 to 8 hours, including a blood-draw for all members of the participating family. These procedures are clearly cumbersome and required a great deal of commitment on the part of the participating families.

Moreover, as discussed previously, families participating in this study were quite similar in terms of educational and income levels. It is possible that the commitment to this level of research participation combined with higher-than-average socioeconomic status might be related to a higher likelihood of knowledge about, accessibility to, and actively seeking treatments for their children. Smith and Antolovich (2000) note that such factors may influence motivation and follow-through with treatment among families of children with ASD.

**Type—School-based therapies.** Speech therapy is often considered a "standard" therapy for children with ASD and is endorsed as being a frequently-used treatment type (Bowker et al., 2011; Green et al., 2006). This makes intuitive sense, as delayed language development is often the first indication to parents that something is askew in

their child's development (Coonrod & Stone, 2004). Children who are eventually diagnosed with an ASD are likely to receive speech-language treatment, even prior to diagnosis, as ASD may be confused with language disorders when the social impairment is not also recognized (Gillberg & Billstedt, 2000, as cited in Wing & Potter, 2009).

However, results of the current study yielded nuanced findings, in that participants more often received School-Based Speech Therapy than Private Speech Therapy. Indeed, the most widely used treatment type endorsed across all three samples was School-Based Speech Therapy, both *Currently* (SSC: 54.1%, BCM: 45.2%, ND: 51.2%) and *Ever* (SSC: 80.4%, BCM: 73.0%, ND: 80.9%). This is consistent with Thomas et al.'s (2007) finding that families most often utilize (and are most pleased with) services delivered in schools. Under the Individuals with Disabilities Education Improvement Act (IDEIA; 2004), children with disabilities must be identified and provided appropriate services by public schools beginning at age 3, but even prior to this, children with disabilities from birth to age 3 years must be provided with early intervention services. While results of the current study do not permit examination of children's progress made in school-based speech therapy, most of the participants had at some point received speech therapy in their school settings.

The high rates of using School-Based Speech Therapy may contribute to the lower utilization of Private Speech Therapy services; perhaps families relied on the school for this treatment rather than seeking service outside of the school. Specifically, though approximately half of the participants in all three groups had at some point received Private Speech Therapy (SSC: 52.6%, BCM: 53.5%; ND: 51.5%), almost half of all participants in all three groups did *not Ever* receive Private Speech Therapy, and the

majority were not receiving this treatment at the time of data collection. Perhaps parents did not view this as a needed treatment, especially if their child did not have a language delay (e.g., Asperger's). Alternatively, perhaps some children had successfully completed Private Speech Therapy and it was no longer indicated. However, it is also possible that issues related to a) accessibility (i.e., insufficient private speech therapy providers in their community, financial constraints or lack of insurance coverage for this treatment) or b) knowledge (i.e., unaware of the treatment type or value) precluded parents' utilization of this type of treatment.

Another treatment examined within this study that could be sought either privately or through the local school district was occupational therapy. Many of the children in these samples were reported to have used Private Occupational Therapy at some point (SSC: 41.4%; BCM: 41.8%; ND: 50.0%). Interestingly, the proportion of participants in the national SSC group who endorsed having *Ever* had School-Based Occupational Therapy (66.4%) was much higher compared to those in the BCM (42.3%) and ND (41.2%) groups. Though the IDEIA (2004) is a federal law, state departments of education determine specific ways in which the IDEIA (2004) is implemented; further, school districts within different states may have varying practices of service delivery. For these reasons, it is possible that states or regions of the United States demonstrate different patterns of service delivery for certain school-based therapies.

Components of some of the "Other Intensive Treatments", including TEACCH, may be included in treatments available in school settings. In addition, many of the parents reporting having *Ever* used "any other" type of treatment indicated that this included "social skills training", which may occur as a part of a student's Individual

Education Plan (IEP) or occur within the context of other school-based treatment approaches. However, it is possible that parents are not aware of whether and when these components are included in their children's school experience, or even what comprises these treatments; social skills, in particular, may be a component of a number of different treatments (Barry et al., 2003). For these reasons, it is possible that there was an underreporting of such services used in the public school setting. For both "Other Intensive Treatments" and "Any Other Treatments" pursued outside of school settings, the same issues related to knowledge and accessibility that have been raised in the preceding paragraphs may also be applicable.

These results highlight the difference between a "clinical diagnosis," as made by comparison of ASD symptomatology to the current DSM-IV-TR (2000) criteria, as opposed to "educational need," as defined in the IDEIA (2004). Specifically, meeting DSM-IV-TR (2000) criteria is not sufficient for demonstrating educational need, and teams of school district personnel (e.g., school psychologists, speech-language pathologists, occupational therapists, etc.) make the determination about whether a child meets this IDEIA (2004) requirement. All children in this study met DSM-IV-TR (2000) diagnostic criteria for an ASD, but 20-27% of them reportedly had not *Ever* had any School-Based Speech Therapy services, and 33-59% had not *Ever* had any School-Based Occupational Therapy services. Potential explanations for these findings may be related to the needs of the individual child, but may also suggest either lack of resources and/or gaps between research and practice. Perhaps children not receiving School-Based Speech Therapy have subthreshold communication deficits (as in PDD NOS) or have well-developed vocabularies but subtle difficulties with give-and-take conversation or

pragmatics (as in Asperger's Disorder), thereby not raising concerns of educators and school personnel about their use of language to the level of requiring services. Perhaps fine motor and sensory issues were not present, or perhaps IEP teams concluded that educational need was not demonstrated. Perhaps children not having *Ever* received school-based speech and/or occupational therapies did not attend public schools and were, therefore, unaware of the requirement that local school districts must provide such services to any eligible constituent of their district (IDEIA, 2004).

Alternatively, perhaps the fact that an average of one-quarter of children diagnosed with an ASD in this sample had not *Ever* received School-Based Speech Therapy is related to either a) insufficient training for school-personnel on identification of ASD-related communication need; b) lack of resources (i.e., SLPs) within school districts to serve children with perceived "less" educational need than others (which is not an acceptable reason for non-delivery of needed services under the IDEIA [2004]); c) too few school-based evidence-based interventions for communication deficits in ASD; and/or d) too little training in delivering such treatments in the school setting.

**Type- Non-school based treatments.** Just over 36% of the national sample (SSC) reported having *Ever* used Intensive Behavioral Treatments, which is a treatment category within the SSC data collection comprised primarily of ABA and related treatments. This is similar to the rate of ABA treatments reported by Bowker et al. (2011), though the 37% of families reporting ABA use in the Bowker et al. (2011) study were *current* users, whereas, the 36.1% found in the current study (SSC sample) were families who had *Ever* used ABA-related treatments. Green et al. (2006) found that 56.3% of families reported currently using ABA treatments. In the current study, a

smaller proportion of the BCM (24.3%) and ND (25.0%) samples *Ever* used ABA treatments. Even fewer reported currently using Intensive Behavioral Treatments (SSC: 16.4%; BCM: 9.0%; ND: 11.8%). While certainly all children's treatment needs are different, these are surprising and somewhat alarming findings given that currently, behavioral interventions, and ABA specifically, are one of the few evidence-based treatments recognized for symptoms of ASD and can be useful for persons with varying abilities (Smith, 2010).

The fact that behaviorally-based treatments were not widely used across these samples suggests the possibility of a gap between theory and practice, particularly between research supporting Intensive Behavioral Treatments and the dissemination of this research. It is possible that families are not getting the information about the effectiveness of treatments like ABA and related behavioral treatments. This has critical implications for researchers and practitioners working in ASD in that there may be a) insufficient translation of research findings into applicable practices, and/or b) insufficient transmission of research findings and/or applicable practices to families. It is also possible that families *do* know about Intensive Behavioral Treatments available for ASD but are unable to locate and/or afford sufficient services. This, again, has important implications for professionals in the ASD field, perhaps suggesting that too few services are available and accessible to families of children with ASD. Another alternative is that these children and adolescents are, in fact, receiving behaviorally-based treatments but their parents may not realize that these are based in behavior theory (e.g., explicit social skills instruction) and thus underreport treatments in this category. This may suggest yet another gap in research to practice.

**Type—Biomedical and medication treatments.** While study results suggest that evidence-based Intensive Behavioral Treatments are not widely utilized in these ASD-diagnosed samples, the results also indicate that the percentages of families in the three groups that endorsed having *Ever* used Biomedical Treatments (SSC: 23.8%; BCM: 21.0%; ND: 23.5%) or using them currently (SSC: 12.1%; BCM: 8.0%; ND: 8.8%) are similar to those using Intensive Behavioral Treatments. It is somewhat difficult to ascertain congruence of Biomedical Treatment use in this study with that from other studies, as different investigations have utilized varying categorization systems and definitions (e.g., Al Anbar et al., 2010; Goin-Kochel et al., 2007; Green et al., 2006; Witwer & Lecavalier, 2005). The category of Biomedical Treatments in this study included special diets, vitamins and supplements, and even chelation therapy, none of which currently have evidence-based support for effectiveness in ameliorating ASD symptomatology, and in some cases may present safety concerns (e.g., chelation) (Levy & Hyman, 2008). Nonetheless, families appear to have *Ever* used evidence-based (e.g., ABA) and non-evidence-based (e.g., biomedical) treatments at similar rates. These findings are consistent with other literature suggesting that "evidence-based" is not as compelling a criterion for parents choosing treatments as it is for professionals studying and developing treatments (Bowker et al., 2011; Goin-Kochel et al., 2007).

Again, this underscores a potential gap between professionals whose practice is informed by evidence-based findings, and parents or other professionals whose practices may not be informed by evidence-based findings. It may suggest that parents are turning to other sources (i.e., Internet, parent support groups, professionals who are less informed by evidence-based results) for guidance on treatment selection. Alternatively, parents

may find information from professionals, whether evidence-based or not, to be inadequate for guiding their treatment selection, which may indicate a gap between professional preparation and demand for professional services, or at least guidance and dissemination practices. To the extent that professionals serving as primary information providers for families of children with ASD (i.e., teachers, pediatricians) lack sufficient training about ASD and related treatment options, this indicates a training and/or dissemination gap that must be addressed by professionals researching and practicing with ASD populations.

While intensive behavioral and Biomedical Treatments were not reported as being widely used compared to other treatment types, almost half of families across all three samples indicated having used Psychotropic Medications at some time (SSC: 41.7%; BCM: 49.0%; ND: 47.1%). This is consistent with the previously identified range of psychotropic medication use in children and adolescents with ASD to be between 30 and 60% (Aman et al., 2005; Green et al., 2006; Mandell et al., 2008; Oswald & Sonenklar, 2007; Witwer & Lecavalier, 2005). Parents may choose to use psychotropic medications in hopes of increasing focus and attention, decreasing hyperactivity and/or aggressiveness or irritability, or addressing symptoms comorbid with—but not diagnostic of—ASD, such as anxiety and mood problems or tics. Parents may choose psychopharmacological treatment in addition to or in place of treatments that require additional (i.e., behavioral) components. Specifically, some families may choose psychotropic medications as a means of bringing problem behaviors under control so that other treatment types may be more effective (Huffman et al., 2011). Other families may hope that psychotropic medications will treat symptoms without requiring other types of treatment. Often,

primary care physicians or pediatricians may recommend psychotropic medications to parents for treatment of specific symptoms, including aggression, irritability, hyperactivity, self-injury, depression, anxiety, or stereotypic or obsessive-compulsive behaviors (Gerhard, Chavez, Olfson, & Crystal, 2009; Myers et al., 2007; Witwer & Lecavalier, 2005).

Across all three samples within the current study, ADHD medications (i.e., stimulants) were the most frequently endorsed type of medication *Ever* having been used (SSC: 27.9%; BCM: 28.5%; ND: 20.6%). This is consistent with prior studies demonstrating that antidepressants and psychostimulants are two of the three (antipsychotics are the third, for which information within the SSC is not available; described below) most commonly prescribed classes of medication within the ASD population (e.g. Aman et al., 2003; Rosenberg et al., 2010). Currently, DSM-IV-TR (2000) precludes making co-morbid diagnoses of ADHD and ASD, but symptoms of inattention, hyperactivity, and impulsivity are very common in children with ASD (Deprey & Ozonoff, 2009). Moreover, prescribers may target specific *symptoms* for pharmacological treatment rather than *diagnoses*, although no stimulant medication is currently FDA approved specifically for the treatment of ADHD symptoms within the ASD population. However, psychotropic medications are often prescribed off-label (Julien et al., 2008), so the practice of having prescribed medication for reasons other than what is indicated by the FDA, known as off-label prescribing, is not surprising.

The only psychotropic medications that currently have indications specific to pediatric patients with ASD are the antipsychotic medications risperidone (Risperdal) and aripiprazole (Abilify), both indicated for irritability associated with ASD. Within the

SSC research protocol, data on the antipsychotic medication class were not collected. Rather, data were collected on "mood stabilizers", which included both antipsychotic and antiepileptic medications (e.g., Depakote). "Mood stabilizers" were the third-most frequently endorsed medication *Ever* used in both the SSC (14.2%) and BCM (11.0%) samples, and the second most frequently endorsed in the ND sample (13.2%). Regardless of FDA indication, research regarding the effectiveness of varying types of psychotropic medications for addressing ASD symptoms is equivocal (Huffman et al., 2011). However, as discussed previously, evidence-basis may not be a primary criterion for parents when choosing what types of treatment to pursue for their children with ASD (Bowker et al., 2011; Goin-Kochel et al., 2007).

**Research Question 2: Are there Characteristics of Children and Families that Change the Likelihood of Choosing Certain Types of Treatment?**

Several authors have pointed out the importance of professionals' understanding of the reasons *why* families of children with ASD choose the treatments they do (Christon et al., 2010; Mandell & Novak, 2005; Smith & Antolovich, 2000). Overall, results of this study suggested that there are several factors that may contribute to families' selection of treatment choices. However, the influence of most predictors had relatively small effects on whether or not families had *Ever* used the various treatments (i.e., as indicated by odds ratios close to 1). Though the influence was small, several predictors had a similar effect on treatment use, even across samples. These findings are discussed in detail in the following paragraphs.

Similar predictors emerged as significant within the SSC and BCM samples, though, overall, more predictors emerged as significant within the SSC sample than in the

BCM sample. It is possible, that this is a function of the much larger sample size (SSC, n = 2,115; BCM, n = 199) rather than representative of practical significance. Even so, there were some predictors for particular treatment types that were not only significant within the SSC but also retained as significant predictors for the BCM sample's use of the same treatment type. For example, for Private Speech Therapy in the SSC and BCM samples, the following variables were significantly predictive that a child had *Ever* had this particular treatment: higher family income, lower child age, lower age of problem onset, and lower verbal cognitive ability. None of these factors were retained as predictive of treatment use in the ND sample.

In some cases, the same predictors contributed to choice of treatment type in all three groups. For example, for Biomedical Treatment, both age of onset and current age of child were among the significant predictors found, and the contribution of these factors appeared to be greater as the group size decreased (e.g., odds ratios were farther from 1 for BCM compared to SSC, as well as for ND compared to BCM).

Within the SSC sample, only gender did not emerge as predictive of any treatment type, and so it was not entered as a potential predictor for any treatment types within the BCM or ND samples. It is possible that this is because a child's gender truly does not make a difference in the likelihood of using various treatment types. However, the disproportionately low representation of females within all samples may have also influenced these statistical analyses and thus informed the decision to drop gender as a potential predictor for the smaller groups. ASD is much more likely to occur in males than in females (APA, 2000), and similar patterns of gender representation are common in studies related to ASD.

Interestingly, though most odds ratios indicated only small changes in the likelihood of using treatments on the basis of one unit increase in the various predictors, consistent trends were noted across all three samples for several treatment types.

**Trends across samples: Lower likelihood of treatments.** When the predictors of age, age of ASD onset, and verbal cognitive scores emerged as being predictive of having *Ever* used treatments, *higher* age, *later* age of onset, and *higher* verbal cognitive scores were consistently associated with *lower* likelihood of having *Ever* used treatments within the SSC, BCM, and ND samples. In other words, the older the child, the later the onset, and the higher the verbal cognitive ability, the less likely it was that a child would have *Ever* had treatments from the corresponding treatment category. Yet, it is important to note that these findings represent trends (i.e., they were not statistically significant).

Consistent with findings of Aman et al. (2005), Witwer and Lecavalier (2005), and Goin-Kochel et al. (2007), one exception to the aforementioned trends in the current study was that *higher* child age was associated with *greater* likelihood of Psychotropic Medication use in the SSC sample. A second exception to this trend was that higher age, *later* age of onset, and *higher* verbal cognitive scores were associated with a *lower* likelihood of having *Ever* used Any Other Treatment in both the SSC and BCM samples (Any Other Treatment could not be reliably predicted within the ND sample because of the small number of participants endorsing this type in the ND sample).

With regard to child age, older children were less likely to endorse having had the following treatments: Private Speech Therapy (SSC, BCM), Intensive Behavioral Treatment (SSC, BCM), Other Intensive Treatment (SSC, BCM), and Biomedical Treatments (SSC, BCM, ND). That older children were less likely to have *Ever* had

treatment may seem counterintuitive; indeed, parents of younger children are more likely to utilize more treatments simultaneously (Green et al., 2007). However, the findings of the current study may represent a cohort effect, in that children who were older at the time of data collection may have had less access to treatments when they were younger, either because there have been substantial increases both in the treatments actually available and the public's awareness of them (Bowker et al., 2011). Moreover, some treatments are more likely to be used by older children compared to younger ones, such as psychotropic medication (Aman et al., 2005; Witwer & Lecavalier, 2005), and families who use such medications are likely to try medications from several different classes (Goin-Kochel et al., 2007); again, only use or non-use of treatment types (rather than specific treatments within the categories) were investigated within this study.

In terms of age of problem onset, when parents noticed problematic symptoms later, they were less likely to have *Ever* had *any* treatments in the SSC sample. They were also less likely to have *Ever* had some treatments in the BCM sample (e.g., Private Speech Therapy, Private Occupational Therapy, and Biomedical Treatments) and in the ND sample (Private Occupational Therapy and Biomedical Treatments). Again, cohort effects may contribute to these findings. Perhaps there are age-related patterns of treatment typically pursued by parents, though this question is beyond the scope of the current study. Further, children with later ages of onset were more likely to have had *no* treatment at any time. Perhaps symptomatology noticed later was less severe/more subtle, which may have also lessened the likelihood of pursuing treatment.

Verbal cognitive score was the predictor most often associated with a change in the likelihood of having used different treatments (i.e., was retained in more final models

than any other variable). More specifically, *higher* verbal cognitive ability was consistently associated with *less* likelihood of receiving many treatments in all three samples. Further, children with higher verbal cognitive scores in the SSC and BCM samples were more likely to have had *no* treatment at any time (not estimable in the ND sample because of the very low proportion of children who had never received any treatment). Why was higher verbal cognitive ability such a common predictor in non-use of most treatment types? One possibility is that parents are often alerted to early problems in development by speech delay or deviance (Coonrod & Stone, 2004). Alternatively, perhaps low verbal functioning suggests to parents that treatment is necessary, even if they are unsure about diagnostic possibilities to explain the delayed language. As noted in the literature review portion of this study, verbal cognitive ability influences others' perceptions about one's overall ability (Sternberg et al., 1981).

**Trends across samples: Higher likelihood of treatments.** There were some predictors that consistently were associated with a higher likelihood of having received certain treatment types. Specifically, when predictors of parent education level and family income emerged as significant, *higher* parent educational level and *higher* family income were consistently associated with *increased* likelihood of having *Ever* received treatments in both the SSC and BCM samples. Intuitively, it makes sense that children from higher SES backgrounds will be more likely to receive treatments, in general, because of access to resources that increase likelihood of receiving these treatments—their parents' higher educational levels make it more likely that they will be knowledgeable about the availability of and processes for accessing certain treatments, and their families' higher incomes make it more likely that they will have insurance to

cover treatment costs. However, the findings that higher SES is associated with greater likelihood of having had some treatments also raises concerns about children from families with less resources having access to similar treatments. It was somewhat surprising to see this trend emerge within these samples because of the relative homogeneity of participants across samples, which makes the finding potentially more compelling.

**Trends associated with race/ethnicity.** The findings related to race/ethnicity must be interpreted cautiously because of the way that race/ethnicity was categorized in this study for analytical purposes and because of the overrepresentation of Caucasian families. These limitations are discussed in subsequent sections. Moreover, effects of race/ethnicity often are secondary to socioeconomic status (SES; i.e., education and income) (Kaufman & Cooper, 2001), and because participants in this study were quite similar in terms of SES, this may limit the effects of racial/ethnic background. However, differences did emerge with regard to race/ethnicity and are worth considering, particularly in planning future investigations on the topic, as understanding the role of culture in treatment decisions is a critical but lacking field (Mandell & Novak, 2005).

Results of the current study indicated that race/ethnicity may be related to using certain treatment types. Specifically, findings from this study indicated that the odds for families from Hispanic/Latino backgrounds in the SSC sample were *higher* than those from Caucasian backgrounds for having *Ever* used School-Based Speech Therapy (134% higher), Intensive Behavioral Treatments (104% higher), Other Intensive Treatments (50% higher), and "any other" treatments (49% higher). However, the odds that SSC families from Hispanic/Latino backgrounds had *Ever* used Psychotropic Medications

were 39% *lower* compared to the odds that Caucasian families had *Ever* used psychopharmacological treatments. Differences were also found between families in the BCM sample who were from Hispanic/Latino and Caucasian backgrounds having *Ever* using various treatments, but these were found in different treatment types than those found in the SSC sample. In particular, the odds were *lower* that Hispanic/Latino BCM families had *Ever* used Private Occupational Therapy (67% lower), School-Based Occupational Therapy (67% lower), or Biomedical Treatments (67% lower).

Treatment utilization for families from "Other" racial/ethnic backgrounds in the SSC sample was also examined, though this category certainly was less than ideal in that it included families from widely varied backgrounds, including African American, Asian American, Native American/Alaska Native, Native Hawaiian or Other Pacific Islander, combinations of these, or "other" races/ethnicities. However, the "Other" race/ethnicity category is extremely diverse (see Methods section), and this must be considered when interpreting any findings related to it. With this in mind, there were differences found among those from "Other" racial/ethnic background when compared to their Caucasian counterparts within the SSC sample. Specifically, the odds were *lower* that those from "Other" backgrounds in the SSC sample had *Ever* used school-based speech-therapy (37% lower), School-Based Occupational Therapy (35% lower), Psychotropic Medications (37% lower), and "any other" treatments (30% lower) when compared to those from Caucasian backgrounds. However, the odds were 91% *higher* that those from "Other" racial/ethnic backgrounds in the SSC sample had endorsed no treatments compared to Caucasian participants.

**Research Question 3: Do Parent Perceptions about ASD Predict *Ever* Having Used Treatment Types?**

Parent perceptions about their child's ASD were demonstrated to contribute to families' choices about using some treatment types, which is consistent with the findings of Al Anbar et al. (2010) and Dardennes et al. (2011). Parent perception was measured with the modified IPQ-R (Moss-Morris et al., 2002) in the ND (n = 68) group, and when perceptions did emerge as influential on treatment types chosen, their contribution was relatively greater than the contribution of child- and family-specific factors, such as clinical presentation and demographics. This finding appears to support the notion that perceptions are often a salient factor in parents' conceptualization of their children's ASD and subsequent treatment choices (Avdi et al., 2000; Hebert & Koulouglioti, 2010).

It is important to understand the IPQ-R (Moss-Morris et al., 2002) subscales when interpreting results. Higher scores on respective subscales are associated with the following strongly-held beliefs: a) Identity, that symptoms are attributable to ASD; b) Timeline-Acute/Chronic, that symptoms of ASD are chronic; c) Consequences, that there are negative consequences of ASD; d) Timeline-Cyclical, that ASD is cyclical/ unpredictable in nature; e) Emotional Representations, that there are negative feelings associated with ASD; f) Personal Control, that parents have control over ASD; g) Treatment Control, that parents have control over treatment for ASD; and h) Coherence, that parents understand ASD.

Al Anbar et al.'s (2010) study on the influence of IPQ-R subscale scores and ASD treatment choices indicated that higher Consequence scores were related to greater likelihood of educative treatments ("behavior or social skills therapy, TEACCH or

PECS", p. 821); higher Timeline-Cyclical scores were associated with increase in use of psychotropic medications. They further found that higher Personal Control scores predicted lower odds of Biomedical Treatments and Psychotropic Medications. Finally, they found that higher scores on Emotional Representations were related to less use of educational treatments.

Findings in the current study were quite different. Results of the current study indicated that as scores indicating belief that their child's ASD is chronic (Timeline-Acute/Chronic) increased, the likelihood of their pursuing Private Speech Therapy decreased. There was a 21% lower likelihood of Private Speech-Therapy for every one-point increase on the Timeline- Acute/Chronic scale. Conversely, perceptions of Treatment Control (i.e., parents perceive having control over the treatment) were associated with a higher likelihood of *Ever* having used Private Occupational Therapy, Other Intensive Treatments, and Psychotropic Medications. Specifically, for each point of increase on the Treatment Control subscale, the likelihood of Private Occupational Therapy increased by 43%, Other Intensive Treatments increased by 61%, and Psychotropic Medication use increased by 49%. The differences between Al Anbar's findings could be related to a) differences in defining treatment categories; b) cultural factors related to treatment choices, as the Al Anbar et al. (2010) study was conducted in France; or c) statistical approach, as the Al Anbar et al. (2010) study utilized only the IPQ-R subscales in their logistic regression analyses, whereas the current study utilized child- and family-specific factors, as well.

The Al Anbar et al. (2010) study also did not include the Identity subscale in their analyses, as a result of their principal components analysis (PCA) demonstrating that this

scale did not represent a dimension of illness perception. While the inclusion of the Identity subscale in the current study may represent a limitation and warrant further investigation, the nature of this study is exploratory and the author wanted to examine all potential contributors to treatment choices, including the number of symptoms parents ascribed to their children's ASD.

Overall, parents' endorsement of symptoms they ascribed to their child's ASD was moderate (Identity subscale: mean = 8.93; standard deviation: 3.16; range = 2 to 14). This may seem surprising, given that the Identity subscale was designed to align with DSM-IV-TR (2000) diagnostic criteria (Al Anbar et al., 2010), and all participants in the current study necessarily met DSM-IV-TR criteria for an ASD. However, the items within the Identity subscale may be most reflective of diagnostic criteria for Autistic Disorder and therefore may not be seen in children with other spectrum diagnoses (e.g., Asperger's, PDD NOS). The score on the Identity subscale, however, is derived not from the number of symptoms endorsed as being observed but from the number of symptoms believed *by the parent* as being associated with their child's diagnosis. Therefore, it is possible that parents truly did not observe the symptoms listed on the Identity subscale or that, even if they did observe these, they did not believe them to be associated with the ASD diagnosis.

In this study, for every additional symptom that parents attributed to ASD (i.e., Identity subscale score), the likelihood that their child would have *Ever* used School-Based Occupational Therapy increased by 28% and likelihood of *Ever* having Intensive Behavioral Treatment increased by 32%. Perhaps the IPQ-R Identity subscale is reflective of overt symptomatology, indicative of perceptions by not only parents but also

by school personnel and other professionals that children would be more likely to benefit from additional school-based services. However, this could not be tested because only parent perceptions were measured in this study. Alternatively, perhaps parents' perceptions about greater number of symptoms being associated with ASD prompted these parents to advocate for more school-based and behavioral services.

Interestingly, however, attributing more symptoms to ASD (Identity) *decreased* the likelihood of Psychotropic Medication use by 18% for every additional symptom endorsed. Perhaps this suggests that parents' choice of Psychotropic Medications were for the management of symptoms other than the core symptoms of ASD, or perhaps parents ascribed the symptoms they observed to something other than their child's ASD diagnosis. This is consistent with previous discussions about high comorbidity of ASD and other diagnoses (Deprey & Ozonoff, 2009), as well as the fact that many prescriptions given to children with ASD target associated symptoms, such as aggression, irritability, hyperactivity, and/or mood (Gerhard, Chavez, Olfson, & Crystal, 2009; Myers et al., 2007; Witwer & Lecavalier, 2005), as no medications currently are known to ameliorate any of the core symptoms of ASD (Huffman et al., 2011).

Higher perceptions of Treatment Control were also related to increased likelihood of Psychotropic Medications. Given that most prescribers of psychotropic medications to children are pediatricians and primary care physicians (Julien et al., 2008), who often do not have extensive specialized training with psychotropic medications, perhaps parents feel that they are able to drive the use of this treatment type.

Parent perceptions did not influence choices about all treatment types in this sample. *Ever* having used School-Based Speech Therapy was predicted only by a child's

verbal cognitive score in the ND sample, such that as verbal cognitive score increased, the likelihood of receiving School-Based Speech Therapy decreased (4% decrease in likelihood for every point increase on verbal cognitive score). This makes sense intuitively in that children with higher verbal functioning may not meet eligibility criteria for School-Based Speech Therapy. That no parent perceptions were significant predictors for School-Based Speech Therapy may be related to the fact that parents do not have complete control over whether or not their child receives this treatment as they do with other treatments, as school-based services require both determination of educational need and agreement among members of an IEP committee. Alternately, because the majority of ND participants had received School-Based Speech Therapy, this may have affected this statistical analysis.

Though these findings suggest that some treatment types investigated are likely influenced by parent perceptions— particularly by their perceptions about the extent to which they can control their child's treatment, the number of symptoms they believe to be directly related to their child's ASD diagnosis, and how chronic they view the ASD— several limitations must be considered.

**Limitations**

**Treatment data.** Though data collection within the SSC protocol was highly standardized across sites and multiple checks were employed to ensure validity and reliability of the data collected on individual participants, there are limitations of the data collection specific to the current study. Of particular interest are issues related to data collection on treatment types endorsed by families, as the use or nonuse of different treatment types was the focus of this study.

***Category confusion.*** First, though some treatment categories were straightforward (e.g., "Speech/Language Therapy with School Therapist"), other treatment categories on the Treatment History Form were somewhat broad (e.g., "Biomedical Treatment"). Also, though some specific examples of treatment were provided on the Treatment History Form (e.g., "special diet, chelation, etc."), the treatments that should or could be endorsed within the respective categories were left open for parents' interpretation. There was also a completely open category, "Other Treatment/Therapy", which allowed parents to endorse treatments they did not identify as belonging within a different category. In the current study, because the focus was on use or nonuse of various treatment *types*, the individual treatments endorsed in this category were not examined (though casual review indicated that "social skills" was often captured within this category). It is possible, then, that some treatments included by parents in this category might have more appropriately fit into another existing category, and social skills specifically has been identified as reasonably belonging to several different treatment categories (Barry et al., 2003). To correct for these limitations, a detailed examination of the qualitative data for the specific treatment types endorsed within each category may allow the researcher to ensure greater consistency among endorsement of use of different categories of treatment.

Further complicating the limitation of vaguely defined treatment categories was that these queries were presented to parents by research coordinators during phone interviews, prior to in-person data collection. Though research coordinators were trained and supervised on an ongoing basis, there were no reliability checks in place to ensure that their responses to potential parent inquiries were uniform. Therefore, a parent who

asked for clarification about a treatment category from one research coordinator may have received a different explanation of that category from a different research coordinator.

***Lack of corroboration.*** Second, no other source of treatment data (e.g., IEPs, treatment plans from private therapists, prescriptions) was utilized in collecting information about what treatments had been used by families. For example, parents may not know that the professional with whom they are working is utilizing "Pivotal Response Training" to address communication deficits. Rather, parents may consider this to be private speech therapy while others may consider this to be social skills training, and the professional may consider it to be a behavioral intervention. As another example, it is possible that either public or private school classrooms are utilizing TEACCH programming but parents are unaware of this. It is also possible that parents omitted (or forgot about) some treatment types they found unhelpful and therefore used only for a short period of time; this appears to be a common occurrence among families of children with ASD (Bowker et al., 2011; Goin-Kochel et al., 2007). For example, Psychotropic Medications were a category of treatment examined in the current study, and some parents may have utilized a particular medication for their child but found the side effects to be intolerable or the medication to be ineffective for ameliorating targeted symptoms, a common reason for parents to pursue Complementary and Alternative Medicine (CAM; Levy & Hyman, 2008). Not only would this have been an important source of information for increasing reliability of parent reports, it also may have aided in determining exactly what treatment types were used.

One approach in future, similar studies may be asking for parents to present additional data about treatment, such as IEPs, prescriptions, or treatment plans, for review by the researcher. Another approach is to utilize a different data collection tool for gathering information on treatment types, such as the one utilized by Green et al. (2006). A data collection form based on this was created by the author and mailed with data collection packets for the ND sample. This form is included in Appendix B and lists very specific treatment types, as well as asks for parents to include date ranges for the use of each treatment. Importantly, data from this measure was not utilized in any of the current analyses, but was gathered for the purpose of exploring specific treatment types in future research. While the use of a more detailed form does not address all the limitations outlined in this section, it may provide a mechanism for collection of additional and useful information in an area where there currently is a paucity of research.

***Retrospective data collection.*** Third, treatment use data were also collected retrospectively, which, while often unavoidable, presents a number of challenges for any study (Field, 2009). Parents were asked not only to endorse categories of treatment their children were currently using but also what they had used in the past, beginning at age 2. For parents of 15 year old participants, remembering what treatments they tried when their child was a preschooler was likely much more challenging than the same task for parents of 5-year-old participants. Use of records, as described previously, may assist parents in remembering accurate details of treatment history, though this assumes that parents keep such records, particularly when treatment types are abandoned for some reason.

***Entering data.*** Finally, there were some inconsistencies noted in the way treatment data were entered into the SSC dataset across the data collection sites. Specifically, in some cases parents' non-endorsement of a treatment type was entered as a "0" in the corresponding cell, while in other cases it was left blank. In the current study, for analytical purposes, all blank cells were assumed to represent nonuse of a treatment type, but it is possible that some blank cells represented truly missing data.

**Predictor variables.** In addition to limitations related to treatment data, there are also limitations to be considered with regard to the demographic and clinical variables for youth participants and their families.

***Cognitive measurement.*** First, in the current study, scores from different measures of cognitive ability were utilized for different participants within the "verbal cognitive ability" predictor variable. The ASD population is a truly heterogeneous one, and this includes measured cognitive ability (Joseph, Tager-Flusberg, & Lord, 2002). Within the SSC, the Mullen Scales, DAS-II, and WISC-IV were available for phenotyping clinicians to use with gathering cognitive information, and were selected for each participant based on the child's developmental level. This resulted in some variation in the instruments used to measure verbal cognitive ability in the current study. Which cognitive instrument was used for respective participants was not available from the data used in this study, though that information is available from the SFARI via request for data.

In addition, both "ratio" and "deviation" scores were calculated for each participant, per the SSC protocol. Ratio scores were calculated by dividing the mean of subtest age equivalent scores (in months, as detailed in the respective test manuals) and

dividing by the chronological age of the child (in months), multiplied by 100. Deviation scores, or norm-referenced scores, are those derived by comparing performance to that of same-age children within the normative group, and these were available for most participants, as described in the Methods section. Deviation scores were not available when participants' performance on subtests yielded scores at or below the floor (i.e., lowest available score), or when participants' required out-of-age-range cognitive testing, in which case the norm-reference group would not include scores for that age participant. All analyses were conducted using deviation scores when available and ratio scores in the absence of deviation scores. Because not all scores are deviation and not all are derived from the same cognitive instrument, the verbal cognitive scores utilized within this study are most appropriately conceptualized as the estimates of participants' verbal cognitive ability. Though the procedures for collecting verbal cognitive data were clearly outlined and stringently adhered to per the SSC research protocol, use of different instruments for measuring verbal ability does represent a limitation in that the scores are not directly comparable (Sattler, 2008). Future studies using this variable may wish to correct for this by transforming this continuous variable into a categorical one by assigning scores to "ranges" of performance; however, such a method reduces the robustness of the statistical analyses (Field, 2009).

***Racial and ethnic categorization.*** A second limitation of the predictor variables within the current study is related to the use of racial and ethnic variables. Six choices of race were presented to families, including African American, Asian American, Caucasian, Native American/Alaskan Native, Native Hawaiian/ Other Pacific Islander, More than One Race, Other, and Not Specified. Parents were also asked to respond for

ethnicity as either Hispanic/Latino or Non-Hispanic/Non-Latino. For the current project, race and ethnicity were combined to create a single race/ethnicity variable. More specifically, if families endorsed Hispanic/Latino for "ethnicity" but "Other" or "Not Specified" for race, their race/ethnicity specifier became "Hispanic/Latino." If families endorsed Hispanic/Latino and Caucasian, African American, etc., their race/ethnicity specifier became "More than One Race." More importantly, the Caucasian race was disproportionately represented in the samples, such that for analytical purposes categories were collapsed to include Hispanic/Latino, Other, and Caucasian. This is certainly not ideal, because it is already known that persons from different racial/ethnic backgrounds may approach treatment for ASD differently (Mandell & Novak, 2005), though studies suggest that the racial/ethnic identity confounds other critical variables, particularly SES (Kaufman & Cooper, 2001). In the current study, the majority of parents had attained bachelor's degrees or higher and the majority of family incomes were above $80,000. This represents an additional limitation of the current study, in that these data indicate that families included in this study are not representative of the U.S. population (U.S. Census Bureau, 2010). Researchers must continually strive to recruit and include diverse racial and ethnic groups within their studies. Nonetheless, these limitations within the current study preclude drawing any conclusions specifically about how racial/ethnic identification may impact treatment decision-making.

***ASD severity.*** Third, the ADOS-derived calibrated severity score (CSS; Gotham et al., 2009) may not be useful for all Modules of the ADOS (de Bildt et al., 2011). The purpose in developing the CSS was to enhance the comparability of scores yielded from different ADOS modules, and the goal was to provide an estimate of the relative severity

of each child's ASD symptomatology, as observed by the clinician and scored on the ADOS (Gotham et al., 2009). However, de Bildt et al. (2011) note that while the CSS is an adequate measurement for ASD symptom severity across time, the validity of the score may be less for Module 2 of the ADOS. An alternative method of comparing ADOS scores that also incorporates an additional source of data to this is to follow a method used by Black, Wallace, Sokoloff, and Kenworthy (2009) by converting raw ADOS and ADI-R scores to standardized *z*-scores, then take the mean of these *z*-scores as composite scores of ASD severity.

***Measurement of parent perceptions about ASD.*** An additional limitation for this study related to predictor variables is related to the IPQ-R, which measured parents' perceptions about the course, nature, and impact of their child's ASD diagnosis. The Though this instrument is widely used with chronic illness research, it has only recently been applied to ASD (Al Anbar et al., 2010), and while the neurodevelopmental nature of ASD is chronic, these diagnoses are not considered "illness". It is possible that this represents a limitation of the current study, though no other measures of parent perceptions could be identified through extensive literature search. However, it is likely that a different measure of parent perceptions would yield different results in terms of the usefulness of parent perceptions as a predictor in choosing treatments for children with ASD.

A clearly identifiable limitation related to the IPQ-R in this study was the author's inadvertent omission of two items from two of the eight different scales of this measure. To correct for this, mean substitution was used (described in the Methods section). Tabachnick and Fidell (2001) note that this is a popular and conservative method of

estimating the value of missing variables. Nonetheless, it is possible that the respective subscales, which were utilized separately as potential predictors for each of the ten treatment conditions, may have made a different contribution as predictors if the item omissions had not occurred.

A third potential limitation for the study is also related to the ND sample, which was the only subsample that completed the IPQ-R. The characteristics of this sample and both of the larger samples (SSC, n = 2,115 and BCM, n = 199) were highly similar, but the new measures used for collecting data to answer the third research question were specific to parent's perceptions rather than to demographic family data or clinical/phenotypic-child data. Therefore, it is possible that the responders in the ND sample differed in some meaningful way from the nonresponders in terms of their perceptions.

**Future Directions**

In the previous section, limitations of the study were reviewed and information about possible approaches for correcting these limitations in future studies were offered. In addition to these suggestions, there are many areas in which the current study may be expanded upon or extended in future research.

**Regional patterns.** The SSC dataset included participants from all twelve North American SFARI SSC sites. In addition, data from the BCM sample were also analyzed. In most ways, the SSC and BCM groups were similar in terms of demographic characteristics, suggesting that the BCM sample is representative of the larger SSC sample. However, there was one notable exception to this, in terms of racial/ethnic background. Specifically, the BCM sample included 26.3 % of participants who self-

identified as Hispanic-Latino—a greater percentage than the 10.9% of participants endorsing this ethnicity in the SSC sample. Future studies may wish to examine potential differences in the characteristics of the other, local sub-samples of the SSC dataset.

Some differences were also noted in terms of treatments used across the samples. Statistically significant differences in the groups' use of School-Based Occupational Therapy and use of Any Other Treatments were found, as well as the reports of never having received any treatment across the samples. Investigating ways in which treatment utilization differs among the SSC sites may assist researchers and practitioners in identifying areas across North America where certain treatment types are more widely used and begin investigating reasons why such patterns may occur. It is possible that differing demographic characteristics, such as higher representation of persons from Hispanic/Latino backgrounds—as well as characteristics not captured in the current study such as religious affiliation and/or political views, for example—may contribute to differing patterns of treatment use in various regions. Future studies may specifically investigate such a hypothesis.

**Treatment use over time.** Parents of children with ASD often utilize treatments simultaneously (Bowker et al., 2011; Goin-Kochel et al., 2007; Green et al., 2006), and they may discontinue treatment types for various reasons (Bowker et al., 2011; Levy & Hyman, 2008). Some treatments may be more likely utilized for younger children, such as behavioral and biomedical (Goin-Kochel et al., 2007), while others treatments are more likely used for older children, such as psychotropic medication (Aman et al., 2005; Witwer & Lecavalier, 2005). Future work building on the current study may investigate whether there are common patterns in terms of the progression of treatment types. The

use of the *Ever* variable in the current study captured valuable information about whether families had used particular treatment types during their child's lifetime, and this may serve as an initial step in further examination of whether there are "typical" patterns of treatment use/exhaustion, as well as what factors may predict the use of different treatment types at various ages. Such findings would have important psychoeducational and practice implications.

**Treatment use in diverse groups.** As noted previously, the current sample is large and well-characterized via rigorous data collection, but it is also more homogenous in terms of socioeconomic status and race/ethnicity than is needed in order to generalize the findings to diverse groups. It is possible that the factors found to predict pursuit of various treatment types in this sample may differ to unknown extents in different samples. Investigation of the same research questions within a different sample (i.e., community mental health clinic, multiplex ASD families) would make a valuable contribution to the generalization of findings. Moreover, recruiting participants from more diverse backgrounds would also provide valuable guidance for professionals striving to ensure that treatment is available for all children who are diagnosed with ASD. However, replication of a study as large and well-characterized as the SFARI SSC would be extremely challenging outside of a research setting.

**School vs. private therapies.** One very interesting finding of the current study was that many parents rely heavily on their child's school to provide therapy, which is consistent with some previous findings (Thomas et al., 2007). Extensions of this finding may include investigation of whether the same children are being served in both school and private settings or whether children who are not found eligible for school-based

therapies via the IDEIA (2004) are more likely to pursue treatment outside the school. Relatedly, future studies in this area should investigate differences in the clinical characteristics of children who are found eligible for therapies under the IDEIA (2004) and those who are not. All youths who participated in the current study were clinically diagnosed with an autism spectrum disorder, yet not all were eligible for school-based supports and services, presumably because they did not meet the IDEIA (2004) requirement of an "educational need." Information on the differences of children clinically diagnosed and eligible for school-based services may offer insight for professionals and parents who are working to meet individual student needs, whether inside or outside of the school setting.

The IDEIA (2004) is federal legislation applicable to U.S. public schools, and some children within the current study doubtlessly attended private schools, some of which may have been designed specifically to serve students with ASD. Future research should also focus on the clinical characteristics of children who attend these schools. In such studies, statistically controlling for family income, which majorly contributes to whether a child attends a private school, may provide valuable information about whether the symptomatology, cognitive functioning, etc., of students attending private and/or specialized schools differs from those attending public schools.

**Evidence-based treatments.** Consistent with previous literature (Bowker et al., 2011; Goin-Kochel et al., 2007), current findings indicate that the majority of children and adolescents within the samples had not *Ever* used ABA treatments, which are the most empirically supported for treatment within ASD (Makrygianni & Reed, 2010). In future studies, exploration of reasons why more families of children clinically diagnosed

with ASD do not pursue evidence-based treatments founded in ABA therapy is needed, as it is the responsibility of professionals to assist families in making informed treatment decisions on the basis of current research.

**Parent perceptions about cause.** Parents' decisions about which treatments to pursue for their children with ASD diagnoses may in part be related to their attribution of the "cause" of their child's ASD (Dardennes et al., 2011). This is an area of very active research, and while no single or definitive cause has been identified, current literature supports that genetic, environmental, and neurophysiological factors are likely to contribute to ASD diagnoses (Wing & Potter, 2009). Some putative causes have been unsupported, such as the link between immunizations and ASD, which has also been shown to have developed from fraudulent studies (Flaherty, 2011).

The influence of parents' perceptions about cause was not examined in the current study, but the IPQ-R included a section that measured the degree to which parents agreed with a number of potential causes for their child's ASD. A brief review of these data indicated that more than half of parent respondents in this sample ($n$ = 68) agreed or strongly agreed with problems in genetics and/or brain structure causing ASD. Just under half of the parents agreed or strongly agreed that the ASD was caused by "the will of God". Alarmingly, however, more than 40% agreed or strongly agreed that toxins in immunizations may have caused their child's ASD—a higher percentage than those who were neutral (23.9%) or disagreed/strongly disagreed (34.3%). If treatment is driven, in part, by perceived cause, and the endorsed cause of ASD is toxins from immunizations, one possible treatment for such a cause is elimination of heavy metals, or chelation therapy. Not only has this practice been unsupported as effective in ASD, it has also

been demonstrated as potentially very dangerous (Levy & Hyman, 2008). Future studies should focus on the role of parent perceptions about causes and the link to treatment, particularly with regard to beliefs about immunizations. Perhaps public dissemination of literature about the lack of connection between immunizations and ASD has been ineffective, an important finding particularly within the current sample, given that families were overwhelmingly from higher SES brackets. Perhaps, then, the statement that it is difficult to "un-scare" parents is true. Alternatively, perhaps the tenacious adherence to unsupported causes such as immunizations represents a modifiable prevention option. Specifically, consent of parents regarding their child's immunizations is modifiable, unlike genetic, structural, or religious beliefs. In any case, further investigation of the role that parent perception about causes is warranted, as this provides professionals with opportunities for parental psychoeducation.

# Chapter V

## Summary and Conclusions

The findings of the current study contribute to the broader understanding of what types of treatments parents of children with ASD are using in a large, well-characterized sample from the Simons Simplex Collection (SSC), as well as two subsamples of this population. Many of the treatment findings were consistent with previous reports of treatment use in the ASD population.

Children and adolescents within the current study were using one or more treatment types at the time of data collection, and almost all of them had received some type of treatment at some time in their lives. However, when considering that previous literature often indicates that families of children with ASD are likely to use many treatment types simultaneously, the average of 1 or 2 treatment types used at one time was surprising. Many families were found to rely heavily on school-based treatments, such as Speech and Occupational Therapies; indeed, School-Based Speech Therapy was the most widely used treatment type across all participants. Psychotropic medication was also used by almost half of the families, and ADHD medications were the most widely reported type of psychotropic utilized. Intensive Behavioral Treatments (e.g., ABA) were not utilized as widely as anticipated in a sample of youths with ASD diagnoses, as behaviorally-based interventions currently have more empirical support for effective use with ASD populations than any other treatment type. However, Biomedical Treatments, many of which are supported by little-to-no scientific study, were used at similar rates as Intensive Behavioral Treatments. These findings may represent a research-to-practice gap, suggesting important implications for practitioners, in particular. Alternately, these

may be reflective of limitations related to retrospective and categorical data collection utilized in the current study. In addition, the sample, though large and well-characterized, was comprised largely of non-Hispanic White families with higher-than-average incomes and levels of parental education.

Nevertheless, the results of the current study suggest that there are many factors that predict what treatment types are chosen for children with ASD. Child- and family-specific factors, as well as parent perceptions, were investigated as potentially contributory to what treatment types are pursued by families of children with ASD. Specifically, when children were older currently, were older when parents first noted ASD symptomatology, and demonstrated higher verbal cognitive ability, families were less likely to have pursued treatment. Higher parent educational level and annual household income (i.e., SES) was associated with a greater likelihood of pursuing treatment. There were also trends noted within the current study suggesting that use of some treatment types may be related to the racial/ethnic background of a child's family, a finding that must be interpreted cautiously because participants overwhelmingly identified as Caucasian; however, the fact that such findings were yielded from this racially/ethnically homogenous sample warrants attention in future studies.

When parent perceptions were found to contribute to choosing particular treatment types, the relative contribution of these factors was somewhat stronger than that of the child- and family-specific factors. The degree to which parents felt they had control over their child's ASD treatment, viewed their child's demonstrated behaviors as related to ASD, and perceived their child's ASD as being chronic were all found to make a difference in whether parents chose some treatment types for their children.

Limitations related to collection of data on treatment types and predictor variables are likely to have influenced the current findings and must be considered during interpretation of all results. However, the findings have important implications for the design and development of future studies focused on how treatment decisions are made. Specifically, identification of regional patterns of treatment use, trajectories of treatment use over time, differences in treatments used in diverse groups, utilization of school-based versus privately delivered treatments, and parent perceptions about cause of ASD are a few additional areas that may build upon the current findings.

Issues related to ASD are increasingly relevant to professionals, as the diagnostic prevalence continues to rise. Treatment for these diagnoses is critical, and research about effectiveness of certain treatments is continuously emerging. Though various professionals are involved in the planning and delivery of treatments for children and adolescents with ASD, ultimately the responsibility for choosing, consenting for, and following through with treatments lies with the parents. Professionals, then, must be positioned to support families' decision-making through such activities as developing effective practices, disseminating research-to-practice information, and advocating for their needs. As researchers and practitioners increasingly understand factors that influence the treatment choices parents make, these professionals' abilities to support families experiencing ASD will be enhanced. As practitioners strive to collaborate with and meet the needs of affected children and their families, it is the hope of this author that the current study will contribute meaningfully to knowledge about the individualized aspects of ASD treatment choices made by parents.

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# Appendix A

## Survey of Parents' Perceptions about ASD Collected from ND Sample

## SURVEY

## Your Observations of Your Child's Autism Spectrum Disorder (ASD)

**An Adaptation of the Revised Illness Perception Questionnaire**

**(Moss-Morris et al., 2002)**

Below are a number of symptoms associated with ASD that you may or may not have seen in your child. Please indicate by checking yes or no, if you observe any of these symptoms, and whether you think these symptoms are related to your child's ASD diagnosis.

Please provide one response for each column, per question.

| | | **I have observed this symptom in my child.** | | **I believe this symptom is associated with my child's ASD.** | |
|---|---|---|---|---|---|
| 1 | Prefers to be alone | [] Yes | [] No | [] Yes | [] No |
| 2 | Resists physical forms of affection | [] Yes | [] No | [] Yes | [] No |
| 3 | Easily agitated | [] Yes | [] No | [] Yes | [] No |
| 4 | Unusual habits or rituals | [] Yes | [] No | [] Yes | [] No |
| 5 | Poor eye contact | [] Yes | [] No | [] Yes | [] No |
| 6 | Becomes fixed on small details | [] Yes | [] No | [] Yes | [] No |
| 7 | Talks less than expected for age, or does not talk at all | [] Yes | [] No | [] Yes | [] No |
| 8 | Repeats words or phrases that have no meaning or are out of context | [] Yes | [] No | [] Yes | [] No |
| 9 | Has repetitive movements | [] Yes | [] No | [] Yes | [] No |
| 10 | Has difficulty with small changes | [] Yes | [] No | [] Yes | [] No |
| 11 | Does not pretend | [] Yes | [] No | [] Yes | [] No |
| 12 | Is more interested in objects than people | [] Yes | [] No | [] Yes | [] No |
| 13 | Does not respond to name | [] Yes | [] No | [] Yes | [] No |
| 14 | Does not point out things that interest him/her | [] Yes | [] No | [] Yes | [] No |

We are interested in your own personal views of how you see your child's ASD. Please indicate how much you agree or disagree with the following statements about your child's ASD by checking the appropriate box.

| | Views | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree |
|---|---|---|---|---|---|---|
| 1 | My child's ASD will last a short time. | [] | [] | [] | [] | [] |
| 2 | My child's ASD is likely to be permanent rather than temporary. | [] | [] | [] | [] | [] |
| 3 | My child's ASD will last a long time. | [] | [] | [] | [] | [] |
| 4 | My child's ASD will pass quickly. | [] | [] | [] | [] | [] |
| 5 | I expect my child will have this illness for the rest of his/her life. | [] | [] | [] | [] | [] |
| 6 | My child's ASD is a serious condition. | [] | [] | [] | [] | [] |
| 7 | My child's ASD has major consequences on my life. | [] | [] | [] | [] | [] |
| 8 | My child's ASD does not have much effect on my life. | [] | [] | [] | [] | [] |
| 9 | My child's ASD strongly affects the way others see me. | [] | [] | [] | [] | [] |
| 10 | My child's ASD has serious financial consequences. | [] | [] | [] | [] | [] |
| 11 | My child's ASD causes difficulties for those who are close to me. | [] | [] | [] | [] | [] |
| 12 | There is a lot I can do to control my child's ASD symptoms. | [] | [] | [] | [] | [] |
| 13 | What I do can determine whether my child's ASD gets better or worse. | [] | [] | [] | [] | [] |
| 14 | The course of my child's ASD depends on me. | [] | [] | [] | [] | [] |
| 15 | Nothing I do will affect my child's ASD. | [] | [] | [] | [] | [] |
| 16 | I have the power to affect my child's ASD. | [] | [] | [] | [] | [] |
| 17 | My actions will have no affect on the outcome of my child's ASD. | [] | [] | [] | [] | [] |
| 18 | My child's ASD will improve with time. | [] | [] | [] | [] | [] |
| 19 | There is very little that can be done to improve my child's ASD. | [] | [] | [] | [] | [] |
| 20 | Treatment for my child's ASD will be effective in curing him/her. | [] | [] | [] | [] | [] |
| 22 | Treatment can control my child's ASD. | [] | [] | [] | [] | [] |

| | Views | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree |
|---|---|---|---|---|---|---|
| 23 | There is nothing which can help my child's ASD. | [] | [] | [] | [] | [] |
| 24 | The symptoms of my child's ASD are puzzling | [] | [] | [] | [] | [] |
| 26 | I don't understand my child's ASD. | [] | [] | [] | [] | [] |
| 27 | My child's ASD doesn't make sense to me. | [] | [] | [] | [] | [] |
| 28 | I have a clear picture or understanding of my child's ASD. | [] | [] | [] | [] | [] |
| 29 | The symptoms of my child's ASD change a great deal from day to day. | [] | [] | [] | [] | [] |
| 30 | My child's symptoms of ASD come and go in cycles. | [] | [] | [] | [] | [] |
| 31 | My child's ASD is very unpredictable. | [] | [] | [] | [] | [] |
| 32 | My child goes through cycles in which his/her ASD gets better and worse. | [] | [] | [] | [] | [] |
| 33 | I get depressed when I think about my child's ASD. | [] | [] | [] | [] | [] |
| 34 | When I think about my child's ASD I get upset. | [] | [] | [] | [] | [] |
| 35 | My child's ASD makes me feel angry. | [] | [] | [] | [] | [] |
| 36 | My child's ASD does not worry me. | [] | [] | [] | [] | [] |
| 37 | That my child has ASD makes me feel anxious. | [] | [] | [] | [] | [] |
| 38 | My child's ASD makes me feel afraid. | [] | [] | [] | [] | [] |

## Causes of Your Child's Autism Spectrum Disorder (ASD)

We are interested in what you consider as likely contributing factors to your child's autism spectrum disorder (ASD). There is no correct answer to this question. What interests us most is your own perspective on the factors that may have caused your child's ASD rather than what others, including a physician or other professional may have suggested. Below is a list of some parents' opinions. Please indicate to what extent you agree or disagree with these causes by checking the appropriate box.

| | **Possible Causes** | **Strongly disagree** | **Disagree** | **Neither disagree nor agree** | **Agree** | **Strongly Agree** |
|---|---|---|---|---|---|---|
| 1 | General life stress | [] | [] | [] | [] | [] |
| 2 | Genetics | [] | [] | [] | [] | [] |
| 3 | A germ or virus | [] | [] | [] | [] | [] |
| 4 | Diet or eating habits | [] | [] | [] | [] | [] |
| 5 | Chance or bad luck | [] | [] | [] | [] | [] |
| 6 | Poor medical care in the past | [] | [] | [] | [] | [] |
| 7 | Environmental pollution | [] | [] | [] | [] | [] |
| 8 | My own behavior or decisions | [] | [] | [] | [] | [] |
| 9 | In utero stress or accident | | | | | |
| 10 | Mental attitude/negative views | [] | [] | [] | [] | [] |
| 11 | Family worries about ASD | [] | [] | [] | [] | [] |
| 12 | Will of God | [] | [] | [] | [] | [] |
| 13 | My own emotional state (e.g., depression, anxiety) | [] | [] | [] | [] | [] |
| 14 | My or my partner's age | [] | [] | [] | [] | [] |
| 15 | My own alcohol consumption | [] | [] | [] | [] | [] |
| 16 | My own tobacco consumption | [] | [] | [] | [] | [] |
| 17 | Accident or injury | [] | [] | [] | [] | [] |
| 18 | My child's brain structure | [] | [] | [] | [] | [] |
| 19 | Deterioration of my child's immunity | [] | [] | [] | [] | [] |
| 20 | Toxins found in vaccines/immunizations | [] | [] | [] | [] | [] |
| 21 | Stress at birth | [] | [] | [] | [] | [] |

On the lines below, please rank order the three most important causal factors you believe underlie your child's ASD. You may use reasons from the table above or add any other opinions. For me, the most likely contributing factors are:

1. _____
2. _____
3. _____

# Appendix B

## Updated Treatment Information Collected from ND Sample

ID #_____

Date_____

**Updated Treatment Form**

We are interested in understanding more about what types of treatments are utilized by parents of children with autism spectrum disorders. Below, you will find a list of treatments that some parents have used either now or in the past. Please indicate which, if any, of the following you have *Ever* tried by checking the appropriate box(es). For those treatments you have utilized, please indicate the date(s) of treatment. For example, you might write "Jan 02" for a single-use treatment, or you might write "Nov 2008-present" for a treatment that was/is on-going.

[] Public school special education supports
Date(s):_____

[] Attendance at private school for kids with ASD
Date(s):_____

[] Attendance at private school, no special service
Date(s):_____

[] Home-schooled
Date(s):_____

| | | |
|---|---|---|
| [] | Abilify/aripiprazole | Date(s): |
| [] | Acupuncture | Date(s): |
| [] | Adderall | Date(s): |
| [] | Antihistamine (sleep aid) | Date(s): |
| [] | Applied behavior analysis—PRIVATE | Date(s): |
| [] | Applied behavior analysis—SCHOOL | Date(s): |
| [] | Aromatherapy | Date(s): |
| [] | Atavin/lorazepam | Date(s): |
| [] | Auditory integration training | Date(s): |
| [] | Augmentative and alternative communication | Date(s): |
| [] | Azrin 24-h toilet training | Date(s): |
| [] | Baudhuin preschool | Date(s): |
| [] | Bethanechol Medication | Date(s): |
| [] | Bolles sensory learning method | Date(s): |

| | | |
|---|---|---|
| [] | Buspar/buspirone | Date(s): |
| [] | Casein-free diet | Date(s): |
| [] | Catapres/clonidine | Date(s): |
| [] | Chelation | Date(s): |
| [] | Clathration | Date(s): |
| [] | Clonopin/ clonazepam | Date(s): |
| [] | Clozaril/clozapine | Date(s): |
| [] | Cognitive/behavioral therapy | Date(s): |
| [] | Conductive education | Date(s): |
| [] | Craniosacral manipulations | Date(s): |
| [] | Cylert/pemoline | Date(s): |
| [] | Dance therapy | Date(s): |
| [] | Depakote/valproic acid/divalproex sodium | Date(s): |
| [] | Dexedrine/dextroamphetamine | Date(s): |
| [] | Diflucan/fluconazole | Date(s): |
| [] | Dilantin/phenytoin | Date(s): |
| [] | Discrete trial training (Lovaas) | Date(s): |
| [] | DMG (dimethylglycine) | Date(s): |
| [] | Dolphin therapy | Date(s): |
| [] | Eden program | Date(s): |
| [] | Electro-aversive therapy (Faradic skin shock) | Date(s): |
| [] | Extended breast-feeding | Date(s): |
| [] | Facilitated communication | Date(s): |
| [] | Fast forward | Date(s): |
| [] | Feingold diet | Date(s): |
| [] | Floor time | Date(s): |
| [] | Folic acid/folate | Date(s): |
| [] | Gentle teaching | Date(s): |
| [] | Giant steps | Date(s): |
| [] | Gluten-free diet | Date(s): |
| [] | Hagashi school | Date(s): |
| [] | Haldol/haloperidol | Date(s): |
| [] | Holding therapy | Date(s): |
| [] | Homeopathy | Date(s): |
| [] | Inderal/propranolol | Date(s): |
| [] | Infant massage | Date(s): |
| [] | Institute for human potential (doman-delacto | Date(s): |

| | | |
|---|---|---|
| | patterning) | |
| [] | Integrated movement therapy | Date(s): |
| [] | Interactive metronome | Date(s): |
| [] | Intravenous immunoglobulin | Date(s): |
| [] | Irlen lenses | Date(s): |
| [] | Joint action routines | Date(s): |
| [] | LEAP | Date(s): |
| [] | L-Glutamine | Date(s): |
| [] | Lindamood bell | Date(s): |
| [] | Lithium | Date(s): |
| [] | Magnesium | Date(s): |
| [] | Mega-vitamin therapy | Date(s): |
| [] | Melatonin | Date(s): |
| [] | Multisensory environments (Snoezelen) | Date(s): |
| [] | Music therapy | Date(s): |
| [] | Naltrexone | Date(s): |
| [] | Neural therapy | Date(s): |
| [] | Neurofeedback (biofeedback) | Date(s): |
| [] | Nystatin | Date(s): |
| [] | Occupational therapy- PRIVATE | Date(s): |
| [] | Occupational therapy- SCHOOL | Date(s): |
| [] | Omega-3/Essential fatty acids | Date(s): |
| [] | Options | Date(s): |
| [] | Osteopathy | Date(s): |
| [] | Paxil/paroxetine | Date(s): |
| [] | Pentoxifylline | Date(s): |
| [] | Pepcid | Date(s): |
| [] | Picture exchange communication systems (PECS) | Date(s): |
| [] | Probiotics | Date(s): |
| [] | Prozac/fluoxetine | Date(s): |
| [] | Pyridoxine | Date(s): |
| [] | Rapid prompting | Date(s): |
| [] | Reduced L-glutathione | Date(s): |
| [] | Risperdal/risperidone | Date(s): |
| [] | Ritalin/methylphenidate | Date(s): |
| [] | Rolfing | Date(s): |
| [] | Rhythmic entrainment interventions | Date(s): |

| | | |
|---|---|---|
| [] | Secretin Medication | Date(s): |
| [] | Self-injurious behavior inhibiting system (SIBIS) | Date(s): |
| [] | Sensory integration | Date(s): |
| [] | Social stories | Date(s): |
| [] | Speech therapy – PRIVATE | Date(s): |
| [] | Speech therapy – SCHOOL | Date(s): |
| [] | Sporanox/ itraconazole | Date(s): |
| [] | TEACCH | Date(s): |
| [] | Tegretal/carbamazepine | Date(s): |
| [] | Tenex/Intuniv/guanfacine | Date(s): |
| [] | Thorazine/chlorpromazine | Date(s): |
| [] | Tofranil/imipramine | Date(s): |
| [] | Transfer factor | Date(s): |
| [] | Vagal nerve stimulation | Date(s): |
| [] | Valium/diazepam | Date(s): |
| [] | Van Dijk approach | Date(s): |
| [] | Vancomycin | Date(s): |
| [] | Visual integration training | Date(s): |
| [] | Visual schedules | Date(s): |
| [] | Vitamin A | Date(s): |
| [] | Vitamin B6 | Date(s): |
| [] | Vitamin C | Date(s): |
| [] | Watsu | Date(s): |
| [] | Weighted vest/blanket | Date(s): |
| [] | Xanax/alprazolam | Date(s): |
| [] | Yeast-free diet | Date(s): |
| [] | Zoloft/sertraline | Date(s): |
| [] | OTHER TREATMENT(S) NOT LISTED (specify): | Date(s): |

THANK YOU!

# Appendix C

## Letter Describing the Study to ND Participants

**(Printed on University of Houston Letterhead Stationary)**

January 17, 2011

Dear Parent,

You are invited to participate in a study focused on enhancing understanding of parents' opinions and perceptions of autism spectrum disorders (ASD), as well as of parents' ASD treatment choices. With the approval of the Simons Foundation, Baylor College of Medicine/Texas Children's Hospital, and University of Houston, I am completing my doctoral dissertation in this area. As a PhD student, I have been a clinician for the Simons Simplex Collection (SSC) for 1 ½ years. My work with families participating in this study has facilitated interest in an ASD-focused career, and my dissertation project is a step in this direction. This type of research may have the potential to enhance treatment information provided by clinicians and researchers who work with families of children with ASD. To date, little information is available about how parents' thoughts drive the treatment process, and for that reason, your participation is very valuable. I very much appreciate your consideration of participation in this study.

Two questionnaires are enclosed: one is focused on gathering information about your thoughts and opinions about your child's ASD, and the other asks for information about all the treatments you have tried in the past (even if these were very brief). Together, these two surveys should take no more than 30 minutes to complete. Once these are completed, please return the completed questionnaires in the addressed, stamped envelope. Your completion and return of these questionnaires to us will indicate your consent to participate in this study.

Please be assured that your confidentiality is extremely important, and all responses will be kept confidential. These returned questionnaires will *not* be kept with any other data collected on your family through the Simons study. There is a four-digit number on all materials that will help me keep organize information but **your family's name will not be included on any data**. You are certainly not obligated to participate, and choosing not to participate does not have any repercussions.

Thank you for considering participating in my dissertation study! Should you have any questions, please feel free to contact me (ssmire@uh.edu) or my advisor, Tom Kubiszyn, Ph.D., at 713-743-9865.

Respectfully,

*Sarah Mire, M.A.*

Sarah Mire, M.A.
Doctoral Candidate in School Psychology
University of Houston, Department of Educational Psychology

Research Associate, Simons Simplex Collection
Baylor College of Medicine/Texas Children's Hospital

# Appendix D

## Informed Consent Sent to ND Participants

# UNIVERSITY OF HOUSTON
# CONSENT TO PARTICIPATE IN RESEARCH

**PROJECT TITLE**: FACTORS RELATED TO TREATMENT CHOICES FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS: THE ROLE OF PARENT PERCEPTIONS AND DECISION-MAKING

You are being invited to participate in a research project conducted by Sarah Mire, M.A. from the Educational Psychology department at the University of Houston. This project is being conducted as part of a collaborative effort between University of Houston and Baylor College of Medicine. Ms. Mire's doctoral dissertation research, is conducted under the supervision of Tom Kubiszyn, Ph.D. of the Educational Psychology department of the University of Houston. Robin Kochel, Ph.D. at Baylor College of Medicine is a co-investigator on this study.

## NON-PARTICIPATION STATEMENT

Your participation is voluntary and you may refuse to participate or withdraw at any time without penalty or loss of benefits to which you are otherwise entitled. You may also refuse to answer any question. You have been selected for the opportunity to participate because of your previous participation in the Simons Simplex Collection (SSC) at Baylor College of Medicine/ Texas Children's Hospital (BCM/TCH), at which time you indicated willingness to be recontacted for future studies about autism spectrum disorders (ASD) which includes the diagnoses Autistic Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified. However, you are free to decline participation in this study, and choosing not to participate will not influence your inclusion in the SSC or your opportunities to participate in additional future studies.

## PURPOSE OF THE STUDY

This study is being conducted to investigate what factors may influence treatments parents chose for their children who have autism spectrum disorders. Data collection for this study will end in March 2011.

## PROCEDURES

You will be one of approximately 200 subjects to be asked to participate in this project. All participants invited to participate are families whose SSC data were collected through BCM/TCH. Two questionnaires, included with this form, are requested for completion. One questionnaire asks for information about your perceptions of the nature and course

of your child's autism spectrum disorder. The other questionnaire asks about the types and dates of treatments you may have used for your child with an autism spectrum disorder, at any time in the past or currently. You will not be asked to complete any additional measures for this study. It will likely take approximately 30 minutes to complete both forms. Here is an example of the kind of question you will be asked:

| YOUR Views | Strongly Disagree | Disagree | Neither Disagree Nor Agree | Agree | Strongly Agree |
|---|---|---|---|---|---|
| I have a clear picture or understanding of my child's ASD. | [] | [] | [] | [] | [] |

When you are finished, you are asked to return the two completed questionnaires enclosed in this packet, using the addressed and stamped envelope included. Once we receive your completed questionnaires, we will link this information with your SSC data.

## CONFIDENTIALITY

Every effort will be made to maintain the confidentiality of your participation in this project. Each subject's name will be paired with a code number. This code number will appear on all written materials. The list pairing the subject's name to the assigned code number will be kept separate from all research materials and will be available only to the study team. This code number will allow us to link this new information with the data you already provided for the SSC. Confidentiality will be maintained within legal limits.

## RISKS/DISCOMFORTS

No foreseeable risks are associated with participation in this study.

## BENEFITS

While you will not directly benefit from participation, your participation may help investigators better understand ways that professionals might more effectively facilitate treatment planning for families of children with autism spectrum disorders.

## ALTERNATIVES

Participation in this project is voluntary and the only alternative to this project is non-participation.

## PUBLICATION STATEMENT

The results of this study may be published in professional and/or scientific journals. It may also be used for educational purposes or for professional presentations. However, **no individual participant will be identified.**

If you have any questions, you may contact Sarah Mire, MA at 832-822-3641. You may also contact Tom Kubiszyn, PhD faculty sponsor, at 713-743-9865.

ANY QUESTIONS REGARDING MY RIGHTS AS A RESEARCH SUBJECT MAY BE ADDRESSED TO THE UNIVERSITY OF HOUSTON COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (713-743-9204). ALL RESEARCH PROJECTS THAT ARE CARRIED OUT BY INVESTIGATORS AT THE UNIVERSITY OF HOUSTON ARE GOVERNED BY REQUIREMENTS OF THE UNIVERSITY AND THE FEDERAL GOVERNMENT.

# Appendix E

## Email Template for ND Participants Not Responding to Mailed Letter

February 14, 2011

Dear Parent,

Recently, you received a research packet in the mail inviting you to participate in a study focused on parents' perceptions about and treatment choices for children and adolescents with an Autism Spectrum Disorder (ASD). I am writing to ensure that you received this packet. If you did not, or if you no longer have the packet, please reply to this email and I will mail you a new packet, including a stamped return envelope. The two questionnaires included in the packet take approximately 25-30 minutes to complete. Please be assured that your confidentiality is extremely important, and all responses will be kept confidential. These returned questionnaires will not be kept with any other data collected on your family through the Simons study. There is a six-digit number on all materials that will help me organize information, but your family's name will not be included on any data. You are certainly not obligated to participate, and choosing not to participate does not have any repercussions.

It has been my work with families participating in the Simons Simplex Collection over the past 1 ½ years that has facilitated interest in an ASD-focused career. For that reason, I am completing my doctoral dissertation in this area. The project has been approved by the Simons Foundation, Baylor College of Medicine/Texas Children's Hospital, and University of Houston. This type of research may help enhance treatment information provided by clinicians and researchers who work with families of children with ASD. To date, little information is available about how parents' thoughts drive the treatment process, and for that reason, your participation is very valuable.

Thank you for considering participating in my dissertation study! Should you have any questions, please feel free to contact me (ssmire@uh.edu) or my advisor, Tom Kubiszyn, Ph.D., at 713-743-9865.

Respectfully,

*Sarah Mire, M.A.*

Sarah Mire, M.A.
Doctoral Candidate in School Psychology
University of Houston, Department of Educational Psychology

Research Associate, Simons Simplex Collection
Baylor College of Medicine/Texas Children's Hospital