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PARENT KNOWLEDGE OF AUTISM SPECTRUM DISORDER

by

Kandice J. Benallie

A thesis submitted in partial fulfillment  
of the requirements for the degree

of

MASTER OF SCIENCE

in

Psychology

Approved:

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Logan, Utah

2019

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## ABSTRACT

## Parent Knowledge of Autism Spectrum Disorder

By

Kandice Benallie, Master of Science

Utah State University, 2019

Major Professor: Gretchen Gimpel Peacock, Ph.D.

Department: Psychology

Parent knowledge of ASD may, theoretically, impact early diagnosis of ASD, and therefore affect access to early intervention services. Improving knowledge of ASD among parents may, in turn, enhance the well-being and developmental outcomes of children affected with ASD. The purpose of this study was to determine the knowledge base of ASD among a sample of parents with children five years and younger. The specific research goals include: 1) determining the knowledge of ASD in the general population of parents with children ages five years and younger and 2) determining whether developmental concerns or concerns with ASD predict ASD knowledge. One-hundred and sixty-seven mothers and fathers were recruited through Qualtrics Panel and completed all measures (i.e., demographics, ASKSG, SDQ, ASRS, developmental milestones questionnaire). Descriptive statistics resulted in an average percentage correct on the ASKSG of 43.9%(SD=20.1). Regression analysis was conducted to determine if developmental and/or ASD concerns predicated knowledge. The overall regression model was not significant,  $F(3, 160)=2.487$ ,  $p=.063$ ,  $r^2=.045$ , but one predictor (i.e., ASD concerns) was significant,  $t(166)=2.498$ ,  $p=.014$ . Based on these findings, it is

recommended that parents be provided with further education about ASD to be aware of the early signs of ASD and to communicate concerns to a professional promptly.

(65 pages)

## PUBLIC ABSTRACT

## Parent Knowledge of Autism Spectrum Disorder

Kandice J. Benallie

Parent knowledge of ASD may be relevant to early identification and intervention services for children with ASD. By understanding how knowledgeable parents of young children are about ASD, researchers and practitioners can intervene and educate this population. This study sought to determine the knowledge base of ASD among parents with children five years and younger and if developmental, behavioral, and autism-related concerns predict knowledge of ASD. The sample of parents consisted of 167 mothers and fathers. All participants completed a knowledge questionnaire (i.e., ASKSG) and reported their level of developmental, behavioral, and autism-related concerns of their oldest child between the ages of 2 and five years. Results revealed that the sample of parents had a relatively low knowledge base of ASD, as determined by a percentage correct on the ASKSG of 43.9% (SD=20.1). Additionally, developmental, behavioral, and autism-related concerns did not collectively predict the sample's knowledge of ASD; however, autism-related concerns independently predicted knowledge. The results of this study provide information to researchers and practitioners that can be used to educate parents of young children regarding ASD. By doing so, early and appropriate identification of ASD may be improved. In turn, children and families may have increased access to early intervention services and thus may result in better developmental outcomes.

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# **CHAPTER I**

## **INTRODUCTION**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder with current prevalence rates estimated to be 1 in 59 children in the United States (Baio et al., 2018). The Diagnostic and Statistical Manual, fifth edition (DSM-5) defines two areas of symptoms necessary for a diagnosis of ASD: (1) persistent deficits in social communication and social interactions across multiple contexts (e.g., avoiding eye contact, unaware when people are talking) and (2) restricted, repetitive patterns of behavior, interests, or activities (e.g., trouble adapting to routine changes, unusual reactions to sensory stimuli; American Psychiatric Association [APA], 2013).

Early intervention for children with ASD has been shown to greatly improve development and daily life (Centers for Disease Control and Prevention [CDC], 2018; Debodiance, Maljaars, Noens & Van den Noortgate, 2017; Hampton & Kaiser, 2016; Peters-Scheffer, Didden, Korzilius, and Sturmey, 2011; Reichow, 2012). Specifically, the most beneficial results have been shown prior to the age of three (CDC, 2018). A meta-analysis (Debodiance et al., 2017) assessed single-subject experimental interventions (i.e., psychosocial interventions) for toddlers with ASD. They found that, on average, interventions for toddlers with or at risk for ASD are successful. Specifically, interventions in the home setting were found to be the most beneficial compared to other settings (e.g., clinic). Another meta-analysis (Hampton & Kaiser, 2016) assessed the effects of early interventions on spoken-language in children with ASD. They found that early intervention improved spoken-language for these children, and the largest effects were found when both the parent and clinician collaboratively implemented the

intervention. An additional meta-analysis (Peters-Scheffer et al., 2011) found that applied behavior analysis (ABA)-based early interventions for children with ASD were effective. Overall, research supports the effectiveness of early intervention services.

Children can be reliably diagnosed with ASD by an experienced professional (e.g., licensed psychologist) as young as two years old (CDC, 2018). Many children, however, are not diagnosed until later. The average age for an ASD diagnosis for children is four years (CDC, 2018). Theoretically, many children are missing out on receiving early intervention services and the benefits that go along with those services. For example, a child that receives early intervention services has an opportunity to improve behavior problems before entering the school setting and therefore may have a better school experience earlier on compared to children who are not diagnosed until later.

Before children start preschool or kindergarten, parents are the ones who see them most often. In many cases, parents are the first to be exposed to the early signs of ASD. However, some parents may not be aware of the early signs, making it challenging for them to recognize signs and seek professional services. Theoretically, parental knowledge of ASD may be crucial to the early diagnosis and early intervention services for children with the disorder. If parents are knowledgeable of the signs and symptoms of ASD they can express concerns to professionals early on which may increase early diagnosis and therefore help children to receive appropriate services. Research shows that early parental concerns predict later ASD diagnosis (Ozonoff et al., 2009). Unfortunately, there is little research that directly investigates the importance of parent knowledge of ASD.

However, the literature of other neurodevelopmental disorders does exist in terms of parent knowledge. For example, most parents report that they have heard of Attention-

deficit/hyperactivity disorder (ADHD) and self-report that they are knowledgeable on the subject but are unaware of school services related to the disorder (Bussing, Gary, Mills & Wilson, 2007; Bussing et al., 2012). However, there is great variability (e.g., between ethnic groups) in the amount of knowledge that parents have regarding ADHD (Bussing et al., 2007; Bussing et al., 2012). Additionally, some of this research shows the importance of understanding parent knowledge. Related to ADHD, providing educational information about the disorder to parents increased knowledge (Nussey, Pistrang, & Murphy, 2013). The authors hypothesized that these outcomes may result in increased positive attitudes and interactions with those with the disorder as well as improve treatment enrollment and adherence.

Parent knowledge of ASD may play an important role in early identification because of parents' exposure to and familiarity with their children. The earlier that children are diagnosed with ASD the more beneficial early interventions will be in helping to reduce ASD symptoms. By helping to reduce symptoms of ASD, children's overall well-being and daily life are likely to improve. The purpose of this study is to evaluate parental knowledge of ASD. Specific research questions were:

1. What is the knowledge of ASD in the general population of parents with children ages five years and younger?
2. Are developmental, behavioral, or ASD-related concerns predictors of ASD knowledge?

## **CHAPTER II**

### **LITERATURE REVIEW**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that significantly impacts an individual's social, communication, and behavioral well-being (CDC, 2018). Between 1 and 2 percent of the population meets the criteria for ASD (CDC, 2018). Criteria include persistent deficits in social communication and social interactions across multiple contexts, and restricted, repetitive patterns of behavior, interests, or activities (APA, 2013).

ASD symptoms appear in early childhood and persist throughout an individual's life (CDC, 2018). Some ASD symptoms may present as early as 12 months of age (Ozonoff et al., 2010), while severe symptoms may become apparent by the time a child is a few months old (CDC, 2018). Even then, some children with ASD develop typically until about 18 to 24 months. At that point, they do not usually gain new skills, or they lose skills that they had once learned (CDC, 2018). All this being said, signs and symptoms of ASD vary greatly and may present at different times. However, the consensus is that ASD can be identified by the age of 2 years.

Social skills deficits are the most common ASD symptom (CDC, 2018). Individuals with ASD do not just experience social difficulties like shyness; their social deficits negatively impact their daily lives. Some areas of social deficiencies often related to ASD include poor social interaction skills (e.g., avoiding eye contact) and weak/inappropriate emotional expression (e.g., facial expressions may not match what they are saying; APA, 2013). Another area of deficit for many children with ASD is communication. Research has found that communication impairments (e.g., expressive

speech, receptive speech, and articulation) are one of the first areas of concern reported by parents (Kozlowski, Matson, Horovitz, & Worley, 2011). Individuals with ASD can be deficient in verbal communication, nonverbal communication, or both. Verbal communication skills may range from typical to nonverbal (CDC, 2018). Some examples of communication symptoms that may be related to ASD include, but are not limited to, delays in speech and language skills, immediate and delayed echolalia, deficits in joint attention (e.g., shared focus between two individuals on one thing), using few or no gestures (e.g., pointing), and not participating in pretend play (CDC, 2018). Additionally, individuals with ASD often have unusual interests or behaviors. Some of their symptoms may include having restricted interests/behaviors/activities, needing strict adherence to routine, or engaging in repetitive actions (e.g., rocking, pacing; CDC, 2018).

Symptoms of ASD present differently for every individual and can range in severity. Though these symptoms may change in presentation, symptoms persist throughout one's lifetime. Other behaviors that may be associated with ASD, such as unusual mood or emotional reactions, may also negatively impact an individual's overall well-being. Having an atypical attitude or emotional reactions may cause problems academically because individuals may react inappropriately to teachers' requests; socially because others may not want to play or interact with them; or, occupationally because their reactions may negatively impact their work habits.

As ASD has become more prevalent, research has emphasized the comorbidity between ASD and other mental health problems. Depression and mood disorders have been targeted as the more problematic and characteristic of these comorbid mental health problems (Matson & Williams, 2014). Other common disorders that cooccur with ASD

include ADHD, anxiety disorders, and obsessive-compulsive behaviors (Matson & Williams, 2014). Suicidal ideation, which relates to depression and mood disorders, has been linked to ASD. One study (Mayes, Gorman, Hillwig-Garcia & Syed, 2013) evaluated 791 children with ASD and 186 typically developing (TD) children between the ages of 1 and 16. Fourteen percent of the children with ASD evidenced suicidal ideation, which was 28 times higher than the TD children. Another study (Pine, Guyer, Goldwin, Towbin, & Leibenluft, 2008), compared youth without a mental health diagnosis and youth with mood or anxiety on ASD symptom scales. There were 352 participants in their study: 107 healthy controls, 32 with major depression, 62 with bipolar disorder, and 63 with a mood disorder with severe non-episodic irritability. All the groups with mental health problems scored higher on ASD symptoms than the healthy controls. Additionally, a study by Strang and colleagues (2012) assessed depression and anxiety symptoms in 95 children who had been diagnosed with ASD. Of this group, 44% met criteria for borderline or clinical depression, 56% met the criteria for anxiety, and 37% met the criteria for depression and anxiety.

ASD can negatively impact individuals' overall well-being from a young age throughout their lives. Problems with their social skills, communication skills, and behavior may negatively impact them academically, socially, and occupationally. Early diagnosis and intervention may allow an individual to overcome or improve symptoms related to ASD before the negative impacts become severe.

### **Early Diagnosis and Intervention**



It is essential that children with ASD are diagnosed as early as possible in order to implement early interventions. Early interventions have been shown to improve language (Hampton & Kaiser, 2016; Bradshaw, Koegel, & Koegel, 2017), social motivation (Bradshaw et al., 2017), development (Debodiance et al., 2017), and behavior (Debodiance et al., 2017), among others, in children with ASD. Previous research shows that a reliable diagnosis of ASD can be made from age three and on (Woolfenden, Sarkozy, Ridley, & Williams, 2012); however, behavioral symptoms of ASD, such as reduced social attention and communication, are noticeable between 1 and 2 years of age (Zwaigenbaum et al., 2015). More recent research suggests that children can be diagnosed with ASD around 18 months of age; a diagnosis at two years of age by a trained professional is considered very reliable (CDC, 2018). However, the average age of diagnosis is four years of age (Christensen et al., 2016). While a diagnosis at four years is still beneficial, providing early intervention services at before the age of 3 is desirable (CDC, 2018). Early intervention services have been shown to significantly improve development and daily life (Debodiance et al., 2017; Hampton & Kaiser, 2016). By receiving intervention services at a young age, a child has an increased likelihood to improve negative symptoms that may interfere with their overall well-being and daily functioning.

A meta-analysis (Debodiance et al., 2017) evaluated the effectiveness of psychosocial interventions broadly for toddlers with ASD. Thirty-four single case design studies were analyzed. There were 74 participants, with a mean age of 27 months. Children that participated in interventions improved 2.14 standard deviations,  $t[32] = 5.99$ ,  $p < 0.0001$ . Specifically, the children's development and behavior improved with

participation in interventions. Overall, the meta-analysis found that on average, psychosocial interventions for toddlers with or at risk for ASD are successful.

Another meta-analysis (Hampton & Kaiser, 2016) assessed the effects of early interventions on spoken-language in children with ASD. Twenty-six studies, with any group design, were analyzed. Of the 26 studies, there were 1,738 total participants with ASD who ranged in age between 1.75 and 4.18 years of age (average age = 3.33 years). The authors found that early interventions improved spoken-language for children with ASD (overall mean effect size of  $g = 0.26$ ). The largest effects were observed when both the parent and clinician worked together to implement the intervention ( $g=0.42$ ), compared to parent-only ( $g=0.11$ ) or clinician only ( $g=0.08$ ) interventions.

Additionally, a meta-analysis (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011) looked at the effectiveness of comprehensive ABA-based early intervention programs for young children with ASD. Eleven studies were included in this review. The average age for participants ranged from 33.56 to 65.68 months. Gender was reported as 65.70% male, 10.47% female, and 23.84% was not reported. IQ was reported as ranging from 27.52 to 76.53. They compared the studies' experimental groups (in which children received on average 12.5 to 38.6 hours of early intensive behavior intervention for ten months to more than two years) and control groups (in which children received less than 10 hours per week of early intensive behavior intervention). Results showed that children in the experimental groups outperformed children in the control groups on measures of IQ ( $d=2.00$ ), expressive ( $d=1.10$ ) and receptive ( $d=2.91$ ) language, adaptive behavior ( $d=0.91$ ), communication ( $d=1.32$ ), daily living skills ( $d=0.68$ ), and socialization ( $d=1.49$ ). Overall, intensive intervention studies were found to be successful in children with ASD.

Reichow (2012) conducted an overview of meta-analyses on early intensive behavioral interventions for young children with autism spectrum disorders. Included meta-analyses could have used either pre/post or control group comparison designs. They analyzed 5 meta-analyses and found that the average effect sizes ranged from  $g = .38$ – $1.19$  for IQ and  $g = .30$ – $1.09$  for adaptive skills. These results reflect an increase in IQ and adaptive skills based on either pre/post or control group comparisons. Most (four of the five) meta-analyses concluded that early intensive behavior interventions were successful for children with ASD. They describe one meta-analysis that concluded that early intensive behavior interventions are not successful (Spreckley and Boyd, 2009) as misinterpreting previous research (Sallows & Graupner, 2005). Therefore, that is the reason that not all five meta-analyses came to the same conclusion.

An additional study (Bradshaw et al., 2017), independent from the previous meta-analyses, looked at improving functional language and social motivation with a parent-mediated intervention for three toddlers with ASD. Their focus was on the feasibility, effectiveness, and parent acceptability of a brief, parent-mediated intervention targeting verbal communication. All participating children were under 2 years of age and diagnosed with ASD. The study used motivational strategies of pivotal response treatment (PRT) to focus on teaching verbal expressive communication. They found that verbal communication improved along with some untreated areas for all children. All three children also improved on standardized assessments. For the Vineland socialization domain, they moved from the moderately low to the adequate range. For the Vineland communication domain, all three children improved, while two of the children moved from the moderately low range to the adequate range. At post-intervention all three

children had a decrease in ASD symptoms as measured by the ADOS-2. Additionally, as determined by a post-intervention survey, parents perceived that their children's skills (e.g., communication, social skills) improved over time.

In summary, early intervention services, prior to 4 years of age, have been shown to improve language skills (e.g., spoken, expressive, receptive, functional; Hampton & Kaiser, 2016; Peters-Scheffer et al., 2011; Bradshaw et al., 2017), adaptive behavior (Peters-Scheffer et al., 2011), communication (Peters-Scheffer et al., 2011), daily living skills (Peters-Scheffer et al., 2011), and social skills (Peters-Scheffer et al., 2011; Bradshaw et al., 2017). Specific interventions include psychosocial (Debodiance et al., 2017), intensive behavioral (Reichow, 2012; Peters-Scheffer et al., 2011), and parent-mediated (Bradshaw et al., 2017).

### **Parent Knowledge**

Theoretically an important factor in early diagnosis, and later being able to provide early intervention, is parent knowledge of ASD and developmental milestones. As noted earlier, the average age of diagnosis is four years old (Christensen et al., 2016). At this age, children are starting to enter the school setting, and therefore, professionals can notice signs of ASD. It has been found that pediatricians are often the first to recognize signs of ASD (Feldman et al., 2005). However, before entering the school setting, parents are the ones who see their children the most and would be the most credible source in recognizing possible symptoms of ASD. Between one-third to one-half of parents of children with ASD recognized symptoms before their child was 12 months, and between 80-90% recognized symptoms by 24 months (Johnson, 2004). Parents may

observe the early signs of ASD but may not link them to the disorder. Therefore, they may not seek the appropriate services or opinion of an experienced professional. If parents were knowledgeable about ASD and developmental milestones, they might bring their concerns regarding their child to their pediatrician or other trained professional earlier. If parent knowledge is lacking in these areas, the child might go undiagnosed for a more extended period. During this time, the child could be receiving early intervention services. Unfortunately, there is little research on parent knowledge of ASD.

One study, conducted by Ozonoff and colleagues (2009), looked at the relationship between parental concerns and later autism diagnosis. Participants included 174 infants with an older sibling with ASD and 100 infants with an older typically developing sibling. They were enrolled in the study from infancy to 3 years. Thirty-one participants withdrew from the study before it was completed. All infants were assessed at 6, 12, 18, 24, and 36 months, and parent concerns were collected at intake, 6, 12, and 18 months. The study found that parents who have an older child with ASD reported more ASD symptoms in their 12-month-old children (area under curve = .74,  $p < .01$ ). This helped in predicting a future diagnosis of ASD. However, parent concerns about their 6-month-old children did not predict later diagnosis of ASD (area under curve = .68). As a result, they found that examining development concerns of parents with an older child with ASD at or after 12 months of age helped in identifying children that were at risk for ASD. This theoretically shows that parent knowledge of ASD is an important factor in early diagnosis of ASD.

Additionally, a study conducted by Kuhn and Carter (2006) looked at the relationship between maternal self-efficacy and autism knowledge, along with other

variables (e.g., agency, guilt), among mothers of children with autism. A measure was created for maternal knowledge of ASD, along with some of the other variables, because of the absence of a validated measure. Results revealed that those with higher knowledge of ASD reported a longer time since their child's diagnosis. This may be because parents of children with ASD seek knowledge about the disorder. The maternal autism knowledge measure had good internal consistency (standardized  $\alpha = 0.79$ ) but did not show adequate variability and range. A ceiling effect occurred for the autism knowledge measure and caused a restricted range among the scores. After review, the authors did not recommend the use of the Autism Knowledge questionnaire because of its restriction in range of the parental responses.

Although literature on ASD knowledge focused on parents is sparse, there is research that exists that looks at ASD knowledge in the general population, which often includes parents (Benallie et al., in review; McClain et al., 2019). Overall, the general population's knowledge of ASD is limited (Benallie et al., in review; Mitchell & Locke, 2015). Current research shows that there are misconceptions of ASD etiology and prevalence (Benallie et al., in review; Dillenburg, Jordan, McKerr, Devine, & Keenan, 2013; Durand-Zaleski, Scott, Rouillon, & Leboyer, 2012; Holt & Christensen, 2013; Mitchell & Locke, 2015) and unequal knowledge across demographic groups (e.g., racial/ethnic groups; Benallie et al., in review; Dillenburg et al., 2013).

In addition to the general population, research exists that analyses professionals' knowledge of ASD. For example, Strunk (2009) looked at school nurses' self-perceived knowledge of ASD. Nurses were given questions related to knowledge of ASD and were asked to rate how familiar they were with the topics. The Likert scale consisted of 4

points ranging from *very familiar* to *minimally familiar*. They found that school nurses reported being *very familiar* with symptomology (43%) and related medications (46%). However, they reported being *minimally familiar* with communication skills (12%), behavioral therapies (23%) and safety issues (36%). The authors concluded that the knowledge of nurses regarding ASD needs to be improved.

An additional study, conducted by Corona, Christodulu, and Rinaldi (2017), looked at variables (e.g., knowledge of ASD) that were associated with self-efficacy of education professionals working with students with ASD and how ASD training impacts knowledge and self-efficacy. Knowledge of ASD was significantly, positively correlated with prior training on ASD ( $p < .01$ ) and positive behavior support (PBS;  $p < .01$ ). Additionally, knowledge and self-efficacy were significantly higher after a training on ASD and PBS compared to before the training ( $t = 4.01$ ,  $p < .001$ ,  $t = 7.81$ ,  $p < .001$ , respectively). The authors suggested that continued training is necessary to improve the self-efficacy and knowledge of ASD among these professionals. Though this research is focused on professionals, the concept of improving knowledge of ASD being beneficial to children can be applied to parents. Specifically, if knowledge of ASD was increased across the entire population (e.g., parents and affiliated professionals) early identification rates may increase.

Additionally, there has been some research conducted on parental knowledge of another neurodevelopmental disorder, ADHD. For example, one study conducted (Bussing, Gary, Mills, & Wilson, 2007) compared African American and Caucasian parents' health beliefs, knowledge, and information sources related to ADHD. Interviews were done on a representative sample of 1,615 parents. They found that most parents had

heard of ADHD (87%,  $n = 1,404$ ) and considered themselves knowledgeable on the subject but were unaware of school services offered for the disorder. Thirty-one percent of the participants ( $n = 437$ ) indicated that they knew a lot, 35% ( $n = 496$ ) indicated they knew some, 30% ( $n = 414$ ) indicated they knew a little, and 3% ( $n = 48$ ) reported they knew nothing about ADHD. Sixty-eight percent of parents ( $n = 1,082$ ) said they had never heard of IEP services. Compared to Caucasian parents, African American parents reported less awareness and lower self-related knowledge. An additional study looking at parent knowledge of ADHD (Bussing et al., 2012), found similar findings. Most parents had heard of ADHD (98%,  $n=366$ ) and considered themselves knowledgeable on the topic (78%,  $n=291$ ). However, misconceptions of ADHD were found among parents. For example, 25% ( $n=92$ ) of parents believed that sugar intake was a cause of ADHD. This lack of knowledge regarding a disorder may inhibit a parents' ability to identify early signs, which, in turn, can minimize the likelihood that parents seek appropriate services.

### **Rationale and Purpose of Study**

ASD impacts an individual's social, communication, and behavioral wellbeing. If individuals do not receive treatment, their problems may persist through childhood, adolescence, and adulthood. This may affect their social and academic wellbeing at a young age and occupational wellbeing in adulthood. Early diagnosis is important because children will be able to receive early intervention at a young age. The younger that children with ASD can receive early interventions, the more likely that they can overcome or improve any problems that they are related to ASD. Parents are around their



child more than anyone else, and therefore if they are knowledgeable about ASD, they can voice their concerns to a trained professional. Parent knowledge of ASD may be an important factor in early diagnosis and early intervention services for children with ASD. An ASD knowledge measure may be used to identify what areas a specific population is lacking in knowledge of ASD. By measuring parents' knowledge regarding ASD, we can target areas that need improvement. Improving parent knowledge may increase early diagnosis and therefore increase early intervention services. In summary, it is necessary to better understand parent knowledge of ASD and factors that are related to knowledge to better help children affected by the disorder.

## CHAPTER III

### METHODS

#### Participants

Participants included 167 mothers ( $n=84$ , 50.3%) and fathers ( $n=83$ , 49.7%) from the United States. The sample was primarily White ( $n=116$ , 69.5%), married ( $n=111$ , 66.5%), the primary caregiver ( $n=151$ ; 90.4%), parents of one child ( $n=98$ , 58.7%), and parents of children without a mental health diagnosis ( $n=148$ , 88.6%), with a mean age of 34.2 ( $SD=7.7$ ). See Table 1 for more demographic details. Inclusion criteria included: (a) be at least 18 years of age, (b) be a parent (including biological, adoptive, or foster), (c) have at least one child between the ages of 2 and 5 years of age, and (d) have all children be 5 years or younger. The requirement of having all their children be 5 years or younger was created because, theoretically, this age group would gain the largest impact of early diagnosis and intervention services.

Table 1

*Participant Demographics (N=167)*

	<i>n (%)</i>
Parent Role	
<i>Mother</i>	84 (50.3)
<i>Father</i>	83 (49.7)
Primary Caregiver	
<i>Yes</i>	151 (90.4)
<i>No</i>	16 (9.6)
Number of Children in Home	
<i>One</i>	98 (58.7)
<i>Two</i>	63 (37.7)
<i>Three</i>	6 (3.6)

Marital Status	
<i>Married</i>	111 (66.5)
<i>Single/Never Married</i>	39 (23.4)
<i>Divorced</i>	5 (3.0)
<i>Divorced/Remarried</i>	4 (2.4)
<i>Widowed</i>	1 (0.6)
<i>Separated</i>	3 (1.8)
<i>Prefer not to Respond</i>	2 (0.6)
Annual Household Income	
<i>Less than \$15,000</i>	12 (7.2)
<i>\$15,000 to \$30,000</i>	28 (16.8)
<i>\$30,000 to \$45,000</i>	23 (13.8)
<i>\$45,000 to \$60,000</i>	30 (18.0)
<i>\$60,000 to \$75,000</i>	25 (15.0)
<i>More than \$75,000</i>	43 (25.7)
<i>Prefer not to Respond</i>	6 (3.6)
Education	
<i>Less than High School</i>	6 (3.6)
<i>High School Graduate/GED</i>	36 (21.6)
<i>Some College/Trade School/Associate's Degree</i>	65 (38.9)
<i>College Graduate/Bachelor's Degree</i>	36 (21.6)
<i>Graduate Degree or Professional Degree</i>	20 (12.0)
<i>Doctorate</i>	4 (2.4)
Race/Ethnicity*	
<i>White</i>	116 (69.5)
<i>Asian</i>	13 (7.8)
<i>Black or African American</i>	19 (11.4)
<i>American Indian or Alaska Native</i>	6 (3.6)
<i>Hispanic or Latino</i>	13 (7.8)
<i>Multiracial</i>	3 (1.8)
<i>Other</i>	2 (1.2)
Child Mental Health Diagnosis	
<i>Yes</i>	19 (11.4)
<i>Attention-Deficit/Hyperactivity Disorder</i>	7 (36.8)
<i>Autism Spectrum Disorder</i>	9 (47.4)
<i>Speech and/or Language Disorder</i>	2 (10.5)
<i>Social Pragmatic Communication Disorder</i>	1 (5.2)
<i>Anxiety</i>	1 (5.2)
<i>Other</i>	1 (5.2)
<i>No</i>	148 (88.6)
Child Special Education Status	
<i>Yes</i>	23 (13.8)
<i>No</i>	144 (86.2)

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\*Participants were able to choose multiple responses; percentages will not add up to 100.

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## Measures

### Demographic Form

A demographic form (see Appendix A) was completed by all participants to gather background information. This information was used to describe the sample.

### Autism Spectrum Knowledge Scale, General Version (ASKSG)

Participants completed the ASKSG (McClain et al., 2019; see Appendix B), a measure of ASD knowledge designed specifically for the general population. The measure consists of 31 items focused on (1) etiology and prevalence, (2) symptoms and behavior, (3) assessment and diagnosis, (4) treatment, and (5) outcomes and prognosis of ASD. Participants respond to the items with either true, false, or “don’t know.” “Don’t know” responses are calculated as incorrect. See Appendix E for the response rate of true, false, and “don’t know” for each item. The original study (McClain et al., 2019) used item response theory (IRT) analysis and found the measure to be reliable ( $\alpha=.73$  raw,  $\alpha=.75$  standardized;  $\lambda_6=.80$ ) and univariate (all MSQs < 1.5). The current study’s internal consistency was analyzed using Cronbach’s alpha. The reliability analyses results support the previous findings and confirm that the ASKSG is reliable (.86). The ASKSG total percent correct was used to evaluate parental knowledge of ASD.

### Strengths and Difficulties Questionnaire (SDQ)

The SDQ (Goodman, 1997) is a 25-item assessment that measures a child’s level of behavioral issues. There are two versions: one for 2-4 year old children and one for 4-10 year old children. For the purposes of this study, the 4-10 year old version was used. Although this version has not been validated for all the children used in this study, there

are only three questions that are different between the two versions. These three questions differ only by phrasing and still focus on the same behaviors. Although this version of the SDQ has been normed for 4 to 10 year-old children, it is not being used to screen or diagnose for this study. It is being used to measure parent behavioral concerns and if they predict ASD knowledge. One review of 48 studies using the SDQ found strong psychometric properties (Stone, Otten, Engels, Vermulst, & Janssens, 2010). The study found acceptable internal consistency for parent reports with a mean Cronbach's alpha of .80 for the total difficulties score and mean Cronbach's alphas of .53-.84 (poor to acceptable) across the different subscales (i.e., prosocial behavior, hyperactivity/inattention, emotional/symptoms, conduct problems, peer problems). Test-retest reliability for the total difficulties scale (.76) was also high as were average test-retest reliabilities across subscales (.72 -.86). They also found that correlations between the SDQ total difficulties score and CBCL total score are high for parents (weighted  $r = 0.76$ ; range of unweighted  $r = 0.70-0.87$ ). In the current study, Cronbach's alpha was .75 which indicates acceptable internal consistency. The total SDQ score for each participant was used in the analyses.

### **Autism Spectrum Rating Scale (ASRS) – Short Form**

The ASRS (Goldstein & Naglieri, 2009) is designed to measure ASD behaviors in children between the ages of 2 and 18 years of age. The short form version is available for young children (2 to 5 years) and youth (6 to 18 years). For the purpose of this study, the short form version for young children (2 to 5 years) was used. The short form is 15 items in length and was designed for screening purposes. Each item is scored on a Likert scale from 0 ("never") to 4 ("very frequently"). High scores on the ASRS short form

indicate that ASD behaviors are present and an in-depth assessment is needed in order to confirm a diagnosis. The ASRS (full-length and short form) have good discriminant validity and are able to distinguish children with ASD from the general population (overall correct classification rate of 92.10%). The short form (for children 2 to 5 years of age) showed good internal consistency with a coefficient alpha of .92 for parent ratings and .93 for teacher ratings. In the current study, Cronbach's alpha was .90 which indicates acceptable internal consistency. The ASRS (short form) total score was used in analyses.

### **Developmental Milestones**

The developmental milestones (see appendix C) measure was developed based off of the Center for Disease Control and Prevention's milestone checklist (CDC, 2018) for the purpose of this study. It is designed to measure whether a child is meeting key developmental milestones. The participant (i.e., parent) was presented with a milestone checklist to mark which behaviors their child is not exhibiting. Each age (i.e., 2, 3, 4, and 5 years) has a different checklist associated with it. A proportion score reflecting developmental milestones parents indicated their child had not met was used in analyses.

### **Procedures**

The study was submitted to the Utah State University Institutional Review Board (IRB) and approval was obtained prior to starting data collection. Participants were recruited using a Qualtrics Panel. Qualtrics provided 167 participants that met participant eligibility. Participants completed all study activities online via Qualtrics. First, participants were asked to read a letter of information and provide consent. Second,

participants completed the demographics questionnaire. Third, participants answered the ASKSG, SDQ, ASRS, and developmental milestones measures. These measures were counter-balanced across participants. Counter-balancing was used in order to control for answers of one measure influencing answers to another measure. When answering specific measures (i.e., SDQ, ASRS, developmental milestones), participants were told to refer to their oldest child that was between the ages of 2 and 5 years. This requirement was created to ensure consistency across participants when choosing which child to complete questions about. At the end of the survey, resources were listed for parents that have concerns that their child may be showing signs of ASD (see appendix D).

## CHAPTER IV

### RESULTS

#### Preliminary Analyses

The measures used in this study to quantitatively represent variables included the ASKSG, ASRS, SDQ, and the developmental milestones questionnaire. See table 2 for the measures' descriptive statistics (i.e., means, standard deviations, range).

Table 2

*Primary Variables' Descriptive Statistics*

Variable	<i>M</i> (SD)	<i>Range</i>
ASKSG	43.9(20.1)	0-87.1
ASRS	19.3(11.1)	0-56
SDQ	13.4(5.5)	4-30
Developmental Milestones Questionnaire	11.9(19.2)	0-96

#### Parent Knowledge of ASD

Descriptive statistics (i.e., means, standard deviations) were examined for the overall ASKSG measure, content areas, and individual questions to explore parent knowledge of ASD (see table 3). The average percentage of correct items on the ASKSG was 43.9% (SD=20.1). The six questions in which participants answered with the highest percentage correct were: "Autism spectrum disorder is caused by a lack of motherly warmth" (False;  $M=81.4$ ,  $SD=39.0$ ), "All individuals with autism spectrum disorder have



low intellectual quotients (i.e., IQs)” (False;  $M=76.6$ ,  $SD=42.4$ ), “If a teacher believes a student has autism spectrum disorder, they can make a diagnosis” (False;  $M=71.9$ ,  $SD=45.1$ ), “Individuals with autism spectrum disorder have difficulties interacting socially with others” (True;  $M=71.3$ ,  $SD=45.4$ ), “Many individuals with autism spectrum disorder have difficulties expressing themselves” (True;  $M=70.1$ ,  $SD=45.9$ ), and “Most individuals with autism spectrum disorder will never learn to speak” (False;  $M=70.1$ ,  $SD=45.9$ ). The six questions that were answered with the poorest accuracy were: “Some individuals with autism spectrum disorder may be uncoordinated or clumsy” (False;  $M=11.4$ ,  $SD=31.8$ ), “A diagnosis of autism spectrum disorder can only be made by a medical doctor” (False;  $M=11.4$ ,  $SD=31.8$ ), “Less than 2% of people in the US have autism spectrum disorder” (True;  $M=20.4$ ,  $SD=40.4$ ), “Advanced paternal (father) age is a risk factor for autism spectrum disorder” (True;  $M=21.6$ ,  $SD=41.2$ ), “Autism spectrum disorder can be diagnosed with brain imaging” (False;  $M=21.6$ ,  $SD=41.2$ ), and “Children who have a brother or sister with autism spectrum disorder are more likely to develop the disorder” (True;  $M=22.2$ ,  $SD=41.7$ ).

Table 3

*Percentage Correct on ASKSG Based on Items, Content Areas, and Overall Measure*

ASKSG Content Areas and Items	Key	$M(SD)$
Overall	--	43.9(20.1)
Assessment and Diagnosis.	--	33.6(20.6)
<i>A diagnosis of autism spectrum disorder can only be made by a medical doctor.</i>	False	11.4(31.8)
<i>Autism spectrum disorder can be diagnosed with brain imaging.</i>	False	21.6(41.2)
<i>It is possible for autism spectrum disorder to develop in adulthood.</i>	False	24.0(42.8)

<i>For a diagnosis of autism spectrum disorder, symptoms must be present from early childhood.</i>	True	25.1(43.5)
<i>Autism spectrum disorder can only be diagnosed after the age of 4 years.</i>	False	35.9(48.1)
<i>Diagnosis of autism spectrum disorder is primarily based on behavioral observations and parent interviews.</i>	True	45.5(49.9)
<i>If a teacher believes a student has autism spectrum disorder, they can make a diagnosis.</i>	False	71.9(45.1)
Etiology and Prevalence	--	38.4(21.0)
<i>Less than 2% of people in the US have autism spectrum disorder.</i>	True	20.4(40.4)
<i>Advanced paternal (father) age is a risk factor for autism spectrum disorder.</i>	True	21.6(41.2)
<i>Children who have a brother or sister with autism spectrum disorder are more likely to develop the disorder.</i>	True	22.2(41.7)
<i>There are no differences in the identification rates of autism spectrum disorder across racial and ethnic groups.</i>	False	27.5(44.8)
<i>Boys are four times as likely than girls to have autism spectrum disorder.</i>	True	40.1(49.2)
<i>Vaccines can cause autism spectrum disorder.</i>	False	55.7(49.8)
<i>Autism spectrum disorder is caused by a lack of motherly warmth.</i>	False	81.4(39.0)
Treatment	--	42.1(30.6)
<i>Restricting certain foods (e.g., gluten) is an effective treatment for autism spectrum disorder.</i>	False	29.3(45.7)
<i>Intellectual quotient (i.e., IQ) and age affect treatment success for children with autism spectrum disorder.</i>	True	31.1(46.4)
<i>There are no beneficial treatments available for individuals with autism spectrum disorder.</i>	False	50.3(50.1)
<i>Social skills training is an effective treatment for some individuals with autism spectrum disorder.</i>	True	57.5(49.6)
Outcomes and Prognosis	--	50.9(32.0)
<i>Up to 70% of individuals with autism spectrum disorder also have an additional mental health diagnosis (e.g., anxiety).</i>	True	36.5(48.3)
<i>Many individuals with autism spectrum disorder have difficulties living and working independently in adulthood.</i>	True	40.7(49.3)
<i>Many children with autism spectrum disorder are at risk for academic difficulties.</i>	True	49.7(50.1)
<i>Symptoms of autism spectrum disorder do not change throughout an individual's life.</i>	False	52.1(50.1)
<i>Autism spectrum disorder only affects children.</i>	False	56.3(49.8)
<i>Most individuals with autism spectrum disorder will never learn to speak.</i>	False	70.1(45.9)

Symptoms and Associated Behaviors	--	54.6(25.8)
<i>Some individuals with autism spectrum disorder may be uncoordinated or clumsy.</i>	False	11.4(31.8)
<i>Symptoms of autism spectrum disorder do not appear before the age of 2 years.</i>	False	32.3(46.9)
<i>Children with autism spectrum disorder may not play with toys the way they are intended.</i>	True	50.9(50.1)
<i>Individuals with autism spectrum disorder may have strict routines or rituals.</i>	True	69.5(46.2)
<i>Many individuals with autism spectrum disorder have difficulties expressing themselves.</i>	True	70.1(45.9)
<i>Individuals with autism spectrum disorder have difficulties interacting socially with others.</i>	True	71.3(45.4)
<i>All individuals with autism spectrum disorder have low intellectual quotients (i.e., IQs).</i>	False	76.6(42.4)

### ASD Knowledge Across and Within Content Areas

Although the ASKSG is a univariate measure and the content areas were not confirmed in its original validation (McClain et al., 2019), the content areas were assessed to give more information in regard to the knowledge of ASD in this population. The results of the descriptive statistics indicate that participants performed best on the symptoms and associated behaviors ( $M=54.6$ ,  $SD=25.8$ ) and outcomes and prognosis ( $M=50.9$ ,  $SD=32.0$ ) content areas. Participants had the weakest performance on the treatment ( $M=42.1$ ,  $SD=30.6$ ), etiology and prevalence ( $M=38.2$ ,  $SD=21.0$ ), and assessment and diagnosis ( $M=33.6$ ,  $SD=20.6$ ) content areas.

### Predictors of ASD Knowledge

Multiple linear regression was performed to predict ASD knowledge from behavioral (i.e., SDQ), developmental (i.e., developmental milestones), and autism-related (i.e., ASRS) concerns. The SDQ, ASRS, and developmental milestones measures were predictor variables and the ASKSG was the outcome variable. The results indicated

that the overall regression equation was not statistically significant and therefore does not support that concerns predict ASD knowledge in a sample of parents,  $F(3, 160)=2.487$ ,  $p=.063$ ,  $r^2=.045$ . Because of the exploratory nature of this study, individual predictors were examined further. Results show that behavioral ( $t(166)=-.0549$ ,  $p=.583$ ) and developmental ( $t(166)=-.725$ ,  $p=.470$ ) concerns are not significantly related to ASD knowledge but ASD concerns ( $t(166)=2.498$ ,  $p=.014$ ) are significantly related. See table 4 for regression details.

Table 4

*Summary of Multiple Regression Analysis for Predicting ASD Knowledge*

Predictor	<i>B</i>	<i>SE B</i>	$\beta$	<i>t</i>	<i>p</i> Value
Strengths and Difficulties Questionnaire (SDQ)	-0.06	.11	-0.06	-0.55	.58
Developmental Milestones	-1.96	2.71	-0.06	-0.73	.47
Autism Spectrum Rating Scales (ASRS)	0.14	0.06	0.26	2.50	.01*

\* $p<.01$

## **CHAPTER V**

### **DISCUSSION**

Parent knowledge of ASD may play an important role in the well-being of children with ASD. Being aware of the etiology, symptoms, and other ASD related concepts may help parents to feel more empowered and comfortable with knowing when to seek an evaluation and feel empowered to ask more questions when communicating with professionals. By enabling better communication, we may see more accurate and early diagnoses. This will help those with ASD and their families to receive appropriate and early intervention services. In order to help parents become more knowledgeable about ASD, their level of knowledge must be understood by researchers and practitioners. This research sought to explore the ASD knowledge and possible predictors of knowledge among a sample of parents.

#### **Parent knowledge of ASD**

Overall, the sample's average performance was 43.9% correct on the ASKSG. This result shows that there is a significant lack of ASD knowledge among the general parent population. When looking at the individual questions on the knowledge measure there was see a wide range of accuracy (11.4%-81.4%). This range shows that there is a wide range of knowledge within the ASD knowledge base of parents. All but one of the items on the knowledge measure were answered with an accuracy of less than 80% correct. In general, parents in this sample had relatively more knowledge in areas that concern overt behavior (e.g., social communication) and less knowledge in areas concerning how to and who can assess for ASD. Content area analyses reveal that the

parent sample is most knowledgeable in the realms of symptoms and associated behaviors (e.g., intelligence, social communication deficits, play behaviors), and outcomes and prognosis (e.g., speech difficulties, symptom perseverance throughout life). In contrast, the sample was least knowledgeable regarding treatment (e.g., effectiveness of food restrictions, what effects treatment success), etiology and prevalence (e.g., racial disparities, risk factors), and assessment and diagnosis (e.g., professionals who can diagnose, age of diagnosis and development). In general, it appears as though parents know what ASD looks like, but they have less understanding regarding the assessment and treatment processes.

Though parents are relatively more knowledgeable about certain aspects of ASD, it is important to understand that none of the items' accuracy rates approached 100% and therefore there is room for improvement in all areas. There are a few ASKSG items that deserve attention. For example, almost 50% of participants believed that vaccines cause ASD. Though there is an overwhelming amount of research that has emerged (e.g., Jain et al., 2015; Price et al., 2010; Richler et al., 2006) that does not support the association between vaccines and ASD, many still believe the contrary. This misunderstanding is detrimental to global health because of the reintroduction of almost eliminated measles and mumps diseases due to the anti-vaccination movement (McGuinness, 2015). Another knowledge item of interest is related to racial disproportionality. Over 70% of the sample believed that there are no differences in the identification rates of ASD across racial and ethnic groups. This false belief supports the research that shows the existence of racial/ethnic disproportionality regarding ASD diagnosis (Travers, Krezmien, Mulcahy, & Tincani, 2014). By not being aware of racial/ethnic disparities, risk factors are also not

being understood. In turn, children may not be diagnosed properly or receiving appropriate services.

An issue that has emerged through the ASD knowledge analyses relates to proper assessment and diagnosis. Almost 70% of parents from the sample believed that symptoms of ASD do not appear before 2 years of age, about 75% believed that symptoms do not need to be present from early childhood, and about 65% thought that ASD could only be diagnosed after the age of 4 years. This lack of knowledge explains the previous research finding stating that the average age of diagnosis (i.e., 4 years) is much higher than the age in which a reliable diagnosis can be made (i.e., 2 years; CDC, 2018). Additionally, a topic that had one of the lowest percentages correct (i.e., 11.4%) on the ASKSG concerned ASD being diagnosed by professionals other than a medical doctor. Specifically, almost 89% of the participants believed that a diagnosis can only be diagnosed by a medical doctor. Though general practitioners are extremely important to the health of society, they are not specially trained to diagnose ASD. This may cause a barrier between children being appropriately diagnosed and accessing services in a timely manner.

### **Predictors of ASD Knowledge**

The results of the regression analyses do not indicate that developmental, behavioral, and ASD-related concerns collectively predict ASD knowledge among parents of children 5 years or younger. However, it does appear as though ASD-related concerns alone may be a predictor of parents' knowledge of ASD. Specifically, as parents become more concerned about the ASD-related concerns, they show increased knowledge of ASD. It is possible that parents engage in personal research or discuss their concerns

with a professional when they become concerned about their child's ASD-related behavior, which in turn would increase their knowledge. This interpretation should be taken with caution because the original multiple regression analyses did not indicate significance.

### **Implications**

Multiple implications resulted from this study related to identification rates of ASD, access to services, and advocacy. By understanding the knowledge of ASD among the general parent population, targeted interventions may be put into place in the community to improve knowledge. In turn, bringing awareness of the etiology, symptoms, outcomes, and other related areas of ASD may improve early and appropriate identification of ASD and access to services. Additionally, by improving parents' knowledge of ASD, a sense empowerment may follow. This empowerment can help families advocate for their children when communicating with professionals and thus help their children receive the most beneficial services.

Parent knowledge of ASD not only has implications with identification and access to appropriate services, but also with parent perceptions and bias of ASD. It is possible that negative perception of ASD may prevent children from being identified because their parents believe that a diagnosis of ASD will impact them more negatively than not receiving services. Improving knowledge of ASD has the potential to lessen the negative bias associated with an ASD diagnosis (Wayment & Brookshire, 2018). This may help children receive beneficial services but also improve relations between families and their children with ASD.



By improving parent ASD knowledge the overall well-being of children with ASD may be improved through better identification, access to services, parent empowerment, and parent perceptions of ASD. In order to improve the knowledge of parents, multiple avenues must be utilized. For one, ASD must be portrayed accurately in media. Misconceptions (e.g., vaccines) are often exploited in media. Media can be used to extinguish these misconceptions and depict ASD in a way that represents it properly. Additionally, schools and community agencies can inform parents about ASD through parenting groups, flyers, and other ways of communication. The more avenues researchers and practitioners can use to communicate with parents regarding ASD, the less misconceptions parents may have of ASD. In conclusion, the better parents understand ASD the more efficient parents can be when concerns of their children arise. In turn, primary care providers can provide better assessment and intervention services when concerns are more efficiently communicated by parents.

### **Limitations**

Like most research, there are limitations associated with this study. First, participation was limited to those who had internet access and chose to participate through Qualtrics Panel. Additionally, we did not ask whether parents had any special training in ASD. This could bias our results. However, based on the low average percentage correct, it is unlikely that this bias impacted the results. Self-selection is also a limitation to the study. It is possible that parents who are more interested in learning about ASD or are already concerned about their child having ASD chose to participate. There is also a limitation associated with SDQ measure. There were two versions

available (i.e., 2-4 year old version, 4 to 10 year old). The 4-10 year old version was used and therefore the regression results may have been skewed. However, there were only three questions that were worded differently but aimed at the same constructs, so it is unlikely that it was significantly skewed. Lastly, neither attention questions nor adequate response time were used to determine response quality. This may have biased the results and resulted in the reported lack of ASD knowledge among parents.

### **Future Research**

Knowledge of ASD is an emerging area of research, therefore there is room for the research to expand. This study adds to the extant literature by discussing the current knowledge base of ASD among parents of children 5 years and younger and potential predictors of knowledge. However, further research is necessary. It is recommended that a larger, more diverse sample, should be utilized for future research. This will help strengthen the sample's representation of the entire population. Additionally, future research can look beyond the general parent population and look at specific demographic groups (e.g., race, gender, socioeconomic status) within the parent population. A way that predictors of knowledge can be expanded upon is to look at other measures that look at similar constructs. For example, there are other measures that assess problem behaviors and thus could act as a behavioral predictor. Researchers could also administer other knowledge measures of other disorders (e.g., ADHD) to see whether knowledge of one disorder predicts knowledge of another disorder. Lastly, research should explore possible interventions for increasing ASD knowledge among parents and their effectiveness.

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## APPENDICES



## APPENDIX A

### Demographics

## Demographics

1. How many children 18 years or younger do you have living in your home?
  - a. 0
  - b. 1
  - c. 2
  - d. 3
  - e. 4 or more

\*If 0, sent to the end of the survey

2. Do you have any children 6 years or older?
  - a. Yes
  - b. No

\*If “Yes”, sent to the end of the survey

3. Do you have at least one child who is between the ages of 2 and 5?
  - a. Yes
  - b. No

\*If “No”, sent to the end of the survey

4. In which state do you currently reside?

\*If “I do not reside in the United States” is selected, sent to end of survey

5. What role with your children do you identify with?
  - a. Mother
  - b. Father

6. What is your age (in years)? (text entry)

7. Would you say that you are a primary caregiver to the children currently living in your home?
  - a. Yes
  - b. No

8. What is your race/ethnicity (Please select all that apply)?
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian and Other Pacific Islander
  - e. White
  - f. Multiracial
  - g. Hispanic or Latino
  - h. Other

9. Which best describes your marital status?

- a. Single/Never married
- b. Married
- c. Divorced
- d. Widowed
- e. Separated
- f. Divorced/Remarried
- g. Prefer not to Respond

10. Education:

- a. Less than High School
- b. High School Graduate/GED
- c. Some College/Trade School/Associate's Degree
- d. College Graduate/Bachelor's Degree
- e. Graduate or Professional Degree
- f. Doctorate
- g. Other (text write in)

11. Annual Household Income

- a. Less than \$15,000
- b. \$15,000-30,000
- c. \$30,000-45,000
- d. \$45,000-60,000
- e. \$60,000-75,000
- f. More than \$75,000
- g. Prefer not to Respond

12. Have any of your children been formally diagnosed with a mental health disorder by an appropriately licensed professional?

- a. Yes
- b. No

\*If yes, display #'s 13, 14, 17

13. With which mental health disorders has (have) your child (children) been diagnosed (please select all that apply)?

- a. Attention-Deficit/Hyperactivity Disorder (ADHD)
- b. Autism Spectrum Disorder (ASD)
- c. Intellectual Disability (ID)
- d. Specific Learning Disorder (SLD)
- e. Speech and/or Language Disorder
- f. Social Pragmatic Communication Disorder
- g. Other (text entry)

14. Do any of your children receive special education services in school?

- a. Yes
- b. No

*Please answer the following questions about your OLDEST child that is between the ages of 2 and 5 years old.*

15. What is your child's gender?

- a. Male
- b. Female

16. How old is your child in years?

- a. 2
- b. 3
- c. 4
- d. 5
- e. Other

\*Will be sent to the end of survey if "other" is chosen

17. Has your child been diagnosed with a mental health disorder by a licensed professional?

- a. Yes
- b. No

\*If Yes, display #'s 18, 19

18. With which mental health disorders has your child been diagnosed (please select all that apply)?

- a. Attention-Deficit/Hyperactivity Disorder (ADHD)
- b. Autism Spectrum Disorder (ASD)
- c. Intellectual Disability (ID)
- d. Specific Learning Disability (SLD)
- e. Speech and/or Language Disorder
- f. Social Pragmatic Communication Disorder
- g. Other (text entry)

19. Do they receive special education services through their school?

- a. Yes
- b. No

## APPENDIX B

### Autism Spectrum Knowledge Scale, General Version

## Autism Spectrum Knowledge Scale, General Version

\*Participants choose True, False, or Don't Know

*Please answer the following questions. If you do not know an answer, select Don't Know. Please refrain from looking up the correct responses.*

### Etiology/Prevalence

1. Less than 2% of people in the US have autism spectrum disorder.
2. Vaccines can cause autism spectrum disorder.
3. Boys are four times as likely than girls to have autism spectrum disorder.
4. Children who have a brother or sister with autism spectrum disorder are more likely to develop the disorder.
5. Autism spectrum disorder is caused by a lack of motherly warmth.
6. Advanced paternal (father) age is a risk factor for autism spectrum disorder.
7. There are no differences in the identification rates of autism spectrum disorder across racial and ethnic groups.

### Symptoms/Associated Behaviors

1. All individuals with autism spectrum disorder have low intellectual quotients (i.e., IQs).
2. Children with autism spectrum disorder may not play with toys the way they are intended.
3. Individuals with autism spectrum disorder may have strict routines or rituals.
4. Individuals with autism spectrum disorder have difficulties interacting socially with others.
5. Some individuals with autism spectrum disorder may be uncoordinated or clumsy.
6. Many individuals with autism spectrum disorder have difficulties expressing themselves.
7. Symptoms of autism spectrum disorder do not appear before the age of 2 years.

### Assessment/Diagnosis

1. Diagnosis of autism spectrum disorder is primarily based on behavioral observations and parent interviews.
2. Autism spectrum disorder can only be diagnosed after the age of 4 years.
3. If a teacher believes a student has autism spectrum disorder, they can make a diagnosis.
4. Autism spectrum disorder can be diagnosed with brain imaging.
5. For a diagnosis of autism spectrum disorder, symptoms must be present from early childhood.
6. It is possible for autism spectrum disorder to develop in adulthood.
7. A diagnosis of autism spectrum disorder can only be made by a medical doctor.

### Treatment

1. There are no beneficial treatments available for individuals with autism spectrum disorder.
2. Restricting certain foods (e.g., gluten) is an effective treatment for autism spectrum disorder.
3. Social skills training is an effective treatment for some individuals with autism spectrum disorder.
4. Intellectual quotient (i.e., IQ) and age affect treatment success for children with autism spectrum disorder.

Outcomes/Prognosis

1. Most individuals with autism spectrum disorder will never learn to speak.
2. Symptoms of autism spectrum disorder do not change throughout an individual's life.
3. Autism spectrum disorder only affects children.
4. Many individuals with autism spectrum disorder have difficulties living and working independently in adulthood.
5. Up to 70% of individuals with autism spectrum disorder also have an additional mental health diagnosis (e.g., anxiety).
6. Many children with autism spectrum disorder are at risk for academic difficulties.

## APPENDIX C

### Developmental Milestones



## Developmental Milestones

*Please continue to answer the following questions about your child who you answered the previous questions about. Answer the best you can even if you are not absolutely certain.*

\*If they answered “2” to #16 (display #1)

1. Please select which behaviors your child is NOT doing

- Copies others, especially adults and older children
- Gets excited when with other children
- Shows more and more independence
- Shows defiant behavior (doing what he has been told not to)
- Plays mainly beside other children, but is beginning to include other children, such as in chase games
- Points to things or pictures when they are named
- Knows names of familiar people and body parts
- Says sentences with 2 and 4 words
- Follows simple instructions
- Repeats words overheard in conversation
- Points to things in a book
- Finds things even when hidden under two or three covers
- Begins to sort shapes and colors
- Complete sentences and rhymes in familiar books
- Plays simple make-believe games
- Builds towers of 4 or more blocks
- Might use one hand more than the other
- Follows two-step instructions such as “pick up your shoes and put them in the closet.”
- Names items in a picture book such as a cat, bird, or dog
- Stands on tiptoe
- Kicks a ball
- Begins to run
- Climbs onto and down from furniture without help
- Walks up and down stairs holding on
- Throws ball overhand
- Makes or copies straight lines and circles
- Please mark here if your child is doing all of the above behaviors

\*If they answered “3” to #16 (display #2)

2. Please select which behaviors your child is NOT doing

- Copies adults and friends

- Shows affection for friends without prompting
- Takes turns in games
- Shows concern for a crying friend
- Understands the idea of “mine” and “his” or “hers”
- Shows a wide range of emotions
- Separate easily from mom and dad
- May get upset with major changes in routine
- Dresses and undresses self
- Follows instructions with 2 or 3 steps
- Can name most familiar things
- Understands words like “in,” “on,” and “under”
- Says first name, age, and sex
- Names a friend
- Says words like “I,” “me,” “we,” and “you” and some plurals (cars, dogs, cats)
- Talks well enough for strangers to understand most of the time
- Carries on a conversation using 2 and 3 sentences
- Can work toys with buttons, levers, and moving parts
- Plays make-believe with dolls, animals, and people
- Does puzzles with 3 or 4 pieces
- Understands what “two” means
- Copies a circle with pencil or crayon
- Turns book pages one at a time
- Builds towers of more than 6 blocks
- Screws and unscrews jar lids or turns door handle
- Climbs well
- Runs easily
- Pedals a tricycle (3-wheel bike)
- Walks up and down stairs, one foot on each step
- Please mark here if your child is doing all of the above behaviors

\*If they answered “4” to #16 (display #3)

3. Please select which behaviors your child is NOT doing
  - Enjoys doing new things
  - Plays “Mom” and “Dad”
  - Is more and more creative with make-believe play
  - Would rather play with other children than by himself
  - Cooperates with other children
  - Often can’t tell what’s real and what’s make-believe
  - Talks about what she likes and what she is interested in
  - Knows some basic rules of grammar, such as correctly using “he” and “she”
  - Sings a song or says a poem from memory such as the “Itsy Bitsy Spider” or the “Wheels on the Bus”

- Tells stories
- Can say first and last name
- Names some colors and some numbers
- Understands the idea of counting
- Starts to understand time
- Remembers parts of a story
- Understands the idea of “same” and “different”
- Draws a person with 2 or 4 body parts
- Use scissors
- Starts to copy some capital letters
- Plays board or card games
- Tells you what he thinks is going to happen next in a book
- Hops and stands on one foot up to 2 seconds
- Catches a bounced ball most of the time
- Pours, cuts with supervision, and mashes own food
- Please mark here if your child is doing all of the above behaviors

\*If they answered “5” to #16 (display #4)

4. Please select which behaviors your child is NOT doing
  - Wants to please friends
  - Wants to be like friends
  - More likely to agree with rules
  - Likes to sing, dance, and act
  - Is aware of gender
  - Can tell what’s real and what’s make-believe
  - Shows more independence (For example, may visit a next-door neighbor by himself – adult supervision is still needed)
  - Is sometimes demanding and sometimes very cooperative
  - Speaks very clearly
  - Tells a simple story using full sentences
  - Uses future tense; for example, “Grandma will be here.”
  - Says name and address
  - Counts 10 or more things
  - Can draw a person with at least 6 body parts
  - Can print some letters or numbers
  - Copies a triangle and other geometric shapes
  - Knows about things used every day, like money and food
  - Stands on one foot for 10 seconds or longer
  - Hops; may be able to skip
  - Can do a somersault
  - Uses a fork and spoon and sometimes a table knife
  - Can use the toilet on her own
  - Swings and climbs

- Please mark here if your child is doing all of the above behaviors

*Please answer the following questions regarding the behaviors you marked previously (behaviors your child is NOT doing).*

5. Have you discussed these behaviors with a professional?
  - Yes
  - No

\*If “no” is selected for #5 skip to end of block (developmental milestones)

6. What type of professional did you talk with?
  - Psychologist
  - Medical Doctor (e.g., pediatrician, psychiatrist, neurologist)
  - Other (text entry)

7. Did a follow-up conversation/appointment occur?
  - Yes
  - No

\*If “no” is selected (display #8)

8. Did you have any other concerns?
  - Yes
  - No
9. Describe your experience when voicing your concerns to a professional (text entry).

## APPENDIX D

### Resource Page

## Resource Page

If you have concerns regarding your child's behavior contact a professional. Here are some links that may be helpful:

<https://www.cdc.gov/ncbddd/adhd/>

<https://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>

<https://ldaamerica.org/types-of-learning-disabilities/>

<https://www.cdc.gov/ncbddd/autism/index.html>

<https://www.autismspeaks.org/>

<http://www.autism-society.org/>

## APPENDIX E

### Responses on ASKSG Items

### Responses on ASKSG Items

ASKSG Items	Key	True <i>n(%)</i>	False <i>n(%)</i>	Don't Know <i>n(%)</i>
Assessment and Diagnosis.	--	--	--	--
<i>A diagnosis of autism spectrum disorder can only be made by a medical doctor.</i>	False	103(61.7)	19(11.4)	45(26.9)
<i>Autism spectrum disorder can be diagnosed with brain imaging.</i>	False	30(18.0)	36(21.6)	101(60.5)
<i>It is possible for autism spectrum disorder to develop in adulthood.</i>	False	30(18.0)	40(24.0)	97(58.1)
<i>For a diagnosis of autism spectrum disorder, symptoms must be present from early childhood.</i>	True	42(25.1)	46(27.5)	79(47.3)
<i>Autism spectrum disorder can only be diagnosed after the age of 4 years.</i>	False	30(18.0)	60(35.9)	84(50.3)
<i>Diagnosis of autism spectrum disorder is primarily based on behavioral observations and parent interviews.</i>	True	76(45.5)	25(15.0)	66(39.5)
<i>If a teacher believes a student has autism spectrum disorder, they can make a diagnosis.</i>	False	12(7.2)	120(71.9)	35(21.0)
Etiology and Prevalence	--	--	--	--
<i>Less than 2% of people in the US have autism spectrum disorder.</i>	True	34(20.4)	55(32.9)	78(46.7)
<i>Advanced paternal (father) age is a risk factor for autism spectrum disorder.</i>	True	36(21.6)	39(23.4)	92(55.1)
<i>Children who have a brother or sister with autism spectrum disorder are more likely to develop the disorder.</i>	True	37(22.2)	68(40.7)	62(37.1)
<i>There are no differences in the identification rates of autism spectrum disorder across racial and ethnic groups.</i>	False	39(23.4)	46(27.5)	82(49.1)



<i>Boys are four times as likely than girls to have autism spectrum disorder.</i>	True	67(40.1)	26(15.6)	74(44.3)
<i>Vaccines can cause autism spectrum disorder.</i>	False	26(15.6)	93(55.7)	48(28.7)
<i>Autism spectrum disorder is caused by a lack of motherly warmth.</i>	False	7(4.2)	136(81.4)	24(14.4)
Treatment	--	--	--	--
<i>Restricting certain foods (e.g., gluten) is an effective treatment for autism spectrum disorder.</i>	False	26(15.6)	49(29.3)	92(55.1)
<i>Intellectual quotient (i.e., IQ) and age affect treatment success for children with autism spectrum disorder.</i>	True	52(31.1)	18(10.8)	97(58.1)
<i>There are no beneficial treatments available for individuals with autism spectrum disorder.</i>	False	18(10.8)	84(50.3)	65(38.9)
<i>Social skills training is an effective treatment for some individuals with autism spectrum disorder.</i>	True	96(57.5)	15(9.0)	56(33.5)
Outcomes and Prognosis	--	--	--	--
<i>Up to 70% of individuals with autism spectrum disorder also have an additional mental health diagnosis (e.g., anxiety).</i>	True	61(36.5)	21(12.6)	85(50.9)
<i>Many individuals with autism spectrum disorder have difficulties living and working independently in adulthood.</i>	True	68(40.7)	38(22.8)	61(36.5)
<i>Many children with autism spectrum disorder are at risk for academic difficulties.</i>	True	83(49.7)	20(12.0)	64(38.3)
<i>Symptoms of autism spectrum disorder do not change throughout an individual's life.</i>	False	10(6.0)	87(52.1)	70(41.9)
<i>Autism spectrum disorder only affects children.</i>	False	15(9.0)	94(56.3)	58(34.7)
<i>Most individuals with autism spectrum disorder will never learn to speak.</i>	False	12(7.2)	117(70.1)	38(22.8)
Symptoms and Associated Behaviors	--	--	--	--

<i>Some individuals with autism spectrum disorder may be uncoordinated or clumsy.</i>	False	73(43.7)	19(11.4)	75(44.9)
<i>Symptoms of autism spectrum disorder do not appear before the age of 2 years.</i>	False	28(16.8)	54(32.3)	85(50.9)
<i>Children with autism spectrum disorder may not play with toys the way they are intended.</i>	True	85(50.9)	37(22.2)	45(26.9)
<i>Individuals with autism spectrum disorder may have strict routines or rituals.</i>	True	116(69.5)	13(7.8)	38(22.8)
<i>Many individuals with autism spectrum disorder have difficulties expressing themselves.</i>	True	117(70.1)	13(7.8)	37(22.2)
<i>Individuals with autism spectrum disorder have difficulties interacting socially with others.</i>	True	119(71.3)	15(9.0)	33(19.8)
<i>All individuals with autism spectrum disorder have low intellectual quotients (i.e., IQs).</i>	False	7(4.2)	128(76.6)	32(19.2)

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