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## Sleep Disorders in Children with Autism Spectrum Disorder: A Pilot Study of an Assessment of Pediatric Providers' Practices and Perceptions

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Sleep Disorders in Children with Autism Spectrum Disorder:  
A Pilot Study of an Assessment of Pediatric Providers' Practices and Perceptions

by

Kristin Lynn Edwards

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Education Specialist  
Department of Educational and Psychological Studies  
College of Education  
University of South Florida

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## **Abstract**

Children with Autism Spectrum Disorder (ASD) have increased rates for sleep problems compared with typically developing children. Although physicians practicing in pediatric primary care settings have the potential to detect and address sleep problems at an early age, research investigating the sleep management practices of pediatricians in primary care is scant and does not particularly address children with ASD. This study investigated the frequency of sleep screening measures utilized by pediatric providers during well-child examinations, the most frequently recommended treatments, the barriers and facilitators to screening for sleep problems, and the perceived confidence of pediatricians with regard to screening for sleep problems in children ages 2-10 years with ASD. Survey data from members of the Hillsborough County Medical Association were collected and analyzed. Seventy-three percent of participants reported almost always screening for a sleep problem during well-child examinations. Findings indicate that pediatric healthcare providers acknowledge the importance of managing sleep problems in primary care settings. Barriers to screening for sleep problems during routine exams included lack of time, resources, and awareness of screening tools. Facilitators to screening for sleep problems during routine exams included shorter sleep screening tools and longer exams. Pediatric providers were moderately confident in their ability to manage sleep problems in primary care settings. A significant relationship was found between confidence level and a number of perceived barriers. Implications of the findings are discussed.



## Chapter One

### Introduction

#### Statement of the Problem

Difficulties related to sleep are among the most common pediatric health issues. *Sleep problems* or *sleep disturbances* such as difficulty falling asleep, early rising, delaying bedtime, and snoring are common symptoms a *sleep disorder*. Sleep disorders (e.g., chronic insomnia disorder, nightmare disorder, and obstructive sleep apnea) involve problems associated with the duration and quality of sleep. The prevalence of childhood sleep problems is estimated to be 20% to 40% (Mindell, Carskadon, & Owens, 1999; Mindell & Owens, 2015). More specifically, researchers have found that sleep problems exist in approximately 50% of preschool age children (Kerr & Jowett, 1994) and 37% of school age children (Owens, Spirito, McGuinn, & Nobile, 2000).

Sleep disorders that interfere with sleep onset and the sleep process such as chronic insomnia disorder and obstructive sleep apnea are classified as dyssomnias. One type of chronic insomnia disorder, behavioral insomnia, affects 20% to 30% of children (Mindell, 1999). Sleep disorders that disrupt the sleep process once sleep onset has occurred, such as nightmare disorder are classified as parasomnias. It is estimated that 25% to 50% of children exhibit night wakings, which include sleep terrors. Sleep terrors are most prevalent in preschool years. Specifically, it is estimated that 1% to 6.5% of young children experience sleep terrors (Mindell & Owens, 2015).

Sleep disturbances related to delaying bedtime and early rising have been found in 20% to 30% of young children (Armstrong, Quinn, & Dadds, 1994).

Children with Autism Spectrum Disorder (ASD) experience more sleep problems than typically developing children (Doran, Harvey, & Horner, 2006). More specifically, approximately 50% to 87% of children with ASD are affected by at least one sleep disturbance or sleep disorder symptom (Couturier et al., 2005; Liu, Hubbard, Fabes, & Adam, 2006; Souders et al., 2009). Souders and colleagues (2009) reported that 66% of children with ASD and 45% of typically developing children experience sleep problems. Given the relationship between ASD and sleep, screening for sleep disorders in this population is critical. Moreover, the National Sleep Foundation determined that “children with ASD are one of the highest priority populations for sleep research” (Mindell et al., 2006, p.2264).

Multiple studies have linked untreated sleep issues to problems in social, emotional, and academic performance (Morris, James-Robert, Sleep, & Gillham, 2001). Children with poor sleep quality may have difficulty with behavior regulation and attention, resulting in increased temper tantrums, aggressive behaviors, hyperactivity, impulsivity, and increased risk of depression and anxiety (Gregory & Sadeh, 2012; Mazurek & Sohl, 2016; O’Brien, 2009). In addition, sleep deprivation in young children may also contribute to physical health problems such as allergies and ear infections (Stein, Mendelsohn, Obermeyer, Amromin, & Benca, 2001), as well as hypertension, insulin resistance, and obesity (Flint et al., 2007). Additionally, sleep disturbances in children often have significant impacts on the family, resulting in an increase of caregiver stress and fatigue, and a decrease in effective parenting (Hoffman et al., 2008; Mindell & Owens, 2015). Sleep problems also are associated with inadequate psychological functioning (Smaldone, Honig, Byrne, 2007) and can exacerbate nearly every coexisting medical,

psychiatric, developmental, and psychosocial condition (Mindell & Owen, 2015). In addition to the consequences stated above, researchers also have suggested that inadequate sleep may significantly exacerbate the symptoms of ASD (Hoffman et al., 2005; Schreck, Mulick, & Smith, 2004). According to Hoffman and colleagues (2005), the severity of autism symptoms (e.g., social interaction deficits) were related to parent reported sleep problems. Other symptoms that may be intensified by sleep disturbances include communication problems, adaptive behaviors, and aggressive behavior (Mazurek & Sohl, 2016; Taylor, Schreck, & Mulik, 2012).

Clearly, it is particularly important for sleep problems to be identified and diagnosed as sleep disorders as soon as they arise. If left unaddressed, childhood sleep problems have been found to contribute to behavior problems in early adolescence (Gregory & O'Connor, 2002). Fortunately, sleep disorders are highly treatable through evidence-based medical and behavioral interventions.

School psychologists often provide assessment and intervention to students within the educational system. School psychologists are individuals with graduate coursework and training in psychology and education, who collaborate with other professionals to ensure safety and promote health among children and adolescents (Fagan & Wise, 2000). In particular, school psychologists with training in pediatric school psychology receive specialized training in treatment and prevention efforts focused on medical aspects of child development, such as sleep problems (Armstrong, Kohler, & Lilly, 2009; Bradley-Klug & Armstrong, 2014). Although sleep disorders can only be diagnosed by a doctor of medicine, school psychologists can contribute to the identification and intervention of sleep problems in students who display sleep disorder symptoms. The Sleep Disorders Inventory for Students (SDIS; Luginbeuhl et al., 2008) was developed for school psychologists in order determine if sleep disorders may be affecting a

student's school performance. However, research has shown that screening for pediatric sleep disorders within a school setting is a relatively new concept and not widely implemented (Everhart, 2011). To date, the SDIS is the only comprehensive sleep screening instrument that was designed and validated for use in a school setting. Current behavioral and social-emotional assessments utilized by school psychologists include an average of two items that address sleep concerns (Sakakini, Braverman, & Terjesen, 2012). Additionally, sleep problems are often mistaken for learning problems, poor motivation, lack of interest, and attention-deficit hyperactivity disorder (Sadeh, Raviv, & Gruber, 2000).

Although school psychologists have knowledge and training in pediatric sleep disorders, school psychologists must communicate and collaborate with other professionals, such as pediatricians, in order to meet the varying needs of all students (e.g., academic, behavioral, social-emotional, environmental, sociocultural). Furthermore, addressing sleep problems in young children would likely be more effective if it occurred before the student started school. For example, a child with ASD will likely be examined by a pediatrician several times throughout their early years before entering school and meeting a school psychologist. Therefore, general pediatricians are in an optimal position to assess and diagnose sleep problems in young children with ASD, while school psychologists are better suited to participate in the intervention of sleep disorders within the school setting.

Pediatric primary care settings are a natural place for screening and management of sleep problems, given the regular access pediatricians have to young children (Mindell & Owens, 2015). The American Academy of Pediatrics (AAP) have published several guidelines regarding best practices when working with young children in primary care settings. Primarily, the AAP issued *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*,

which provides pediatricians with essential background information and recommendations critical to healthy child development, including guidelines for screening and treating autism. The “Bright Futures” handbook recommends sleep screening in young children and provides trigger questions for sleep problems which can be used during well-child visits (Hagan, Shaw, & Duncan, 2017). In 2002, the AAP issued a set of evidence-based guidelines recommending that screening for snoring should occur during all well-child examinations (American Academy of Pediatrics, 2002). More recently, the AAP published a revised set of guidelines on this topic for the purpose of increasing pediatric primary care physicians’ recognition and diagnostic techniques of pediatric obstructive sleep apnea, and to provide evidence-based treatment options (Marcus et al., 2012).

Early identification and treatment of sleep problems may potentially counteract some of the secondary consequences of sleep disorders such as disruptive behaviors, lack of attention, and learning problems (Moore et al., 2017). Identifying sleep disorders at an early age is likely to increase favorable daytime behaviors and also may have a positive impact on family functioning (Cortesi, 2010). However, it has been suggested by several researchers that sleep management practices do not occur in well-child examinations as often as they could (e.g., Faruqui et al., 2011). Additionally, research investigating the sleep management practices of pediatricians in primary care is scant and does not particularly address children with ASD. Thus, the sleep management practices among pediatricians with regard to children with ASD remains unclear. In order to make evidence-based recommendations for improved patient care in this population of children, more information on the current practices and perceptions of pediatricians is needed.

## **Theoretical Framework**

One theory that formed the theoretical basis of the present study is Bronfenbrenner's ecological systems theory to human development (1977, 1979). Ecological systems theory provides an explanation of how a child's environment affects development. According to Bronfenbrenner, child development is influenced by factors across multiple systems such as the microsystem (i.e., a child's immediate environment), the mesosystem (i.e., interactions between microsystem components), the exosystem (e.g., outside people and places that may influence the child), and the macrosystem (i.e., cultural values, general beliefs, the economy, and laws of a society).

More specifically, improving outcomes for children with ASD with sleep disorders is grounded in ecological systems theory because sleep-wake patterns and behaviors are influenced by several biological and socio-cultural factors that have been found to contribute to child development. Within the microsystem, each child has individual characteristics that can impact their sleep development (El Sheikh & Sadeh, 2015). Genetic factors may result in vulnerability or protection from developing a sleep disorder (Sehgal & Mignot, 2011). Medical issues commonly found in children with ASD that involve symptoms of discomfort, such as digestive problems (Kahn, Mozin, Rebuffat, Sottiaux, & Muller, 1989), allergies (Koinis-Mitchell et al., 2012), headaches (Bruni, Russo, Violani, & Guidetti, 2004), and ear infections (Tudor, Walsh, Mulder, & Lerner, 2015) can disrupt sleep patterns. Within the mesosystem, families and caregivers can create conditions (e.g., light exposure, caffeine consumption, and monitor bedtimes and wake times) which contribute to children's sleep patterns (El Sheikh & Sadeh, 2015). For example, family sleep arrangements (e.g., whether a child sleeps alone or co-sleeps) are often determined by factors related to culture (Ball, Hooker, & Kelly, 2000; Mindell et al.,

2010; Thoman, 2006). Additionally, school factors (e.g., homework, school start times, and demands related to alertness and learning) can significantly impact a child's sleep quality and duration (Owens, Belon, & Moss, 2010). Moreover, these variables influence each other bidirectionally, in that school factors have a direct influence on sleep, and vice versa (El Sheikh & Sadeh, 2015; Sadeh, Gruber, & Raviv, 2003). Within the exo- and macrosystems, cultural factors (e.g., co-sleeping vs. sleeping alone), community norms and expectations (e.g., bedtimes), and poverty (e.g., noise in the home, crowded environment) contribute to a child's sleep development (El Sheikh & Sadeh, 2015). These factors, combined with factors from other systems, highlight the necessity of appropriately managing sleep problems in this population of children in order to promote healthy sleep in early childhood.

Finally, the organizational dynamic of the settings pediatricians work in, as well as the specific motivational characteristics of the provider, may have an influence on day-to-day practices. For example, Human Motivation Theory (McClelland, 1961) suggests that people are motivated by three needs: a need for achievement, affiliation, or power. Further, McClelland suggests that people have different characteristics based on their dominant motivator. Based on this theory, participants in this study were likely to possess various motivational characteristics that may influence the degree to which they are motivated to accomplish certain responsibilities, such as screening for sleep problems.

### **Purpose of the Study**

The purpose of this study was to pilot test a survey that investigated the current practices and perceptions of general pediatricians relative to managing sleep problems in children with ASD. This study collected data regarding the type of tools used by general pediatricians to screen for sleep problems during well-child examinations. Also, this study acquired information on the

sleep treatments pediatricians are most likely to recommend. Additionally, this study collected data on what general pediatricians perceive as barriers and facilitators to managing sleep issues in primary care settings. Lastly, this study gathered data on general pediatricians' perceived level of confidence in detecting and addressing sleep problems.

### **Research Questions**

To investigate the current practices and perceptions of pediatricians relative to managing sleep problems in children with ASD, the following research questions were addressed on a web-based survey that general pediatricians in West Central Florida were asked to complete.

**Research question 1.** What are the current practices of pediatricians with regard to detecting and addressing sleep problems in children ages 2 to 10 years with ASD?

- a. What screening tools are used by pediatricians to screen for sleep problems during well-child exams?
- b. Which treatments for sleep problems are pediatricians most likely to recommend?

**Research question 2.** To what extent do pediatricians perceive various factors to serve as facilitators to screening for sleep problems?

**Research question 3.** To what extent do pediatricians perceive various factors to serve as barriers to screening for sleep problems?

**Research question 4.** How confident are pediatricians in managing sleep issues in children with ASD?

### **Importance of the Study**

It is estimated that 50% to 87% of young children with ASD will develop a comorbid sleep problem (Couturier et al., 2005; Liu, Hubbard, Fabes, & Adam, 2006; Richdale & Schreck, 2009; Wiggs & Stores, 1996). Learning, executive function, and attention are negatively



impacted by sleep problems (Maski & Kothare, 2013; Morris, James-Robert, Sleep, & Gillham, 2001). If left unaddressed, sleep problems may lead to anxiety and disruptive daytime behavior (May et al., 2013; Sikora, Johnson, Clemons, & Katz, 2012), which also may negatively impact academic performance. Issues related to communication, social interactions, and behavior are inherent in children with ASD; sleep disturbances can significantly exacerbate these symptoms (Hoffman et al., 2005; Schreck et al., 2004; Tudor et al., 2012).

This study collected data on the current practices and perceptions of general pediatricians in relation to the management of disturbed sleep in young children with ASD. Obtaining information on the barriers and facilitators to detecting and addressing sleep problems can lead to the development of strategies to enhance the care of children with ASD. Moreover, by investigating the perceived level of confidence of pediatricians, information can be gathered to determine if improved formal education and training is necessary.

### **Definition of Key Terms**

The following key terms are defined by Mindell and Owens (2015) in the third edition of *A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems* unless otherwise specified.

*Apnea*: a pause in breathing lasting 10-20 seconds.

*Confusional Arousals*: disorientation and confusion during sleep.

*Delayed sleep-wake phase disorder (DSWPD)*: a shift or delay of the normal wake-sleep schedule.

*Nightmare Disorder*: repeated occurrences of frightening dreams, which can cause significant distress or impairment upon awakening (World Health Organization, 2016).

*Obstructive Sleep Apnea (OSA)*: prolonged obstruction of the airway during sleep resulting in a breathing problem.

*Periodic Limb Movement Disorder*: a neurological disorder that involves episodes of repetitive movements (e.g., jerking movements).

*Polysomnogram (PSG)*: an overnight sleep study that provides information on breathing, body movements, and arousals during sleep.

*Primary Snoring*: the most common symptom of OSA.

*Restless Legs Syndrome*: involves the movement of the legs during sleep.

*Sleep Terrors*: Sleep involve an abrupt disruption of sleep followed by vocalizations such as a frightening scream, and intense fear with signs of unconscious arousals including rapid heart rate, dilated pupils, heavy breathing, and sweating.

*Sleep Walking*: a sleep problem that involves walking while still asleep.

## **Chapter Two**

### **Literature Review**

This chapter reviews the professional literature relevant to this study. Specifically, this chapter reviews the literature in four primary areas: 1) prevalence and prognosis of pediatric sleep disorders among children with ASD, 2) the need for early identification of sleep problems, 3) best practices of screening for sleep problems in primary care settings, and 4) current practices of managing sleep problems in primary care settings. The current study is guided by this review of literature.

#### **Prevalence and Prognosis of Pediatric Sleep Disorders**

Sleep is vital to the brain during early development. Throughout childhood, it is recommended that sleep constitute 40% of a child's day (Mindell & Owens, 2015). Difficulties related to sleep are among the most common pediatric health issues. *Sleep problems* or *sleep disturbances* such as difficulty falling asleep, early rising, delaying bedtime, and snoring are common symptoms a *sleep disorder*. Sleep disorders (e.g., chronic insomnia disorder, nightmare disorder, and obstructive sleep apnea) involve problems associated with the duration and quality of sleep. The prevalence of childhood sleep problems is estimated to be 20% to 40% (Mindell, Carskadon, & Owens, 1999; Mindell & Owens, 2015). More specifically, researchers have found that sleep problems exist in approximately 50% of preschool age children (Kerr & Jowett, 1994).

**Pediatric Sleep Disorders.** For clarity and consistency, this chapter discusses pediatric sleep disorders as described in the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth

Edition (DSM-5; American Psychological Association, 2013) and the *International Classification of Sleep Disorders*, 3rd Edition (ICSD-3; American Academy of Sleep Medicine, 2014), as well as the *International Classification of Diseases* (ICD-10; World Health Organization, 2016), as these are the principle diagnostic systems used in primary care settings. Furthermore, the terms ‘sleep problem’ and ‘sleep disturbance’ refer to the symptoms of sleep disorders (i.e., difficulty falling asleep, sleepwalking), and do not necessarily indicate the existence of a sleep disorder diagnosis. Sleep disorders that interfere with sleep onset and the sleep process are classified as dyssomnias (e.g., chronic insomnia disorder). Sleep disorders that disrupt the sleep process once sleep onset has occurred are classified as parasomnias (e.g., nightmare disorder).

***Chronic Insomnia Disorder.*** According to Mindell and Owens (2015), bedtime resistance is often a result of parents having difficulty setting bedtime limits and managing child behavior. Bedtime sleep problems often occur after the age of two years and involve stalling behaviors that delay bedtime such as watching more television or making requests (e.g., asking for a drink of water) which cause further delay. Bedtime problems in young children were referred to as “behavioral insomnia of childhood: limit-setting type” by the ICSD-3 (American Academy of Sleep Medicine, 2014), but now fall under the category of chronic insomnia disorder. Twenty to thirty percent of children are affected by behavioral insomnia (Mindell, 1999). The primary cause of insomnia in typically developing children is behaviorally based (Armstrong et al., 1994); however, insomnia is multifactorial in children with ASD. Causes of insomnia in children with ASD are related to medical, neurological, and psychiatric comorbidities (Johnson & Malow, 2008). The American Psychological Association (APA) characterizes insomnia by difficulties initiating and maintaining sleep, accompanied by feeling

unrested after sleep (American Psychological Association, 2013). Sleep disorders involving bedtime problems, including insomnia, are often treated with behavioral interventions; however, given that insomnia can become a learned behavior, the disorder is likely to persist if untreated (Mindell & Owens, 2015).

***Obstructive Sleep Apnea (OSA).*** Obstructive sleep apnea involves prolonged obstruction of the airway during sleep, often resulting in snoring. Snoring is the most common symptom of OSA. Primary snoring has been found to occur in 11% of children. The prevalence of OSA is estimated to be 1% to 5% of children as measured by overnight sleep studies, and 4% to 11% of children when defined by parent reported symptoms (Mindell & Owens, 2015).

***Circadian Rhythm Sleep–Wake Disorders.*** Delayed sleep-wake phase disorder (DSWPD) is a disorder that involves the habitual shift of more than two hours in the wake-sleep schedule, which conflicts with normal work, school, lifestyle demands. DSWPD is common in adolescents (7% to 16%), but can present in young children with marked phase delay. DSWPD is a chronic disorder that can be treated with behavioral interventions; however, relapse following initial treatment is common (Mindell & Owens, 2015).

***Confusional Arousals.*** Confusional arousals involve disorientation, confusion, and unresponsiveness to the environment during sleep, including limited dream imagery, full or partial amnesia of the episode, and confused behavior while the child is in bed (American Academy of Sleep Medicine 2014; Mindell & Owens, 2015). According to Mindell and Owens (2015), most children will outgrow these sleep behaviors in childhood. More specifically, 50% of children who experience confusional arousals will resolve these episodes by the age of 8 years.

***Sleepwalking.*** Sleepwalking is a fairly common sleep disturbance, with prevalence rates of 15% to 40% of children sleepwalking on at least one occasion, and 17% of children regularly

sleepwalking (Mindell & Owens, 2015). Sleep walking occurs early in the night and involves the symptoms of confusional arousals, but includes leaving bed and walking while still asleep (American Academy of Sleep Medicine, 2014). Injuries can occur during sleepwalking, as children who sleepwalk are typically clumsy and may perform dangerous actions such as leaving the house. Similar to the prognosis of confusional arousals, most children naturally stop sleepwalking by late childhood. However, some children continue to sleepwalk for 10 or more years (Mindell & Owens, 2015).

***Sleep Terrors.*** Twenty to fifty percent of children exhibit night wakings, which include sleep terrors. Sleep terrors are most prevalent in preschool years. Specifically, it is estimated that 1% to 6.5% of children experience sleep terrors (Mindell & Owens, 2015). The ICSD-3 diagnosis for sleep terrors include the criteria for confusional arousals, abrupt disruption of sleep followed by vocalizations such as a frightening scream, and intense fear with signs of unconscious arousals including rapid heart rate, dilated pupils, heavy breathing, and sweating (American Academy of Sleep Medicine, 2014).

***Nightmare Disorder.*** Seventy-five percent of children will experience at least one nightmare in their lifetime. Frequent nightmares, lasting longer than three months, have been found to occur in 24% of preschool children and 41% of school-age children (Li et al., 2011). The ICSD-3 and DSM-5 classifies Nightmare Disorder as “repeated occurrences of extremely dysphoric and well-remembered dreams”, which can cause distress upon awakening (American Academy of Sleep Medicine, 2014; World Health Organization, 2016). Young children who experience nightmares may be fearful of going to sleep. Moreover, children may have difficulty returning to sleep, resulting in reduced sleep quality and total sleep time (Schnoes, 2016). According to Mindell and Owens (2015), behavioral strategies are used to treat nightmares.

Nightmares are typically short-lived, but can persist in children if the nightmares are related to a traumatic event.

**Prevalence of Sleep Disorders in Children with Autism Spectrum Disorder.** The Centers for Disease Control and Prevention (Christensen et al., 2016) reports that approximately 1 in 68 children are diagnosed with Autism Spectrum Disorder (ASD). ASD is a developmental disability identified as impairment in communication, social interaction, and repetitive and stereotyped patterns of behavior that present before age 3 and last through a person's lifetime (DSM-5; APA, 2013). Other common symptoms may include attention problems, high levels of anxiety, difficulty regulating emotions, gastrointestinal problems, and sleep deficits (Mannion & Leader, 2016). Increased sleep latency, decreased sleep quality, difficulty maintaining sleep, and shortened sleep duration are among the most frequently reported sleep concerns in children with ASD (Humphreys et al., 2014; Wiggs & Stores, 2004). The prevalence of sleep problems in children with Autism Spectrum Disorder is markedly higher than typically developing children (Doran, Harvey, & Horner, 2006). More specifically, approximately 50% to 87% of young children with ASD are affected by at least one sleep disturbance or sleep disorder symptom (Couturier et al., 2005; Liu, Hubbard, Fabes, & Adam, 2006; Souders et al., 2009). Souders and colleagues (2009) reported that 66% of children with ASD and 45% of typically developing children experience sleep problems. Given the relationship between ASD and sleep, screening for sleep disorders in this population is critical. Moreover, the National Sleep Foundation determined that "children with ASD are one of the highest priority populations for sleep research" (Mindell et al., 2006, p.2264).

**Etiology of Sleep Problems in Children with Autism Spectrum Disorder.** Although the underlying cause of increased sleep problems in the ASD population is unknown, several

researchers have offered possible explanations. One hypothesis involves a genetic predisposition. Chromosome 15q, which contains gamma-aminobutyric acid (GABA) neurons, may negatively affect sleep regulation by interrupting the normal GABA-related functions in the body (Cortesi, Giannotti, Ivanenko, & Johnson, 2010). Other researchers propose that genetic abnormalities associated with melatonin synthesis could explain circadian rhythm abnormalities (Cortesi et al., 2010). Additionally, some researchers have reported that a reduction of melatonin could be explained by the lack of ASMT, a gene that encodes the enzymes necessary for melatonin synthesis, and is often deleted in individuals with ASD (Maski, Jeste, & Spence, 2011; Melke et al., 2008).

In addition, sleep problems among children with ASD can be caused by factors that can affect any child (Cavalieri, 2016; Mannion & Leader, 2016; Mindell & Owens, 2015). OSA has been found to affect approximately 1% to 10% of all children (Chan, Edman, & Koltai, 2004). Decreased oxygen levels during sleep from OSA result in frequent night wakings, which can adversely affect a child's overall quality of sleep. In addition, behavior disorders and neurological disorders such as epilepsy can disrupt the sleep process. It is not uncommon for children with ASD to have a comorbid behavior disorder (e.g., anxiety, ADHD, or mood disorder) which can contribute to sleep problems (de Bruin, Ferdinand, Meesters, deNijs, & Verheij, 2007). Researchers have shown that 11% to 39% of children with ASD have epilepsy (Ballaban-Gil & Tuchman, 2000; Kawasaki et al., 1997; Tuchman & Rapin, 1997). If left untreated, epilepsy can significantly affect quality of sleep. Lastly, according to Mindell and Owens (2015), insufficient sleep is predominately due to environmental factors. Academic and extracurricular activities may delay bedtime in some families. In addition, electronic media devices (i.e., television, computers, video games, tablets) may take priority over bedtime.



Electronic devices emit bright lights that can affect a child's ability to regulate melatonin, which may prevent a child from falling asleep if used before bed (Maski & Owens, 2016). Of note, it is estimated that children with ASD spend more time on electronic devices than typically developing children (Engelhardt, Mazurek, & Sohl, 2013; Orsmond & Kuo, 2011).

**Effects of Sleep Disorders in Children with Autism Spectrum Disorder.** Inadequate sleep can significantly affect daytime functioning in academic performance, behavior, social development, and health (Meltzer & Crabtree, 2015). The following section describes the negative effects sleep disorders have on children.

Multiple studies have linked untreated sleep issues to problems in social, emotional, and academic performance (Morris, James-Robert, Sleep, & Gillham, 2001). Children with poor sleep quality may have difficulty with behavior regulation and attention, resulting in increased temper tantrums, aggressive behaviors, hyperactivity, impulsivity, and increased risk of depression and anxiety (Gregory & Sadeh, 2012; Gruber et al., 2012; Mazurek & Sohl, 2016; O'Brien, 2009). In addition, sleep problems are related to difficulties in concentrating, learning, and problem-solving (Beebe, 2011; Meltzer & Crabtree, 2015). In particular, inadequate sleep negatively effects executive functioning, which involves skills necessary for attention, planning, shifting from one task to another, self-regulation, and working memory (Maski & Kothare, 2013). Several researchers have found that sleep problems are likely to contribute to poor grades and grade retention (Asarnow, McGlinchey, & Harvey, 2014; de Carvalho et al., 2013). Furthermore, a study that examined the frequency of injury rates in preschool and early-school aged children (Owens, Fernando, & McGuinn, 2005) found that young children with more frequent injuries experienced significantly more sleep problems, suggesting that sleep problems could potentially increase the risk of injury.

Sleep disturbances also have an effect on physical health outcomes such as hypertension, obesity, and insulin resistance (Flint et al., 2007; Javaheri, Storfer-Isser, Rosen & Redline, 2008; Javaheri et al., 2011). Additionally, research indicates that sleep problems increases susceptibility to the common cold or other viral illnesses (Cohen, Doyle, Alper, Janicki-Deverts, & Turner, 2009).

In addition to the consequences stated above, researchers also have suggested that inadequate sleep may significantly exacerbate the symptoms of ASD (Hoffman et al., 2005; Schreck, Mulick, & Smith, 2004). Hoffman and colleagues (2005) found that the severity of autism symptoms (e.g., social interaction deficits) were related to parent reported sleep problems. Similarly, a study by Tudor, Hoffman, and Sweeney (2012) examined the correlation between symptoms of ASD and sleep disturbances, while controlling for comorbid Developmental Delay diagnoses. Likewise, Schreck, Mulik, and Smith (2004) found that reduced total hours of sleep resulted in more severe symptoms of autism, including increased severity of stereotypic behaviors and social deficits. Other symptoms that may be intensified by sleep disturbances include communication problems, adaptive behaviors, and aggressive behavior (Mazurek & Sohl, 2016; Taylor, Schreck, & Mulik, 2012).

The effects of sleep problems in children are likely to extend to their families. Childhood sleep problems can interfere with parental sleep, which can affect mood, marriage, work performance, and overall ability to parent (Meltzer & Mindell, 2007). In particular, one study found that parents of children with ASD sleep less and experience more sleep disturbances than parents of children with typical development (Meltzer, 2008). Furthermore, parents of children with ASD experience stress more frequently than parents of children with typically developing

children with sleep disorders, and parents of children with ASD without sleep disorders (Eisenhower, Baker, & Blacher, 2005; Hoffman et al., 2008).

### **Identifying and Treating Sleep Problems in Schools**

School psychologists promote healthy development through prevention and intervention services for children in educational settings. In particular, school psychologists with training in pediatric school psychology receive specialized training in treatment and prevention efforts focused on medical aspects of child development, such as sleep problems (Armstrong, Kohler, & Lilly, 2009; Bradley-Klug & Armstrong, 2014). Although a doctor of medicine is needed to make sleep disorder diagnoses, school psychologists can identify and provide intervention for sleep problems in students who display sleep disorder symptoms at school. The Sleep Disorders Inventory for Students (SDIS; Luginbeuhl et al., 2008) was developed for school psychologists in order to determine if sleep disorders may be affecting a student's school performance. However, research has shown that screening for pediatric sleep disorders within a school setting is a relatively new concept and not widely implemented (Everhart, 2011). To date, the SDIS is the only comprehensive sleep screening instrument that was designed and validated for use in a school setting. Current behavioral and social-emotional assessments utilized by school psychologists include an average of two items that address sleep concerns (Sakakini, Braverman, & Terjesen, 2012). Additionally, sleep problems are often mistaken for learning problems, poor motivation, lack of interest, or attention-deficit hyperactivity disorder (Sadeh, Raviv, & Gruber, 2000). Although school psychologists have knowledge and training in pediatric sleep disorders, school psychologists must communicate and collaborate with other professionals, such as pediatricians, in order to provide sleep disorder interventions that meet the ecological needs of the child (e.g., social-emotional, environmental, sociocultural). Furthermore, the identification of

sleep disorders would likely be more effective if it occurred prior to a child starting school. Identifying sleep problems during early developmental evaluations in primary care settings would ensure timely identification, referral, and treatment of sleep disorders well before the child reaches school-age. A child will likely be examined by a pediatrician several times throughout their early years before entering school and meeting a school psychologist. For this reason, general pediatricians working in primary care settings may be more appropriate professionals to identify sleep problems in a timely manner, while school psychologists may be better suited to serve as a liaison between medical and educational systems in order to provide comprehensive care for children.

### **Necessity of Managing Sleep Problems in Pediatric Primary Care**

The research previously described in this chapter illustrates the critical need for screening and identification of sleep problems in children with ASD. The negative impact which untreated sleep disorders have on mood, self-regulation, attention, concentration, learning, and physical health are some of the most serious reasons to manage sleep disorders in primary care, particularly in children with ASD. Research suggests “parents and pediatricians agree that there are unmet needs related to associated medical and psychiatric conditions in children with ASD” (Carbone et al., 2013, p.969). The number of trained pediatric sleep providers has significantly increased in the last decade. Despite this increase, the pediatric sleep medicine subspecialty remains one of the lowest certified. Between 2007 and 2015, the American Board of Pediatrics certified 274 sleep subspecialists compared to 775 developmental-behavioral specialists, and over 115,000 pediatricians in the United States (American Board of Pediatrics, 2015). In addition, research indicates that sleep specialists are likely to practice in academic settings, typically located in large urban areas, which may limit the availability of providers to a

significant portion of the general population (Honaker & Meltzer, 2016). Despite the lack of access to pediatric sleep specialists, there are alternative ways to identify pediatric sleep disorders. Pediatric primary care settings are a natural place for screening and management of sleep problems, given the regular access pediatricians have to young children (Mindell & Owens, 2015). Further, children with ASD have been found to visit their pediatrician more frequently than typically developing children (Gurney, McPheeters, & Davis, 2006). The following section explains how sleep problems can be addressed early in a child's development in pediatric primary care settings, and how comprehensive care of these children can be established through collaboration with other professionals.

### **Best Practices in Managing Sleep Problems in Pediatric Primary Care**

**Practice Guidelines.** The American Academy of Pediatrics (AAP) published several resources, including *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents*, which equips general pediatricians with essential background information and recommendations critical to healthy child development, including guidelines for screening and treating autism. The “Bright Futures” resource recommends sleep screening in young children and provides trigger questions for sleep problems which can be used during well-child visits (Hagan et al., 2017). In addition, the American Academy of Sleep Medicine (AASM) have disseminated practice guidelines and position statements related to pediatric sleep. In particular, the AAP issued a statement supporting the AASM guidelines on recommended sleep duration for children and adolescents (Paruthi et al., 2016). In 2002, the AAP published a set of evidence-based guidelines recommending that screening for snoring should occur during all well-child examinations (American Academy of Pediatrics, 2002). More recently, the AAP published a revised set of guidelines on this topic for the purpose of increasing pediatric primary care

physicians' recognition and diagnostic techniques of pediatric OSA, as well as to provide evidence-based treatment options (Marcus et al., 2012). Although this publication illustrates an awareness of the negative consequences of OSA on typically developing children, the guidelines do not address children with disabilities such as ASD, nor is there evidence to show that the guidelines are adhered to. Specifically, one study that reviewed 1,032 electronic charts of children ages 4 to 17 years presenting to 17 pediatricians for well-child exams found that 24% of children, or their caregivers, were asked a snoring-related question. Of those children, 34% responded affirmatively. Although 30% of those children were referred for further evaluation or treatment, 62% received no further evaluation, and 0.5% were diagnosed with OSA (Erichsen et al., 2012). Erichsen and colleagues (2012) indicate that the low-frequency of sleep screening could possibly confirm that adherence to AAP guidelines regarding OSA screening and treatment is low.

Several researchers have attempted to address the lack of professional guidelines within this population. The Autism Treatment Network (ATN) published a "clinical practice pathway" aimed at increasing awareness of the need for sleep screening with this population, as well as to provide a framework of best practices for pediatricians to reference while working in primary care settings. The ATN Sleep Committee advocates screening for insomnia occur in all patients with ASD. If treatment is necessary, behavioral interventions such as parent education should be considered first line of treatment. Further, pharmacologic agents may be useful on an individual basis, and the effectiveness and tolerance of treatments should be measured through follow-up. The practice pathway report was published in *Pediatrics*, the official journal of the AAP (Malow et al., 2012).

**Assessment.** Sleep assessments can be classified as an objective or subjective measure. Objective measures directly assess sleep habits through the use of various technologies, yet present unique challenges for children with ASD. Polysomnography (PSG) can be troublesome for children with sensory issues or difficulties with change, as PSG involves the attachment of several electrodes to the child's face and scalp during treatment in an unfamiliar, laboratory setting (Moore, Evans, Hanvey, & Johnson, 2017). In contrast, subjective measures (e.g., sleep screening tools), which use history-taking and parent report questionnaires to identify sleep problems, are an efficient and cost-effective way to inform clinical practice (Armstrong, Rowe, & Kohler, 2015). However, sleep screening tools are not without limitations. Although sleep screeners are economical and user-friendly, few have adequate psychometric properties. More specifically, few instruments have been validated for the ASD population (Malow et al., 2009; Spruyt & Gozal, 2011). Additionally, some researchers have found that parent reports of sleep problems on sleep questionnaires are not consistently associated with results of objective measures, suggesting that some parents may over or under report sleep issues based on how problematic they perceive the sleep disturbance (Hodge et al., 2012). Nonetheless, several researchers have indicated that subjective measures are appropriate and useful in the screening and identifying sleep problems during well-child visits (Bauer & Blunden, 2008; Hodge, Parnell, Hoffman, & Sweeney, 2012). The following sleep screening tools are brief, user-friendly, and widely used in primary care settings, particularly with children with ASD.

***Sleep Screening Tools.*** The Children's Sleep Habits Questionnaire (CSHQ; Owens; Spirito, & McGuinn, 2000) is a sleep instrument used to assess parent-reported problems in typically developing children ages 4-10 years. However, in recent years, it has become the most widely used standardized screening instrument to identify symptoms of sleep disorders in the

ASD population (Goodlin-Jones, Tang, Liu, & Anders, 2008; Hodge et al., 2012; Malow et al., 2006; Souders et al., 2009). The CSHQ contains 33 items categorized into 8 subscales: “Bedtime Resistance”, “Sleep Onset Delay”, “Sleep Duration”, “Sleep Anxiety”, “Night Wakings”, “Parasomnias”, “Sleep Disordered Breathing”, and “Daytime Sleepiness”. The psychometric properties were evaluated with 469 children with diagnosed sleep disorders in a community and clinical sample. Results indicated adequate internal consistency (Owens et al., 2000). The CSHQ has been translated and evaluated in Dutch (Waumans et al., 2010), Chinese (Li et al., 2007), Portuguese (Silva, Silva, Braga, & Neto, 2014), German (Schlarb et al., 2010), Persian (Fallahzadeh, Etesam, & Asgarian, 2015), and Spanish (Lucas-de la Cruz et al., 2016), as well as for children with behavioral sleep problems (Bonuck, Goodlin-Jones, Schechter, & Owens, 2017). Of note, a recent study that examined the psychometric properties with 310 children ages 2-10 years with ASD found that a modified version of the scale, obtained using a principle component analysis, indicated poor to strong internal consistency, suggesting the scale should be used with caution when identifying sleep problems in children with ASD.

The Family Inventory of Sleep Habits (FISH; Malow et al., 2009) is an instrument that was designed to measure healthy sleep habits in children with ASD. The FISH is a 12-item scale which addresses “daytime habits”, “pre-bedtime habits”, “sleep environment”, “presence of a bedtime routine”, and “parental behaviors”. Parents report how often each item is ‘true’ (never-1; occasionally-2; sometimes-3; usually-4; always-5) within the previous month. The psychometric properties of the FISH were evaluated with 157 children ages 3 to 10 years. Results indicated high test-retest reliability for children with ASD (0.82) and below adequate internal consistency (.61) (Malow et al., 2009). The internal consistency suggests that the items on the FISH do not measure a single construct; however, as noted by several researchers, questionnaire items related



to sleep hygiene may represent a variety of factors that are independent and unrelated to one another (Malow et al., 2009; Mastin et al., 2006). Construct validity was supported between the FISH and the CSHQ, a previously established measure of sleep behaviors (Malow et al., 2009; Owens et al., 2000). These findings suggest that the FISH may be a reliable instrument for measuring healthy sleep habits in this population of children.

The BEARS (“B = Bedtime Issues, E = Excessive Daytime Sleepiness, A = Night Awakenings, R = Regularity and Duration of Sleep, S = Snoring”) is a simple instrument developed by Owens and Dalzell (2005) to assess for symptoms of sleep disorders during routine examinations. The five subscales on the BEARS include: “Bedtime Problems”, “Excessive Daytime Sleepiness”, “Awakenings During the Night”, “Regularity and Duration of Sleep”, and “Snoring”. This instrument provides pediatric providers with a list of simple questions (e.g. yes or no) that can be quickly asked to parents. Owens and Dalzell (2005) examined the validity of the BEARS by comparing the use of the BEARS form with a standardized well-child documentation form. BEARS forms were included in 195 children’s medical records, ages 2 to 12 years that presented for a well-visit over a 5 month period. Data were compared with a historical control group (pre-BEARS), which involved the examination of the clinic’s standardized well-child documentation form of the subject’s prior well-child visit. Problems related to sleep that were documented in medical records during the BEARS visit, as well as the pre-BEARS visit, were coded to indicate whether or not a sleep problem was identified and addressed. Results indicated that the BEARS visits included significantly more documentation and identification of sleep problems than the pre-BEARS visits, and suggest that the BEARS is an efficient tool for collecting information and identifying sleep concerns during well-child examinations.

**Treatment.** The proper identification of sleep problems in the ASD population is extremely important given the detrimental effects inadequate sleep has on daytime functioning and behavior. Treatment may not only improve child and family outcomes, but may also reduce the severity of symptoms related to ASD (Malow et al., 2012). Although there is sufficient literature on the importance of sleep disorder treatment, research on the efficacy of sleep-related interventions are limited. The following section outlines the current literature on the use of behavior management and pharmacological agents to manage sleep problems.

***Behavioral Interventions.*** There are currently no behavioral interventions for sleep concerns that meet the criteria outlined by Chambless et al., 1998 as “well-established” or “probably efficacious” with the population of ASD children. However, two methods, standard extinction and scheduled awakenings, have been classified as “possibly efficacious” (Schreck, 2001; Vriend et al., 2011). Although research on the management of sleep problems with the ASD population is limited, the use of sleep-related behavioral interventions in typically developing children is highly effective (Mindell, et al., 2006). Because the behavior problems of children with ASD are manageable by behavioral interventions, some experts have suggested that behavioral problems related to sleep are likely treatable by these same methods (Hall, 1997; Vriend et al., 2011).

***Sleep Hygiene.*** Sleep hygiene includes healthy habits such as a consistent bedtime routine, minimal use of stimulating activities or beverages before bedtime, and having a dark and quiet place to sleep. Most behavioral sleep interventions incorporate some form of sleep hygiene (Vriend et al., 2011). According to sleep intervention research, sleep hygiene alone is not effective enough in extinguishing sleep disorder symptoms in children with ASD, but has been shown to be an effective component to more intensive behavioral treatments (Piazza, Fisher, &

Sherer, 1997; Vriend et al., 2011; Weiskop, Richdale, & Matthews, 2005). Moreover, school-based sleep education programs that target sleep hygiene have been associated with improved sleep and academic performance in typically developing children (Gruber, Somerville, Bergmame, Fontil, & Paquin, 2016).

*Standard Extinction.* Standard extinction is the practice of ignoring inappropriate or unwanted behavior. Parents are instructed to implement a scheduled bedtime routine and ignore all disruptions from the child that deviate from that routine such as a child crying, whining, or leaving the bedroom. Standard extinction has been shown to decrease night wakings in young children that are diagnosed with ASD (Weiskop, Richdale, & Matthews, 2005). Moreover, the use of standard extinction has been classified as “possibly efficacious” with this population (Schreck, 2001; Vriend et al., 2011).

*Scheduled Awakenings.* Scheduled awakening is a technique used by parents of children who experience night terrors. It involves parents waking up their child about 30 minutes prior to a typical night terror episode and consoling them back to sleep. Scheduled awakenings are effective in treating night terrors in typically developing children (Durand & Mindell, 1999). Durrand (2002) recently discovered that scheduled awakenings are also effective for treating night terrors in children with ASD, and has been classified as a “possibly efficacious” intervention (Vriend et al., 2011).

*Faded Bedtime, Chronotherapy, and Stimulus Fading.* Faded bedtime involves parents systematically starting bed time earlier every night while maintaining the same wake time each morning in order to set a desired bedtime. This procedure is beneficial for children with ASD with regard to initiating and maintaining sleep (Christodulu & Durand, 2004). Although several researchers have supported the use of faded bedtime with the ASD population, this intervention

is not identified as “efficacious” or “possibly efficacious”, due to the lack of rigorous methodological design (Vriend et al., 2011). Chronotherapy involves parents systematically delaying bedtime until the child is back to a normal sleeping schedule. One case study was found that investigated the use of chronotherapy as an intervention for sleep disorders in children diagnosed with ASD (Piazza, Hagopian, Hughes, & Fisher, 1998). More research on the use of chronotherapy is needed to determine if it meets criteria as an “efficacious” or “possibly efficacious” sleep treatment for children with ASD (Vriend et al., 2011). Stimulus fading targets co-sleeping, the practice of a child sleeping in close proximity to their parent (Dunn, 2017). Stimulus fading targets problems of co-sleeping and involves gradually increasing the distance of the child and parent until the child is out of the room. One case study was found that investigated the use of stimulus fading for children with ASD (Howlin, 1984). Although this study demonstrated a reduction of co-sleeping, there is not enough research in the current literature to classify stimulus fading as an “efficacious” treatment (Vriend et al., 2011).

***Pharmacological Agents.*** Pharmacological agents (e.g., prescription and over-the-counter medications) can be used to manage sleep problems in children diagnosed with ASD, specifically when behavioral interventions are not effective or only lead to partial response (Cortesi et al., 2010). Nevertheless, research on the usefulness of pharmacologic agents as sleep interventions in all children is limited (Bruni & Novelli, 2010; Owens et al., 2005). Furthermore, given the neurological nature of autism, children that experience adverse side effects of the medication may not be able to communicate their discomfort (Armstrong, Rowe, & Kohler, 2015).

***Melatonin.*** Melatonin treatments for this population are of interest to researchers and clinicians because of the irregular melatonin production in children with ASD (Leu et al., 2011).

Several experts have supported the use of melatonin for children with ASD (Malow et al., 2012; Wasdell et al., 2008). These researchers discovered that melatonin was effective at improving daytime behaviors, increasing sleep onset, and decreasing sleep disturbances. Moreover, the use of melatonin is widely accepted by parents (Harrington et al., 2006).

**Interdisciplinary Collaboration with Other Professionals.** The etiology of sleep disorders is complex, and the appropriate assessment, management, and/or treatment can potentially involve many specialties (e.g., pediatrics, psychiatry, neurology, psychology, dentistry, surgery). For example, restless leg syndrome is a neurological disorder, OSA is a pulmonary disorder, and insomnia in young children is a behavioral disorder. In addition, children with sleep problems often have comorbid medical (e.g., obesity, asthma) and psychiatric (e.g., anxiety) issues. For this reason, it is important for pediatricians to collaborate with professionals of different disciplines to manage pediatric sleep disorders (Meltzer, Moore, & Mindell, 2008; Wiggs, 2003).

The term collaboration involves several types of interactions. Collaboration refers to the ongoing, bi-directional sharing of information between two or more professionals that is aimed at problem solving on behalf of a patient (Bradley-Klug et al., 2010). The AAP recognizes the importance of collaboration among the major systems (i.e., families, schools, healthcare) in children's lives (AAP, 2000; 2001), particularly with respect to children with comorbid medical concerns.

***Collaboration with Educational Professionals.*** Although the call for collaboration across fields is not new (APA, 1995; APA Practice Organization, 2009; NASP, 1995; The Preventive Health Amendments of 1992), recent policies and position statements have called for the establishment of routine medical and educational collaboration. In order to promote healthy

behavior among children, medical and educational professionals must collaborate in a consistent fashion (DuPaul, 2011). The AAP recommends that physicians become systems level leaders in the development and implementation of services for children with chronic medical conditions, as well as seek representation on local interagency committees that oversee educational placement (American Academy of Pediatrics Council on Children With Disabilities, 2007).

School psychologists have the unique opportunity to advance collaboration between educational and medical systems. School psychologists receive training in problem-solving and consultation (Bradley-Klug et al., 2010). Further, school psychologists with additional training in pediatric school psychology are prepared to support children with chronic health conditions in school settings, and can proficiently serve as a liaison between systems in order to provide comprehensive care for children (Bradley-Klug & Armstrong, 2014). Additionally, school nurses and social workers are professionals that can provide valuable assistance in implementing case management and care coordination activities.

### **Current Practices in Managing Sleep Problems in Pediatric Primary Care**

**Prevalence of Sleep Disorder Diagnosis and Treatment.** Despite the recent publications and guidelines aimed at increasing the awareness of the need for sleep screening, many researchers have consistently reported a low incidence of sleep disorder management in primary care settings (Chervin, Archbold, Panahi, & Pituch, 2001; Faruqui, Khubchandani, Price, Bolyard, & Reddy, 2011; Meltzer, Johnson, Crosette, Ramos, & Mindell, 2010; Meltzer, Plaufcan, Thomasodi, & Mindell, 2014; Owens & Dalzell, 2005; Smedje, Broman, & Hetta, 1999). The following section briefly describes the findings from this research.

Chervin and colleagues (2001) investigated the frequency that sleep problems were addressed, diagnosed, and managed at two general pediatric clinics. Participants included parents

of young children ages 2 to 13 years who presented for previously scheduled clinic appointments. While waiting for appointments, the clinic requested that parents complete the Pediatric Sleep Questionnaire (PSQ). A total of 86 typically developing children ages 2 to 13 years with sleep disorder symptoms identified by the PSQ participated in the study. Medical records from the previous two years were then used to investigate the frequency that sleep disturbances were addressed in that particular set of children. Results indicated that sleep concerns were documented in less than 15% of medical records. In addition, sleep diagnoses were documented for two of the 86 patients and no recommended sleep interventions were noted. The results of this study suggest that pediatricians rarely address, diagnose, or manage sleep disorder symptoms in young children. Limitations of this study were that data were collected only at two general pediatric clinics. In addition, the numbers used to identify participants with sleep problems reflect the protocol used and not necessarily the prevalence of sleep problems.

Meltzer and colleagues (2010) identified a sleep disorder diagnosis rate of 3.7% of a sample of 154,975 patients from birth to 18 years. Notably, younger patients with a comorbid diagnosis of ASD received more sleep disorder diagnoses than typically developing children in the study. In a subsequent study, researchers reviewed the records of 750 randomly selected participants from the Meltzer and colleagues (2010) sample from 2007 through 2010 in order to determine the frequency of sleep treatment recommendations (Meltzer et al., 2014). Meltzer and colleagues (2014) found that treatment was recommended to 8% of patients who presented with a sleep disorder (e.g., obstructive sleep apnea), and 2% of patients with documentation of a sleep concern (e.g., bedtime problems). Of those who received a treatment recommendation (n=26), 41 recommendations were documented. A little more than half were recommended a behavioral intervention or strategy, 34% were referred for further evaluation, 7% were recommended to

continue to monitor the problem, and 7% were given a general discussion of the sleep issue.

Limitations of this study include the possibility that sleep recommendations were provided, but not documented in patient medical records.

**Knowledge, Training, Current Practices, and Perspectives.** Research on the knowledge and training of general pediatricians with regard to pediatric sleep management has been documented for quite some time. In 1994, a study that investigated the training, knowledge, and practices among pediatricians related to sleep disorders found significant gaps in training and clinical practice. Mindell and colleagues (1994) developed a brief survey which was sent to 215 residency programs across the United States. A total of 156 programs responded. Results of this study indicated that pediatricians received, on average, 4.8 hours of training related to sleep disorders. In a second study within this publication, 88 practicing pediatricians completed a survey regarding their knowledge of pediatric sleep disorders. The results suggest that pediatricians have more knowledge on sleep hygiene and developmental aspects of sleep than they do parasomnias, such as night terrors; however, the average total knowledge score was 72%, indicating a lack of knowledge about specific sleep disorders. In a third study, 183 pediatricians completed a questionnaire on their actual practices regarding pediatric sleep problems. As a whole, pediatricians in this sample reported that approximately one quarter of their patients experience symptoms of sleep disturbance. The majority of the sample endorsed recommending behavioral interventions such as establishing a bedtime routine (95%) and letting the child cry (85%). Few pediatricians (15%) recommended pharmacologic treatments such as antihistamines. Furthermore, almost half of the sample (49%) indicated they inform parents that their child is likely to outgrow their sleep problems. The results of this study suggest that pediatricians encounter sleep problems during well-child exams on a frequent basis. Altogether,



these three studies suggest a need for improved education in the area of pediatric sleep, and increased updates on advances in the field for practicing pediatricians (Mindell et al., 1994).

In a similar study, a 42-item cross-sectional survey was sent to 2,740 community-based and academic general pediatricians in the Southern New England region in order to determine knowledge, screening, assessment, and intervention practices. A total of 828 surveys were completed and returned. On the knowledge section, which included 30 true/false items, 24% of the sample responded correctly to less than half of the items. Items that were scored correctly were related to behavioral characteristics of sleep, which is consistent with Mindell and colleagues' (1994) study. With regard to sleep screening, 26% of the sample reported they routinely ask snoring-related questions. In contrast, the majority of pediatricians in this sample (80%) endorsed that they routinely inquire about methods of falling asleep when presented with a toddler with frequent night wakings, and 63% agreed that they would discuss parental discipline when presented with a preschooler with bedtime resistance. When presented with a sleep complaint of OSA, 53% indicated they never refer children to a sleep study or a sleep specialist, and more than half (64%) reported they refer children with such symptoms directly to an otolaryngologist. In terms of treatment practices, the majority of pediatricians in this sample (90%) endorsed recommending graduated extinction for toddlers with frequent night wakings. Responses to treatment recommendations for children with night terrors were less appropriate, with 43% recommending psychological evaluation. These results suggest that pediatric providers may have little understanding of sleep disorders, which is consistent with previous research (Mindell et al., 1994). Findings from this survey also suggest that sleep screening rarely occurs in a pediatric setting, despite the recognition of the effects these disorders have on children.

Overall, this study documents significant gaps in knowledge, as well as clinical practice of managing pediatric sleep problems and sleep disorders (Owens, 2001).

Faruqui and colleagues (2011) recently examined pediatrician knowledge, training, and practices related to sleep across the nation. A random sample of AAP pediatricians were sent a 15-item, closed-format survey on sleep problems in children. Out of the 700 who were sent the survey, 346 responded. The majority of the sample (96%) reported giving advice on sleep hygiene as part of their job responsibilities; however, only 18% experienced formal training on sleep disorders. Of those who received training, scores on the knowledge assessment were significantly higher, as well their perceived confidence. Less than a fifth of the sample (19%) answered half or more of the knowledge questions correctly and fewer than 15% endorsed being confident in their ability to counsel children and families regarding sleep issues. Similar to the findings of Mindell and colleagues (1994) and Owens (2001), results of this study indicate a low level of knowledge on pediatric sleep disorders among pediatricians. Limitations of this study were that the survey design (e.g., closed-format) may have left out relevant sleep questions, thus possibly affecting the validity of the results.

**Pediatrician Perspectives on Meeting the Needs of Children with ASD in Primary Care.** Although a few studies have documented the current practices of pediatricians regarding sleep management of children in general, this thesis project is the first to investigate the current sleep practices specific to children with Autism. However, some studies have investigated the perspectives of pediatricians with regard to primary care for children with a ASD (Carbone et al., 2010; Carbone et al., 2013; Golnik, Ireland, and Borowsky, 2009). Golnik and colleagues (2009) surveyed 449 pediatricians and 90 family physicians in order to assess their perspectives and experiences of caring for children with ASD. Results from this study suggest that physicians feel

less competent working with patients with ASD than they do with patients of typical development, and patients with other neurodevelopmental disabilities. Identified barriers to providing primary care to this population included a lack of practice guidelines, insufficient time during office visits, and lack of reimbursement. Carbone and colleagues (2013) conducted a study in which 144 parents of children with ASD and 144 pediatric primary care physicians completed surveys which indicated the areas that pediatricians are most able to address including gastrointestinal and feeding problems, ADHD, anxiety, and sleep problems. Slightly more than half of the pediatricians (54%) and 44% of parents perceived the ability of pediatricians to address sleep problems as excellent, very good, or good. Despite these relatively low ratings, “ability to address sleep problems” was ranked third highest by parents and fourth highest by pediatricians out of nine ASD-associated symptom categories, with “ability to address gastrointestinal problems” as the highest and “ability to address aggressive behaviors” as the lowest. The results of this study identify several areas of practice that can be improved when working with children who have a diagnosis of ASD. Limitations of this study were that parents were recruited from schools that are exclusive to the ASD population; therefore, these parents may have perceptions of pediatricians that differ from other parents. Additionally, the pediatricians and parents that participated in the survey did not have a provider-patient relationship, therefore the perspectives of one may not apply to the other.

**Facilitators to Managing Sleep Problems in Pediatric Primary Care.** Formal education on sleep hygiene and sleep disorders has been documented as a variable that significantly affects the likelihood of pediatricians appropriately managing sleep disorders in children (Faruqui et al., 2011; Mindell et al., 1994; Owens, 2001). Other facilitators which have been found to significantly increase sleep management practices in primary care settings are

short screening tools placed in all patient medical records (Owens & Dalzell, 2005) and having access to a published practice pathway (Malow et al., 2012). The following section outlines this research.

***Access to Screening Tools.*** Based on the previously described study by Owens and Dalzell (2005), the BEARS screening tool appears to be an effective and user-friendly tool for collecting information and identifying pediatric sleep problems. Owens and Dalzell (2005) examined the validity of the BEARS by comparing the use of the BEARS form with a standardized well-child documentation form. BEARS forms were included in 195 children's medical records, ages 2 to 12 years that presented for a well-visit over a 5 month period. Data were compared with a historical control group (pre-BEARS), which involved the examination of the clinic's standardized well-child documentation form of the subject's prior well-child visit. Problems related to sleep that were documented in medical records during the pre-BEARS visit and in the BEARS visit were coded to indicate whether or not a sleep problem was identified and addressed. Results indicated that the BEARS visits included significantly more documentation and identification of sleep problems than the pre-BEARS visits, suggesting that sleep screening tools (i.e., BEARS) are more likely to be utilized when access to them is provided.

***AAP Practice Pathway.*** The clinical practice pathway that was previously described in this chapter by Malow and colleagues (2012) has provided medical professionals with guidelines for identifying and managing symptoms of insomnia in youth with ASD. Specifically, the practice pathway provides a framework to assist pediatricians in evaluating the impact of a variety of factors on insomnia. Further, the practice pathway informs pediatricians of the effectiveness of behavioral and pharmacologic treatment strategies. Several barriers to identification of sleep problems were identified in the process of piloting the practice pathway,

such as competing demands on pediatric providers in busy clinical practices and degree of knowledge of the physician. Based on the identified barriers, the researchers developed tools such as screening questionnaires for insomnia in the form of a checklist. In addition, a sleep education toolkit was created to facilitate parent teaching (Malow et al., 2012).

**Barriers to Managing Sleep Problems in Pediatric Primary Care.** Although several resources have been recently developed in order to facilitate sleep screening, much of the existing literature identifies the barriers that prevent pediatricians from addressing sleep problems in primary care settings. The following section provides a brief overview of this research.

***Pediatrician Perceptions of Barriers.*** In the study by Faruqui and colleagues (2011) previously described in this chapter, few pediatricians acknowledged the existence of barriers to identifying sleep concerns with the use of a screening tool. Of the 346 providers who responded to the survey, 147 reported a barrier to sleep screening. Forty-three percent of participants believed “that parents will indicate if there is a [sleep] problem anyway, even without screening” (Faruqui et al., 2011, p. 543). Similarly, Owens (2001) found that one of the most common reasons for the absence of sleep screening included the notion that parents would communicate a sleep concern, regardless of whether or not a sleep disorder screening tool was used. Other common barriers from both of these studies included insufficient time during well-child visits, other health concerns need to be discussed, and the lack of knowledge about sleep problems (Faruqui et al., 2001; Owens, 2001).

***Pediatrician Education and Training on Pediatric Sleep.*** In the previously described study conducted by Mindell and colleagues (1994), the results of a survey completed by 156 pediatric medicine residency programs indicate that pediatricians received, on average, 4.8 hours

of training related to sleep disorders. More specifically, 85 programs offered formal didactic instruction, while 71 programs did not. Of these 85 programs, 93% offered less than 10 hours of instruction. By contrast, two programs offered more than 60 hours. The study conducted by Faruqi and colleagues (2011) suggest similar results. Results of the 15-item survey completed by 346 general pediatricians indicate that very few pediatricians receive formal training on sleep problems and sleep disorders.

Mindell and colleagues (2013) investigated the international prevalence of sleep education in pediatric residency programs. More specifically, they surveyed 152 pediatric residency directors across 10 countries. Results of this study indicated that, on average, 4.4 hours of pediatric residency is spent on sleep education. Moreover, 23% of the sample responded that their program does not provide any sleep education. Prior to this study, Mindell and colleagues (2011) conducted a similar study which identified the prevalence of sleep education in 106 medical school programs across 10 countries. Similar to Mindell and colleagues' pediatric residency study (2013), findings suggest that training and education on pediatric sleep is very limited, with under 2.5 hours of education spent on sleep. Further, 27% of the sample responded that their medical school does not provide any sleep education. Reported barriers to providing sleep education from both of these studies included not having enough time, insufficient resources and qualified staff, and the belief that sleep education was not relevant or a priority (Mindell et al., 2011; Mindell et al., 2013).

***Pediatrician Knowledge on Pediatric Sleep.*** At least four studies have documented that pediatricians have more knowledge on the developmental aspects of sleep than specific sleep disorders (Bruni et al., 2004; Faruqi et al., 2011; Mindell et al., 1994; Owens, 2001). In addition, Faruqi and colleagues (2001) found that total knowledge scores were negatively

correlated with perceived barriers. Moreover, pediatricians who were formally trained on pediatric sleep obtained scores significantly higher than those without formal training.

One study specifically examined pediatrician knowledge of OSA in Turkey. A total of 138 pediatricians, 70 general practitioners, and 21 pulmonologists from different districts of Istanbul completed an 18-item true/false questionnaire designed to measure the level of knowledge that providers have on pediatric OSA. The average knowledge score was 67%, which is consistent with previous findings of general pediatric sleep knowledge. Furthermore, total OSA knowledge scores were positively correlated with having subspecialty training in sleep. Results of this study further confirm the existence of physician deficits in childhood sleep, with particular regard to OSA (Tamay et al., 2006). In a similar study, Owens (2001) found that pediatricians who were more recently trained appeared more knowledgeable on pediatric OSA.

***Pediatrician Confidence related to Pediatric Sleep.*** Of the 828 pediatricians who completed the survey conducted by Owens (2001), less than half (46%) endorsed being “confident in their ability to *screen* for sleep problems”, 34% felt “confident in their ability to *evaluate* sleep problems”, and 25% felt “confident in their ability to *treat* sleep disorders” (p.6). Similarly, Faruqui and colleagues (2011) found that 57% of the 346 pediatricians who responded to the survey felt “confident in their ability to screen for sleep problems”, and 63% endorsed being “confident in their ability to manage and refer children with sleep problems” (p.544). Providers with training on pediatric sleep perceived higher confidence scores at a statistically significant level. Additionally, confidence scores were negatively associated with the barriers, and positively correlated with knowledge scores.

Boreman and colleagues (2007) developed a national survey to assess the perceived confidence of pediatricians with regard to diagnosing and treating a variety of

developmental/behavioral conditions, including sleep disorders. A total of 334 pediatricians completed the 24-item questionnaire. Results indicate several domains that pediatricians feel uncomfortable working on, including “general behavior problems, learning disabilities, depression/anxiety, language disorders, and sleep problems” (Boreman et al., 2007, p.143). Not only did participants feel unprepared to manage these domains, but they indicated a high level of occurrence. More specifically, sleep disorders were identified as the 11<sup>th</sup> most relevant disorder in primary care practice out of 28 conditions.

In a similar study, David and colleagues (2012) surveyed 70 pediatricians in Kentucky in order to assess comfort level with diagnosing and treating behavioral disorders during well-child examinations. Of particular interest are the responses to questions which inquired specifically about behavioral sleep problems. Results showed that the majority of the pediatricians in the sample (94%) encounter sleep behavior problems in primary care at least monthly. In addition, 77% of the pediatricians felt comfortable diagnosing sleep behavior problems, and 59% felt comfortable treating these problems. The findings from these studies suggest a relatively low level of perceived confidence among pediatricians when addressing pediatric sleep problems.

***Caregiver Reporting of Sleep Problems.*** A common barrier identified by pediatricians is the assumption that parents will indicate a sleep problem, regardless of whether sleep screening occurs (Faruqui et al., 2011; Owens, 2001). Several studies have examined this area of research more closely (Blunden et al., 2003; Blunden et al., 2004; Owens & Jones, 2011; Stein, Mendelsohn, Obermeyer, Amromin, & Benca, 2001). In particular, Blunden and colleagues (2004) investigated the frequency of sleep disturbances in 361 children ages 4 to 16 years in Australia. Parents who presented with their child for a sick visit were asked to participate in the study by completing the Sleep Disturbance Scale for Children (SDSC), and to report if they ever



mentioned sleep problems to their child's pediatrician. Results showed that 25% met criteria sleep disorder, yet 4% of parents mentioned a sleep concern to their child's pediatrician. Moreover, 14% of the parents of children with identified sleep disorder symptoms discussed these problems with their pediatrician within the last year. Findings indicate that sleep-related concerns in Australian children are underreported by parents in primary care settings.

A study by Owens and Jones (2011) investigated a group of parents' current practices and attitudes regarding healthy sleep in a hospital-based clinic. Parents (n=184) of children ages 3 months to 12 years completed a brief survey. Results showed that 42% of parents did not enforce consistent bedtimes, 76% allowed an in-room television, and 69% regularly co-sleep with their child. These findings suggest that parents of young children may be in need of increased sleep education regarding healthy practices.

## **Conclusion**

Considering the benefits of early identification of childhood sleep problems, the substantial amount of literature on the limited training pediatric providers receive on sleep disorders, as well as the availability of psychometrically sound instruments for measuring sleep, the current study aimed to collect data from pediatricians to investigate their current practices and perceptions on screening, assessing, and treating sleep problems in children with ASD in primary care settings. Managing sleep disturbances in primary care settings may potentially counteract some of the secondary consequences of sleep disturbances such as disruptive behaviors, lack of attention, and learning problems (Moore et al., 2017). Identifying sleep disorders at an early age is likely to increase favorable daytime behaviors and also may have a positive impact on family functioning (Cortesi, 2010). Moreover, this study provides a unique contribution to the literature, as it is the first survey of pediatricians' perceptions of facilitators to

screening for sleep problems in children with ASD. Understanding the current practices of pediatricians may potentially lead to improved outcomes and increased interdisciplinary collaboration on behalf of this population of children.

## **Chapter Three**

### **Methods**

This study investigated the current practices of pediatricians with regard to managing sleep problems in children ages 2-10 years with ASD in primary care settings. This study aimed to pilot test the PSM-ASD survey in order to gather more information on the sleep management practices of pediatricians, as well as to identify strategies for maximizing outcomes for children with ASD. Based on a potentially small sample size, the PI and thesis committee decided to open the survey to all pediatric providers who interact with children ages 2-10 years with ASD. The methods used to collect and analyze data are described in this chapter and outlined as follows: (1) description of instruments developed for the survey; (2) analyses necessary for survey validation; (3) description of participants; (4) description of the data collection procedures; and (5) review of the data analysis plan.

#### **Instrumentation**

A cover letter was used to explain the purpose and importance of the study, and an online survey was used to obtain information concerning the identification and treatment of sleep disorder symptoms in children ages 2-10 years with ASD in pediatric primary care settings. The following section provides information on these two instruments (i.e., cover letter and survey).

**Survey.** The Pediatric Sleep Management of Children with Autism Spectrum Disorder (PSM-ASD) survey was developed by the primary investigator (PI) to investigate pediatricians' current practices and perceptions of screening, assessing, and treating sleep problems in children

with ASD in primary care setting. The PSM-ASD is a password protected web-based Qualtrics survey divided into five sections: current sleep screening practices, treatment of sleep problems, perceived barriers and facilitators to screening for sleep problems, perceived confidence of pediatricians with regard to screening for sleep problems, and demographic information (Appendix D). The survey consisted of 18 questions. Each section utilized Likert response and multiple choice questions. The first section of the survey collected information regarding current sleep screening practices including the frequency of sleep screening, sleep related questions asked, and screening measures utilized during well-child examinations. The second section includes questions related to the treatment of sleep problems such as which types of treatments are most frequently recommended. The third section of the survey assesses the perceived barriers and facilitators to screening for sleep problems. The fourth section assesses the perceived confidence of pediatricians with regard to screening for sleep problems and the fifth section collects demographic information of the provider such as gender, age, race/ethnicity, area of specialty, type of practice setting, and years in practice.

**Development Process.** Current literature on pediatric sleep medicine was reviewed by the PI in order to determine gaps in the research. In particular, there is very little research on the current practices of pediatricians with regard to sleep problems in primary care (e.g., Faruqui et al., 2011; Mindell et al., 1994; Owens, 2001). Moreover, no studies were found in the extant literature that examined pediatricians' current practices regarding sleep problems in primary care, with specific regard to children with ASD. Thus, the PSM-ASD survey was designed under the guidance of an expert panel comprised of dissertation committee members and practicing general pediatricians, and in concert with the recommendations of Robert DeVellis (2017) in scale development. DeVellis (2017) suggests eight specific guidelines for researchers to reference

when developing instruments. These guidelines include: “(1) determine clearly what it is you want to measure, (2) generate an item pool, (3) determine the format for measurement, (4) have the initial item pool reviewed by experts, (5) consider inclusion of validation items, (6) administer items to a development sample, and (7) evaluate the items” (pp. 105-151). All steps recommended by DeVellis (2017) were followed and are described in the following section, with the exception of Step 5 because it was not the aim of this study.

The PSM-ASD survey was developed after a comprehensive examination of professional research (e.g., academic journals, dissertations) on sleep disorders and ASD, the best practices and current practices of general pediatricians regarding sleep disorders in children with ASD, and questionnaires related to pediatrician practices. The initial item pool was modeled after similar studies that used survey methods (e.g., Faruqui et al., 2011; Friedrich, 2010, Mindell et al., 1994; Owens, 2001). Two cognitive interviews were conducted with general pediatricians in order to evaluate the clarity of the items, structure, question order, ease of completion of the survey, and response options. In addition, the survey was reviewed by a panel of experts comprised of general pediatricians, pediatric school psychology faculty members, a measurement and survey development professor, and school psychology graduate students with survey research experience. This expert panel reviewed the initial item pool numerous times. The survey was revised based on feedback from the interviews and expert panel. Specifically, changes were made to the overall organization of the survey including reducing the number of questions on the survey from 30 to 18 items.

Each item on the PSM-ASD survey followed recommendations by Dillman, Smyth, and Christian (2014) in order to ensure “that every potential respondent will be willing to answer, will be able to respond to accurately, and will interpret in the way the surveyor intends” (Dillman

et al, 2014, pp.4). All questions on the PSM-ASD survey are closed-ended. According to Fowler (1984) closed-ended questions have been shown to increase the reliability of the survey, and increase the probability of having enough analytically interesting responses from participants. The survey utilized a variety of nominal and ordinal closed-ended questions. Nominal closed-ended questions include responses in which the categories are unordered. Nominal closed-ended questions on the survey were written to follow the guidelines of Dillman and colleagues (2014). For example, forced-choice questions were developed instead of check-all-that-apply questions. Forced-choice questions require participants “to make an explicit judgement about each item independently” (Dillman et al., 2014, p.148). Research has consistently indicated that forced-choice responses result in more options being endorsed (Smyth, Dillman, Christian, & Stern, 2006). Questions on the PSM-ASD survey also included ordinal closed-ended questions. Ordinal closed-ended questions include responses where the categories have an inherent underlying order. Ordinal closed-ended questions are commonly used in surveys because of their ability to measure variations of opinions, attitudes, and behaviors (Dillman et al., 2014). Ordinal closed-ended questions on the survey were written to follow the guidelines of Dillman and colleagues (2014). For example, the length of scale responses was limited to four or five categories when possible in order to increase the likelihood of a participant being able to place themselves on the scale, and to avoid the loss of item meaning or ambiguity.

**Cover Letter.** A cover letter was developed to inform potential participants of the goals of the study, the approximate time it would take to complete the survey, and outlined the confidentiality of the study (Appendix A). In addition, potential participants were informed that the survey was voluntary and no compensation was provided for participation. The PI followed guidelines by Dillman and colleagues (2014) when creating the cover letter.

## **Field Test**

A field test was conducted prior to data collection to assess the cover letter and survey for validity and reliability. Field test participants included physicians from a university-based clinic. Potential participants were recruited by e-mail. The demographic characteristics of the field test participants are listed in Table 1.

**Validity.** The field test provided feedback on the structure, clarity, ease of completion, and time required to take the survey. In addition, the field test assessed the survey for face and content-related validity. Additionally, the cover letter was field tested to obtain feedback on the clarity and length of the letter. Following completion of the survey, field test participants were asked 7 additional questions related to the validity of the survey (Appendix B). The field test sample was comprised of 10 respondents between the ages of 20 and 59. Ninety percent of respondents indicated ‘General Pediatrics’ as their primary area of specialty and all participants held medical degree credentials. Based on these demographic characteristics, all of the field study participants were considered experts on the survey topic. Ninety percent of participants felt that the survey included all necessary and relevant topics. One participant noted that the cover letter could be improved by adding a sentence that stated how the survey intended to address the needs and strengths of pediatricians. Eighty-nine percent of field test participants indicated that the survey took them less than 8 minutes to complete. Completion time ranged from 3 to 14 minutes, with 80% completing the survey in less than 7 minutes. Participants indicated that there were no words or phrases in the survey that were incomprehensible, and that the overall organization of the survey was clear.

**Reliability.** The respondents who participated in the field test were asked to retake the survey one week later in order to determine for test-retest reliability. In order to maintain

confidentiality of responses, a separate survey opened on completion of the field test survey. This survey included one question that asked respondents if they were interested in taking the survey again one week later. This study intended to analyze these responses for test-retest reliability using Pearson correlation; however, only two respondents indicated they would be willing to retake the survey one week later. Due to the low number of respondents who chose to participate, test-retest reliability was not able to be calculated. Specifically, having only two respondents with two scores (i.e., test score and retest score) would have yielded a perfect correlation. Based on this information, the PI proposed to assess test-retest reliability via review of descriptive analysis. However, the two participants who expressed interest in participating in the test-retest survey did not submit a second survey upon email request. Therefore, test-retest reliability was unable to be calculated.

### **Ethical Considerations**

Prior to data collection of the field test and the current study, the approval to conduct the research was obtained from the Institutional Review Board (IRB) at the University of South Florida (USF). Participants were provided a cover letter, which outlined the study's research questions and risks and benefits of participation in the study. This study was considered minimal risk to participants, given that information submitted by participants was based on memory. Moreover, the identity of participants was protected. Participation in this study was voluntary. Informal consent was obtained (i.e., a participant's response to the survey was considered consent). All information gathered from the survey was kept in a confidential database.

### **Participant Recruitment and Sampling for the Current Study**

The Hillsborough County Medical Association (HCMA) is a voluntary membership organization comprised of over 1,800 allopathic (MD) and osteopathic (DO) physicians and



medical students in Tampa, Florida. The August 2018 HCMA membership directory contained 66 pediatric physicians. Because the survey was sent to the entire membership directory, the researcher carefully screened the demographic information provided by each participant in the survey in an effort to only select physicians in the pediatric fields related to this study (e.g., general pediatrics, developmental/behavioral pediatrics, pediatric psychiatry). In order to participate in the study, respondents had to be a pediatric provider, currently working in an academic or community setting. Pediatric residents and fellows were included; however, medical students were excluded.

**Response Rate.** Literature on pilot study research suggests that samples should include 10-30 participants (Hill, 1998; Issac & Michael, 1995). In particular, researchers suggest at least 12 participants for pilot studies within the medical field (Julious, 2005; van Belle, 2002). Moreover, several researchers have concluded that response rates of under 20% are not uncommon in web-based surveys completed by physicians (Dykema, Jones, Pichè, & Stevenson, 2013). Similar studies of pediatricians have reported relatively low return rates in the range of 19% to 31% (Owens, 2001; Mack, 2008). However, Faruqui and colleagues (2011) obtained a 49% response rate to a mail-based survey of general pediatricians. Based on the likelihood of a low response rate, a nonprobability sample was used.

## **Procedures**

**Survey Distribution.** All potential participants were sent an email that was created by the PI with a link to the survey and cover letter. An executive board member of the HCMA disseminated the email to current HCMA members. A brief statement describing the study and amount of time required to take the survey was included in the body of the email (Appendix C). Participants' names and email addresses were not requested to uphold confidentiality of the

study. Participants were asked to complete the survey within 14 days of receiving the first email. A second email was disseminated by the organizational leader of HCMA after 7 days to remind members of the study.

## **Demographics**

**Sample Demographic Characteristics.** The final dataset included 15 useable surveys, yielding a 23% response rate. Exactly half of the sample was between the ages of 40 and 59 years, and more than three-quarters of the sample (79%) were female. All participants indicated that they see less than 5 patients with ASD per day. Demographic characteristics of study participants are reported in Table 2. Demographic characteristics, when applicable, were compared to the demographics of a national random survey of pediatricians related to pediatric sleep disorders (Faruqui et al., 2001), in addition to the American Medical Association Physician Report (AMA, 2015), to verify that this study's sample represented the field of pediatrics. Results are presented in Table 3. Chi-square goodness of fit tests were calculated to determine if this study's sample was comparable to the AMA Physician Report and the national survey participants for gender, race/ethnicity, and age. Results are presented in Table 4. Analyses indicated that the current study sample tended to include more females than the AMA Physician Report or the national survey participants. Also, participants' age appeared to be relatively similar to the AMA Physician Report and the national survey participants. Of note, the chi square analyses for race/ethnicity had expected (i.e., what the population was presumed to be) frequencies less than five, which fails an assumption of the chi-square goodness of fit test. To address this assumption, the PI collapsed the race/ethnicity categories to Hispanic and Non-Hispanic; however, due to a small sample size, one cell still had expected frequencies less than five. Based on these results, the representativeness of the demographic category of race/ethnicity

was unable to be calculated. Of note, the sample from this study includes pediatric providers with varying credentials. While a large portion of participants (79% and 71%, respectively) held a medical degree and indicated their primary area of specialty to be general pediatrics, a small percentage of participants (28% and 21%, respectively) were from other areas and held other credentials.

### **Review of Data Analysis Plan**

All data were exported from Qualtrics into SPSS Statistics 21 (IBM Corp, 2012) by the PI. Data were analyzed using SPSS in order to address each research question. The following section explains the analyses that were used to examine each research question of the study.

*Research Question 1. What are the current practices of pediatricians with regard to detecting and addressing sleep problems in children with ASD? (a) What screening tools are used by pediatricians to screen for sleep problems during well-child exams? (b) Which treatments for sleep problems are pediatricians most likely to recommend?*

The first research question collected information on the current sleep management practices of general pediatricians in primary care settings. The frequencies of responses from survey items 1-7 and 10 were analyzed in order to answer this research question. Specifically, for items 1-6 and 10, descriptive statistics with percentages respondents endorsed (e.g., Yes or No) are reported. Question 7 on the survey asks “In general, which treatments do you recommend for sleep disorders in children ages 2-10 years with Autism Spectrum Disorder?”. Each factor was represented by the following numeric ratings: 1=*Never*, 2=*Rarely*, 3=*Sometimes*, 4=*Often*, 5=*Very Often or Always*, and N/A=*Not familiar with this treatment*. Minimum and maximum numeric ratings with confidence intervals, the mean average rating, and standard deviations for each treatment method are reported. The percentage of participants that marked N/A for this item

are reported. Lastly, Spearman correlations were computed to identify whether a relationship existed between participants' perceived barriers and perceived confidence scores.

*Research Question 2. To what extent do pediatricians perceive various factors to serve as barriers to screening for sleep problems?*

The second research question collected information on the perceived barriers of general pediatricians, specific to the process of screening for sleep issues in primary care settings. Responses to question 8 were analyzed in order to answer this research question. Specifically, question 8 asks "To what extent do you feel each of the following factors presents a barrier to your sleep screening practices during well-child examinations?". Each factor was represented by the following numeric ratings: 1= *Not a Barrier*, 2=*Slight Barrier*, 3=*Moderate Barrier*, 4=*Significant Barrier*, 5=*Extreme Barrier*, and N/A=*Have not personally experienced this factor*. Minimum and maximum numeric ratings with confidence intervals, the mean average rating, and standard deviations for each factor are reported. The percentage of participants that marked N/A for this item are reported.

*Research Question 3. To what extent do pediatricians perceive various factors to serve as facilitators to screening for sleep problems?*

The third research question collected information on the perceived facilitators of general pediatricians, specific to the process of screening for sleep issues in primary care settings. Responses to question 9 were analyzed in order to answer this research question. Specifically, question 9 asks "To what extent do you feel each of the following factors serves to enable your sleep screening practices during well-child examinations?". Each factor was represented by the following numeric ratings: 1=*Not an Enabler*, 2=*Slight Enabler*, 3=*Moderate Enabler*, 4=*Significant Enabler*, 5=*Extreme Enabler*, and N/A=*Have not personally experienced this*

*factor*. Minimum and maximum numeric ratings with confidence intervals, the mean average rating, and standard deviations for each factor are reported. The percentage of participants that marked N/A for this item are reported.

*Research Question 4. How confident are pediatricians in managing sleep issues in children with ASD?*

The fourth research question collected information on the perceived level of confidence among general pediatricians when screening and treating sleep problems in children. Responses to question 11 were analyzed in order to answer this research question. Specifically, question 11 asks “Please indicate your perceived level of confidence in managing sleep problems in children ages 2-10 years with Autism Spectrum Disorder?”. Each factor was represented by the following numeric ratings: 0= *Not Confident*, 1=*Slightly Confident*, 2=*Somewhat Confident*, and 3=*Moderately Confident*, and 4=*Extremely Confident*. Minimum and maximum numeric ratings with confidence intervals, the mean average rating, and standard deviations for each level of confidence are reported. Lastly, a confidence interval was developed around the mean numeric rating for each item.

Table 1

*Demographic Characteristics of Field Study Participants (n=10)*

Variable	Field Test Participants	
	N	%
Gender		
Female	8	80%
Male	2	20%
Age		
20 – 29 years	1	10%
30 – 39 years	4	40%
40 – 49 years	2	20%
50 – 59 years	3	30%
60 – 69 years	0	0%
> 69 years	0	0%
Race/Ethnicity		
Asian	0	0%
Black/African American	1	10%
Hispanic/Latino	1	10%
White/Caucasian	7	70%
Other	1	10%
Provider Credentials		
Doctor of Medicine (MD)	10	100%
Doctor of Osteopathic Medicine (DO)	0	0%
Doctor of Nursing Practice (DNP)	0	0%
Certified Nurse Practitioner (CNP)	0	0%
Physician Assistant (PA)	0	0%
Other	0	0%
Primary Area of Pediatrics		
Developmental/Behavioral Pediatrics	0	0%
Family Medicine	0	0%
General Pediatrics	9	90%
Other Pediatric Subspecialty	0	0%
Pediatric Pulmonology	0	0%
Pediatric Psychiatry	1	10%
Pediatric Resident	0	0%
Practice Setting		
Academia	8	80%
Community	0	0%
Academia and Community	2	20%
Number of Children with ASD seen per day		
5 or less	10	100%
6 - 10	0	0%
11 – 20	0	0%
21 - 30	0	0%
31 or greater	0	0%

Table 2

*Demographic Characteristics of Study Participants (n=14)*

Variable	N	%
Gender		
Female	11	79%
Male	3	21%
Age		
20 – 29 years	1	7%
30 – 39 years	3	21%
40 – 49 years	5	36%
50 – 59 years	2	14%
60 – 69 years	2	14%
> 69 years	1	7%
Race/Ethnicity		
Asian	0	0%
Black/African American	1	7%
Hispanic/Latino	5	36%
White/Caucasian	8	57%
Other	0	0%
Provider Credentials		
Doctor of Medicine (MD)	11	79%
Doctor of Osteopathic Medicine (DO)	0	0%
Doctor of Nursing Practice (DNP)	0	0%
Certified Nurse Practitioner (CNP)	2	14%
Physician Assistant (PA)	0	0%
Other	1*	7%
Primary Area of Pediatrics		
Developmental/Behavioral Pediatrics	1	7%
Family Medicine	2	14%
General Pediatrics	10	71%
Other Pediatric Subspecialty	0	0%
Pediatric Pulmonology	0	0%
Pediatric Psychiatry	1	7%
Pediatric Resident	0	0%
Practice Setting		
Academia	5	36%
Community	6	43%
Academia and Community	3	21%
Number of Children with ASD seen per day		
5 or less	14	100%
6 - 10	0	0%
11 – 20	0	0%
21 - 30	0	0%
31 or greater	0	0%

\*Other was reported to be 'ARNP'

Table 3

*Demographic Characteristics of Participants, National Survey Participants, and the American Medical Association Physician Report*

Variable	Current Study N=14		National Pediatrician Survey (Faruqui et al., 2011) N=346		AMA Physician Report (AMA, 2015) N=87,111*	
	N	%	N	%	N	%
<b>Gender</b>						
Female	11	79%	222	63%	50,472	58%
Male	3	21%	128	37%	36,639	42%
<b>Race/Ethnicity</b>						
American Indian/Alaskan	N/A	N/A	N/A	N/A	207	.3%
Asian	0	0%	44	13%	13,875	19%
Black/African American	1	7%	14	4%	4,776	6%
Hispanic/Latino	5	36%	21	6%	6,188	8%
White/Caucasian	8	57%	256	74%	47,040	64%
Other	0	0%	11	3%	1,531	2%
<b>Age</b>						
Under 40	4	29%	79	23%	40,887	47%
40-49	5	36%	131	38%	N/A	N/A
50-59	2	14%	84	24%	N/A	N/A
60 and Older	3	21%	52	15%	N/A	N/A

N/A indicates information that was not collected/available.

\*13,494 pediatricians did not report race/ethnicity. Percentages reflect N=73,617.

Table 4

*Chi-Square Analyses for Representativeness*

Variable	National Pediatrician Survey (Faruqui et al., 2011)		AMA Physician Report (AMA, 2015)	
	X <sup>2</sup>	P	X <sup>2</sup>	P
Gender	1.46	0.23	2.43	0.12
Race/Ethnicity	21.92**	0.00*	14.61**	0.00*
Age	0.06	0.80	1.909	0.17

\* $p < .05$ ,  $df = 1$

\*\*Due to a small sample size, race/ethnicity had an expected frequency cell less than five, which fails an assumption of the chi-square goodness of fit test. Results should be interpreted with caution.



## **Chapter Four**

### **Results**

This study explored the current practices of pediatric providers with regard to the management of sleep problems in young children with ASD in primary care settings. This study pilot tested the PSM-ASD survey to identify the sleep management practices of pediatricians. Based on a potentially small sample size, the PI and thesis committee decided to open the survey to all pediatric providers that interact with children ages 2-10 years with ASD. The final dataset included 15 useable surveys, yielding a 23% response rate. This chapter begins with the results of the field test which includes information on the validity and reliability of the PSM-ASD survey, followed by the results of the pilot test.

#### **Data Screening**

Surveys were submitted by 17 out of 66 participants, yielding a 26% response rate. One survey was returned incomplete. The responses of this participant were included in the analyses when possible. In addition, two surveys were submitted with no responses and were removed from the final analyses. The participant recruitment email was sent to all members of HCMA so it's likely that these two participants were not pediatric physicians and, therefore, exited the survey without responding. The final dataset included 15 surveys, yielding a 23% response rate.

#### **Research Question 1**

*What are the current practices of pediatricians with regard to detecting and addressing sleep problems in children with ASD?* The frequencies of responses from survey items 1-4 and

item 10 were analyzed in order to answer this research question. Specifically, for items 1, 2, 4, and 10, descriptive statistics with percentages respondents endorsed (e.g., Yes or No) are reported and shown in Table 5 and Table 6. The frequencies of responses from survey item 3 were analyzed and are reported below.

As shown in Table 5, the majority of participants (87%) indicated they use a visit documentation form during routine examinations. Of those participants, 92% endorsed that their documentation form addressed sleep problems at least once. The most common sleep topic participants ask to screen for sleep problems were related to routine sleep problems (100%), followed by sleep-related breathing problems (80%), disturbed sleep (80%), problems related to lack of sleep (73%), and co-sleeping (73%). More than half of respondents (73%) endorsed they do not ask screening questions related to a family history of sleep problems, and 53% do not ask sleep-related movement questions. All participants endorsed they either ‘*Almost Always*’ or ‘*Sometimes*’ screen for sleep problems during routine examinations, with the majority of the sample (73%) almost always screening for sleep problems. Slightly more than a quarter (27%) endorsed ‘*Sometimes*’ screening for sleep problems, and none of the respondents (0%) indicated they never screen for sleep problems. As shown in Table 6, the majority of participants (80% or more) endorsed ‘*Disagree*’ or ‘*Strongly Disagree*’ with each sleep screening perception: (1) “screening is not needed, as parents/caregivers will indicate if there is a problem”, (2) “screening is not necessary because low incidence of sleep problems”, and (3) “sleep problems are not as important as other health issues”. Less than a quarter of participants endorsed ‘*Neither agree nor disagree*’. There were no participants who endorsed ‘*Agree*’ or ‘*Strongly Agree*’.

**Research question 1a.** *What screening tools are used by pediatricians to screen for sleep problems during well-child exams?* The frequencies of responses from survey item 5 were

analyzed in order to answer this research question. This item included four factors: (1) BEARS Sleep Screening Tool, (2) Pediatric Sleep Questionnaire (PSQ), (3) Sleep Disorders Inventory for Students (SDIS), and (4) Children’s Sleep Questionnaire (CHSQ). Specifically, descriptive statistics with percentages respondents endorsed (e.g., Yes or No) for item 5 are reported in Table 7. As shown in Table 7, 15% to 39% of the respondents endorsed ‘Yes’ for using a sleep screening measure during routine exams. The most frequently used measure (39%) was the Pediatric Sleep Questionnaire, followed by the BEARS Sleep Screening Tool (23%). Less than a quarter (15%) of participants endorsed using the Children’s Sleep Questionnaire and the Sleep Disorders Inventory for Students to screen for sleep problems during routine exams.

**Research Question 1b.** *Which treatments for sleep problems are pediatricians most likely to recommend?* The frequencies of responses from survey item 7 were analyzed in order to answer this research question. On the survey, question 7 asks “In general, which treatments do you recommend for sleep disorders in children ages 2-10 years with Autism Spectrum Disorder?”. This item included five factors: (1) prescription sleep aides, (2) over the counter products (e.g., Benadryl), (3) melatonin, and (4) behavioral management (e.g., parent training, sleep hygiene resources), and (5) referral to a sleep specialist. Each factor was represented by the following numeric ratings: *1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very Often or Always, and N/A=Not familiar with this treatment.* The minimum and maximum numeric ratings, mean average rating, confidence intervals, and standard deviation for each treatment method are reported in Table 8. The percentage of participants that marked N/A for this item also are reported in Table 8. Overall, the majority of participants reported recommending one or more treatments. One treatment (prescription sleep aides) was reported as unfamiliar by 13% of participants. The most recommended sleep treatments were behavioral management, melatonin,

and referral to a sleep specialist. Participants were least likely to recommend prescription sleep aides and over-the-counter products such as Benadryl.

The majority of participants reported numeric ratings between the minimum rating of one and maximum rating of five. There were no mean numeric ratings that were consistent with recommending a particular treatment ‘Very Often or Always’ ( $M = 4.51$  to  $5.00$ ). One factor, ‘Behavioral Management (e.g., parent training, sleep hygiene resources, relation techniques)’, had a mean numeric rating that corresponded to ‘Often’ ( $M = 3.51$  to  $4.50$ ). Three factors, (1) prescription sleep aides, (2) melatonin, and (3) referral to a sleep specialist, had mean numeric ratings that were consistent with ‘Sometimes’ ( $M = 2.51$  to  $3.50$ ). One factor, over-the-counter products, had a mean numeric rating that was consistent with ‘Rarely’ ( $M = 1.51$  to  $1.50$ ). There were no mean numeric ratings that were consistent with ‘Never’ recommending a particular treatment ( $M = 1.00$  to  $1.50$ ). Two participants reported additional treatments through the ‘Other’ response option, including “referral if sleep aides fail” and “book; Good Night Sleep Tight by Kim West”.

## **Research Question 2**

*To what extent do pediatricians perceive various factors to serve as barriers to screening for sleep problems?* Responses to survey question 8 were analyzed in order to answer this research question. Specifically, question 8 asks “To what extent do you feel each of the following factors presents a barrier to your sleep screening practices during well-child examinations?”. This item included seven factors: (1) not enough time during exams to address sleep problems, (2) length of sleep screening tools are too long/too time consuming, (3) not aware of sleep screening tools, (4) lack of knowledge about sleep problems, (5) lack of resources and materials (e.g., availability of diagnostic services), (6) lack of access to sleep specialists, and (7) lack of

reimbursement. Each factor was represented by the following numeric ratings: 1= *Not a Barrier*, 2= *Slight Barrier*, 3= *Moderate Barrier*, 4= *Significant Barrier*, 5= *Extreme Barrier*, and N/A= *Have not personally experienced this factor*. The minimum and maximum numeric ratings, mean average rating, confidence intervals, and standard deviation for each factor are reported in Table 9. The percentage of participants that marked N/A for this item are also reported in Table 9. Participants who marked N/A were not included in the mean rating analyses for this question.

As shown in Table 9, the majority of participants (79%) reported personally experiencing each of the potential barriers to screening for sleep problems during routine examinations. Four factors were not personally experienced (i.e., marked N/A) by less than 21% of participants: (1) length of sleep screening tools are too long, (2) not aware of sleep screening tools, (3) lack of knowledge about sleep screening tools, and (4) lack of reimbursement. The three factors that 100% of participants reported personally experiencing were (1) not enough time during exams to address sleep problems, (2) lack of resources and materials, and (3) lack of access to sleep specialists.

The majority of participants reported numeric ratings between the minimum rating of one and maximum rating of five. There were no mean numeric ratings that were consistent with 'Extreme Barrier' ( $M = 4.51$  to  $5.00$ ). One factor, length of sleep screening tools are too long/too time consuming, had a mean numeric rating corresponding with 'Significant Barrier' ( $M = 3.51$  to  $4.50$ ). The other six factors, (1) not enough time during exams to address sleep problems, (2) not aware of sleep screening tools, (3) lack of knowledge about sleep problems, (4) lack of resources and materials, (5) lack of access to sleep specialists, and (6) lack of reimbursement, had mean numeric ratings that were consistent with 'Moderate Barrier' ( $M = 2.51$  to  $3.50$ ). There were no factors with mean numeric ratings that corresponded with 'Slight Barrier' ( $M = 1.51$  to

2.50) or ‘Not a Barrier’ ( $M = 1.00$  to  $1.50$ ). None of the participants reported additional barriers through the ‘Other’ response option.

### **Research Question 3**

*To what extent do pediatricians perceive various factors to serve as facilitators to screening for sleep problems?* Responses to survey question 9 were analyzed in order to answer this research question. Specifically, question 9 asks “To what extent do you feel each of the following factors serves to enable your sleep screening practices during well-child examinations?”. This item included six factors: (1) resources and materials (e.g., availability of diagnostic services), (2) longer routine exams, (3) shorter sleep screening tools, (4) access to sleep specialists, (5) experience (i.e., years in practice), and (6) personal desire to provide sleep screening and treatment recommendations. Each factor was represented by the following numeric ratings: 1=*Not an Enabler*, 2=*Slight Enabler*, 3=*Moderate Enabler*, 4=*Significant Enabler*, 5=*Extreme Enabler*, and N/A=*Have not personally experienced this factor*. The minimum and maximum numeric ratings, mean average rating, confidence intervals, and standard deviation for each factor are reported in Table 10. The percentage of participants that marked N/A for this item also are reported in Table 10.

As shown in Table 10, all participants reported personally experiencing two factors, (1) access to sleep specialists and (2) personal desire to provide sleep screening and treatment recommendations. The other four factors were personally experienced by 80% or more of participants. Four factors were not personally experienced (i.e., marked N/A) by less than a quarter of participants: (1) resources and materials, (2) longer routine exams, (3) shorter sleep screening tools, and (4) experience (i.e., years in practice).

The majority of participants reported numeric ratings between two and the maximum rating of five. There were no mean numeric ratings that were consistent with ‘Extreme Enabler’ ( $M = 4.51$  to  $5.00$ ). Three factors, (1) resources and materials, (2) longer routine exams, and (3) shorter sleep screening tools, had mean numeric ratings that corresponded to ‘Significant Enabler’ ( $M = 3.51$  to  $4.50$ ). The other two factors, (1) access to sleep specialists and (2) experience, had mean numeric ratings that were consistent with ‘Moderate Enabler’ ( $M = 2.51$  to  $3.50$ ). There were no factors with mean numeric ratings that corresponded with ‘Slight Enabler’ ( $M = 1.51$  to  $2.50$ ) or ‘Not an Enabler’ ( $M = 1.00$  to  $1.50$ ). None of the participants reported additional facilitators through the ‘Other’ response option.

#### **Research Question 4**

*How confident are pediatricians in managing sleep issues in children with ASD?* Responses to survey question 11 were analyzed in order to answer this research question. Specifically, question 11 asks “Please indicate your perceived level of confidence in managing sleep problems in children ages 2-10 years with Autism Spectrum Disorder?”. This item included three factors: (1) I am able to screen children for sleep problems, (2) I am able to advise children (or their caregiver) regarding healthy sleep habits, and (3) I am able to recommend appropriate treatment to children with sleep problems. Each factor was represented by the following numeric ratings: 0=*Not Confident*, 1=*Slightly Confident*, 2=*Somewhat Confident*, and 3=*Moderately Confident*, and 4=*Extremely Confident*. The minimum and maximum numeric ratings, mean average rating, confidence intervals, and standard deviation for each level of confidence are reported in Table 11. Lastly, Spearman correlations were computed to identify whether a relationship existed between participants’ perceived barriers and perceived confidence scores. Results are reported in Table 12.

As shown in Table 11, most of the respondents reported numeric ratings between one and the maximum rating of four. Participants reported numeric ratings between the minimum rating of zero and maximum rating of four for one factor: ‘I am able to recommend appropriate treatment to children with sleep problems’. The mean numeric ratings for each factor indicated that most pediatric providers in the study perceive they are ‘Somewhat Confident’ in their ability to (1) screen children for sleep problems, (2) advise children (or their caregiver) regarding healthy sleep habits, and (3) recommend appropriate treatment to children with sleep problems ( $M = 1.51$  to  $2.50$ ). There were no mean numeric ratings that were consistent with ‘Extremely Confident’ ( $M = 3.51$  to  $4.00$ ), ‘Moderately Confident’ ( $M = 2.51$  to  $3.50$ ), ‘Slightly Confident’ ( $M = 0.51$  to  $1.50$ ), or ‘Not Confident’ ( $M = 0.00$  to  $0.50$ ). As can be seen in Table 12, a series of Spearman’s rank correlations were calculated to identify whether a relationship existed between participants’ perceived barriers and perceived confidence scores. Results demonstrated a statistically significant negative correlation between the barrier of having insufficient time during exams to address sleep and participants’ perceived confidence level related to sleep screening ( $r_s = -.58, p < .05$ ). A statistically significant positive correlation existed between the perceived barrier of screening tools being too long and participants’ perceived confidence level related to sleep screening ( $r_s = .80, p < .01$ ).

### **Summary**

Results of these analyses indicate that most pediatric providers use a visit documentation form that addresses sleep at least once, and almost always ask a sleep-related question during routine exams. However, the vast majority of pediatric providers do not use a sleep screening tool during routine exams. Of the pediatric providers that do, the majority use the Pediatric Sleep Questionnaire. The pediatric providers in this study were more likely to recommend behavioral



management (e.g., parent training, sleep hygiene resources, relation techniques) to treat childhood sleep problems. Participants were least likely to recommend over-the-counter medications such as Benadryl.

In addition, findings from these analyses indicate that pediatric providers perceive a number of barriers and facilitators to screening for sleep problems during routine exams. Pediatric providers reported the most significant barrier to screening for sleep problems during routine exams to be the length of sleep screening tool (i.e., too long/too time consuming). Pediatric providers reported the most significant facilitators to screening for sleep problems during routine exams to be (1) resources and materials, (2) longer routine exams, and (3) shorter sleep screening tools. Finally, all pediatric providers reported that they were somewhat confident in their ability to (1) screen children for sleep problems, (2) advise children (or their caregiver) regarding healthy sleep habits, and (3) recommend appropriate treatment to children with sleep problems. There were no mean numeric ratings that were consistent with a confidence level of *moderately confident* or *extremely confident*. Lastly, a series of Spearman's rank correlations were calculated to identify whether a relationship existed between participants' perceived barriers and perceived confidence scores. Results indicated a statistically significant inverse correlation between sleep screening confidence scores and perceived barrier scores of not having enough time during routine exams to address sleep problems ( $r_s = -.58, p < .05$ ). Sleep screening confidence scores were significantly inversely correlated with the perceived lack of resources available to screen for sleep problems ( $r_s = -.58, p < .05$ ). Sleep screening confidence scores were significantly positively correlated with perceived barrier scores related to the length of sleep measures ( $r_s = .80, p < .01$ ). Finally, confidence scores related to advising children or caregivers of healthy sleep habits was significantly inversely correlated with barriers related to

lack of diagnostic and treatment resources ( $r_s = -.58, p < .05$ ). In other words, pediatric providers who were more confident in screening for sleep problems perceived fewer barriers related to time during routine exams and lack of available resources. Providers who were more confident in sleep screening perceived fewer barriers related to the length of sleep screening measures, and pediatric providers who were more confident in their ability to advise children and their caregivers on healthy sleep habits perceived many barriers related to lack of diagnostic and treatment resources.

Table 5

*Current Sleep Screening Practices (n=15)*

Screening Practices	% Sample Endorsed 'Yes'	% Sample Endorsed 'No'
Do you use a visit documentation form (i.e., intake form or visit checklist) during routine examinations?	86.7%	13.3%
Does your visit documentation form address sleep problems at least once?*	92.3%	7.7%
Which sleep topic(s), if any, do you ask to screen for sleep problems?		
Routine sleep problems (e.g. usual bedtime/wake time)	100%	0%
Lack of sleep (e.g. daytime sleepiness, difficulty waking, frequent awakenings)	73.3%	26.7%
Disturbed sleep (e.g. bedtime resistance/fears, night terrors/nightmares, bedwetting)	80%	20%
Family history of sleep problems	26.7%	73.3%
Sleep related breathing problems (e.g. snoring/breathing issues)	80%	20%
Sleep related movement (e.g. frequent leg kicking, teeth grinding)	46.7%	53.3%
Co-sleeping (e.g. parents sleeping in close proximity to child)	73.3%	26.7%

\*Participants were only shown this question if they responded 'Yes' to using a visit documentation form during routine exams.

Table 6

*Frequency of Sleep Screening Perceptions (n=15)*

Sleep Screening Perceptions	% Sample Endorsed 'Strongly Disagree'	% Sample Endorsed 'Disagree'	% Sample Endorsed 'Neither agree nor disagree'	% Sample Endorsed 'Agree'	% Sample Endorsed 'Strongly Agree'
Screening is not needed, as parents/caregivers will indicate if there is a problem.	40%	40%	20%	0%	0%
Screening is not necessary because low incidence of sleep problems.	47%	40%	13%	0%	0%
Sleep problems are not as important as other health issues.	53%	40%	7%	0%	0%

Table 7

*Measures Used by Pediatric Providers to Screen for Sleep Problems (n=13)*

Screening Measures	% Sample Endorsed 'Yes'	% Sample Endorsed 'No'
BEARS Sleep Screening Tool	23.1%	76.9%
Pediatric Sleep Questionnaire (PSQ)	38.5%	61.5%
Sleep Disorders Inventory for Students (SDIS)	15.4%	84.6%
Children's Sleep Questionnaire (CHSQ)	15.4%	84.6%

Table 8

*Numeric Ratings of Recommended Treatments for Sleep Disorders in Children Ages 2-10 Years with ASD (n=14)*

	%	%					
	Sample	Sample	<i>M</i>				
	Reported	Reported	Rating*	<i>SD</i>	CI	Min	Max
Sleep Disorder Treatments	N/A	1-5					
Prescription Sleep Aides	13.3%	86.7%	2.60	1.72	1.71 - 3.14	1	5
Over the Counter Products (e.g., Benadryl)	0%	100%	2.00	0.68	1.64 – 2.29	1	3
Melatonin	0%	100%	3.34	1.09	2.86 – 3.93	1	5
Behavioral Management (e.g., parent training, sleep hygiene resources, relation techniques)	0%	100%	3.71	1.20	3.14 – 4.36	2	5
Referral to a Sleep Specialist	0%	100%	3.00	1.24	2.36 – 3.64	1	5

\* Note: The numeric rating for each treatment method were represented by the following values: 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very Often or Always, and N/A=Not familiar with this treatment.

Table 9

*Numeric Ratings of Possible Barriers to Screening for Sleep Problems During Routine Examinations (n=14)*

	%	%					
	Sample	Sample	<i>M</i>				
	Reported	Reported	Rating*	<i>SD</i>	CI	Min	Max
Possible Barriers	N/A	1-5					
Not enough time during exams to address sleep problems	0%	100%	3.00	0.88	2.50 – 3.43	1	4
Length of sleep screening tools are too long/too time consuming	14.3%	85.7%	3.79	1.05	3.29 – 4.36	3	5
Not aware of sleep screening tools	21.4%	78.6%	3.43	1.56	2.71 – 4.21	1	5
Lack of knowledge about sleep problems	7.1%	92.9%	2.57	1.34	1.93 – 3.36	1	5
Lack of resources and materials (e.g., availability of diagnostic and/or treatment services for pediatric sleep disorders)	0%	100%	2.64	0.75	2.21 – 3.00	1	4
Lack of access to sleep specialists	0%	100%	2.64	1.08	2.07 – 3.21	1	4
Lack of reimbursement	21.4%	78.6%	3.14	1.75	2.29 – 4.07	1	5

\*Note: The numeric rating for each factor were represented by the following values: 1= Not a Barrier, 2=Slight Barrier, 3=Moderate Barrier, 4=Significant Barrier, 5=Extreme Barrier, and N/A=Have not personally experienced this factor.

Table 10

*Numeric Ratings of Possible Facilitators to Screening for Sleep Problems During Routine Examinations (n=15)*

Possible Facilitators	%	%	<i>M</i>	<i>SD</i>	CI	Min	Max
	Sample Reported	Sample Reported					
	N/A	1-5	Rating*				
Resources and materials (e.g., availability of diagnostic and/or treatment services for pediatric sleep disorders)	13.3%	86.7%	3.57	1.40	2.93 – 4.29	2	5
Longer routine exams	13.3%	85.7%	4.07	0.92	3.64 – 4.57	3	5
Shorter sleep screening tools	20%	80%	4.29	1.07	3.79 – 4.86	3	5
Access to sleep specialists	0%	100%	3.50	0.86	3.07 – 3.93	2	5
Experience (i.e., years in practice)	14.3%	85.7%	3.43	1.56	2.64 – 4.21	1	5
Personal desire to provide sleep screening and treatment recommendations	0%	100%	2.93	1.27	2.21 – 3.57	1	5

\*Note: The numeric rating for each factor were represented by the following values: 1=*Not an Enabler*, 2=*Slight Enabler*, 3=*Moderate Enabler*, 4=*Significant Enabler*, 5=*Extreme Enabler*, and N/A=*Have not personally experienced this factor*.

Table 11

*Numeric Ratings of Perceived Level of Confidence Regarding Sleep Management Practices (N=14)*

Sleep Management Practices	<i>M</i>		CI	Min	Max
	Rating*	<i>SD</i>			
I am able to screen children for sleep problems.	2.07	1.00	1.57 – 2.57	1	4
I am able to advise children (or their caregiver) regarding healthy sleep habits.	2.29	0.99	1.79 – 2.79	1	4
I am able to recommend appropriate treatment to children with sleep problems.	1.71	1.20	1.14 – 2.36	0	4

\*Note: The numeric rating for each level of confidence were represented by the following values: 0= *Not Confident*, 1=*Slightly Confident*, 2=*Somewhat Confident*, and 3=*Moderately Confident*, and 4=*Extremely Confident*.

Table 12

*Spearman Rank Correlation Coefficients for Perceived Barriers and Confidence Levels*

Confidence Statements		Potential Barriers						
		Lack of Time	Length of Sleep Tools	Not Aware of Sleep Tools	Lack of Knowledge	Lack of Resources	Lack of Access to Specialists	Lack of Reimbursement
I am able to screen children for sleep problems.	Spearman correlation	-.58*	.80**	-.27	-.51	-.58*	-.28	-.32
	Significance (2-tailed)	.04	.00	.35	.06	.03	.34	.27
	N	13	14	14	14	14	14	14
I am able to advise children regarding healthy sleep habits.	Spearman correlation	-.28	.58*	-.33	-.57*	-.48	-.26	.34
	Significance (2-tailed)	.36	.03	.24	.03	.09	.38	.24
	N	13	14	14	14	14	14	14
I am able to recommend appropriate treatment to children with sleep problems.	Spearman correlation	-.53	.54	-.09	-.53	-.48	-.30	-.31
	Significance (2-tailed)	.06	.07	.75	.06	.10	.31	.28
	N	13	12	14	13	13	13	14

## **Chapter Five**

### **Discussion**

This study investigated the current practices of pediatric providers with regard to sleep screening and treatment of children ages 2-10 years with ASD. This study pilot tested the PSM-ASD survey to identify the sleep management practices of pediatricians. Given the likelihood of a small sample size, the PI and thesis committee decided to survey all pediatric providers who interact with children ages 2-10 years with a diagnosed ASD. The final dataset included 15 useable surveys, yielding a 23% response rate. This study collected data regarding the type of tools used by pediatric providers to screen for sleep problems during well-child examinations, the sleep treatments pediatric providers are most likely to recommend, what pediatric providers perceive as the barriers and facilitators to detecting sleep issues in primary care settings, and pediatric providers' level of confidence in detecting and addressing sleep problems. This chapter interprets and summarizes the findings previously reported in Chapter Four. Although response rates of 23% are not uncommon in the medical field, the sample size for this study was relatively small. Moreover, much of the prior literature reviewed specifically pertained to pediatricians rather than pediatric providers in general. Based on these factors, findings from this study should be interpreted with caution. The results from each research question will be discussed, followed by implications for pediatric healthcare providers and school psychologists, limitations of the study, and future directions.



### **Research Question 1: Frequency of Sleep Management Practices**

Findings from this study indicate that most pediatric providers use a visit documentation form that addresses sleep at least once. Additionally, pediatric providers almost always ask a sleep-related question during routine exams. Notably, the vast majority of pediatric providers do not use a sleep screening tool during routine exams. Of the few pediatric providers who use sleep screening tools during routine exams, the majority use the Pediatric Sleep Questionnaire followed by the BEARS Sleep Screening Tool. Nonetheless, all pediatric providers reported asking a screening question related to routine sleep problems. Additionally, most pediatric providers ask screening questions on the topics of sleep-related breathing problems, disturbed sleep, problems related to lack of sleep, and co-sleeping. The majority of pediatric providers either disagreed or strongly disagreed that: (1) “screening is not needed, as parents/caregivers will indicate if there is a problem”, (2) “screening is not necessary because low incidence of sleep problems”, and (3) “sleep problems are not as important as other health issues”. Less than a quarter of pediatric providers neither agreed nor disagreed with those statements.

These findings suggest that pediatric providers are highly likely to ask at least one sleep-related question during exams, but less likely to use an actual sleep screening measure. One explanation for the low use of sleep screening measures may be that pediatric providers feel they have very little time during exams to complete them. This is supported by high percentage of participants that endorsed the barrier of lack of time during exams to address sleep problems (e.g., Mean Numeric Rating = 3.00/Moderate Barrier). In spite of that, most pediatric providers believe that sleep screening is necessary and just as important as other health issues. Some of these findings are consistent with the previous research in this area (Faruqui et al., 2011; Mindell

et al., 1994; Owens, 2001). Faruqui and colleagues (2011) found that most pediatricians ask at least one question related to routine sleep problems, bedtime/wake time, and snoring/breathing related problems during well-child exams. In addition, pediatricians were least likely to ask screening questions related to a family history of sleep problems. Similarly, findings suggest that pediatric providers are most likely to ask at least one question related to routine sleep problems and sleep-related breathing problems, and least likely to ask screening questions related to a family history of sleep problems. In contrast to Faruqui and colleagues' (2011) findings, results from the current study indicate that pediatric providers also are likely to ask at least one question related to lack of sleep, disturbed sleep, and co-sleeping.

Notably, some findings related to sleep screening practices differed from previous studies. A common barrier to sleep screening is the assumption that parents will indicate a sleep problem, regardless of whether sleep screening occurs (Faruqui et al., 2011; Owens, 2001). Findings from this study show that most pediatric providers disagreed with that statement. One possible explanation for this inconsistency may be explained by the low percentage of pediatric providers in this study that endorsed *never* screening for sleep problems. Pediatric providers that are 'almost always' screening for sleep problems might not naturally make the assumption that parents will raise sleep concerns, given that they will be screening for a sleep problem regardless of what parents bring up. This explanation is supported by the low percentage (0%) of pediatric providers that endorsed *never* screening for sleep problems in children, compared to 35% of participants in Faruqui and colleagues' (2011) study, and about 20% in Owens and colleagues' (2001) study.

### **Research Questions 2 & 3: Barriers and Facilitators to Sleep Screening**

Findings from this study indicate that pediatric providers perceive a number of barriers to screening for sleep problems during routine exams. Almost all factors had mean numeric ratings that were indicative of a moderate barrier. These six factors included not enough time during exams to address sleep problems, not aware of sleep screening tools, lack of knowledge about sleep problems, lack of resources and materials, lack of access to sleep specialists, and lack of reimbursement. Pediatric providers reported the most significant barrier to screening for sleep problems during routine exams to be the length of sleep screening tools (i.e., too long/too time consuming). Similarly, pediatric providers reported a number of facilitators to screening for sleep problems during routine exams. The two factors that 100% of participants reported as facilitators they have personally experienced were access to sleep specialists and personal desire to provide sleep screening and treatment recommendations. On average, pediatric providers reported the most significant facilitators to be resources and materials, longer routine exams, and shorter sleep screening tools. The two factors that pediatric providers endorsed as moderate facilitators were access to sleep specialists and years of experience.

With regard to perceived barriers, findings from this study were consistent with what has been found in the current literature. Prior research (e.g., Faruqui et al., 2001; Owens, 2001) has shown that the most significant barriers to screening for sleep problems included screening being too time consuming, insufficient resources and qualified staff, and lack of knowledge about sleep problems. Similarly, participants in this study reported the most significant barriers to be the length of the screening tool (i.e., too time consuming) and lack of awareness of screening tools. One possible explanation for the discrepancy between pediatric providers' perceived importance of sleep screening and the reported low rates of sleep screening measures used may be explained

by several barriers. Specifically, pediatric providers perceived screening tools to be too time consuming, in addition to reporting not having enough time during routine exams to address sleep problems. Furthermore, a high percentage of pediatric providers reported that they were not aware of sleep screening tools. These findings suggest that providers who are unaware of sleep screening tools, or believe them to be too time consuming, may be less likely to use them during routine exams. Another perspective may be that providers do not feel the need to ask sleep problems during exams because they have already been addressed in another capacity. As presented in Chapter Four, many pediatric providers in this study (80%) endorsed their visit documentation form (i.e., intake form or visit checklist) addressed sleep at least once. If sleep is already addressed on the form, providers may not feel there is time to address it during the exam as well. These findings are consistent with prior research that has shown that pediatricians perceive there is not enough time during routine exams to screening for sleep problems (Faruqui et al., 2001).

#### **Research Question 4: Confidence Level of Pediatricians**

The majority of participants endorsed being 'Somewhat Confident' in their ability to manage sleep problems (i.e., screen for sleep problems, advise children and caregivers of healthy sleep habits, and recommend appropriate treatment). Despite the high number of participants that endorsed they almost always screen for sleep problems, participants were only somewhat confident in their ability to do so. Specifically, participants were the least confident in their ability to recommend appropriate treatment for sleep problems, and only somewhat confident in their ability to advise children regarding healthy sleep habits. This relatively low level of confidence may be explained by a number of perceived barriers. For example, pediatric providers who recognize time as a barrier to sleep screening may be less likely to use sleep

screening tools, and therefore be less confident in their screening practices. This explanation is supported by a significant inverse correlation between sleep screening confidence scores and perceived barrier scores of not having enough time during routine exams to address sleep problems ( $r_s = -.58, p < .05$ ). Additionally, pediatric providers who do not have the resources necessary to provide sleep screening may be less confident in their screening practices. Sleep screening confidence scores were significantly inversely correlated with the perceived lack of resources available to screen for sleep problems ( $r_s = -.58, p < .05$ ). Similarly, confidence scores related to advising children or caregivers of healthy sleep habits were significantly inversely correlated with the perceived lack of resources available to treat sleep problems ( $r_s = -.58, p < .05$ ). Lastly, sleep screening confidence scores were positively correlated with perceived barrier scores related to the length of sleep measures ( $r_s = .80, p < .01$ ). This finding is particularly interesting because it suggests that providers who perceive the length of screening tools to be a significant barrier, are more confident in their sleep screening practices. Given that the majority of participants reported asking at least one sleep question, it is possible that providers feel confident in their ability to screen for sleep problems on their own, as opposed to using a standard measure. This may potentially explain the positive relationship between sleep screening tools as a significant barrier and perceived confidence in sleep screening abilities. In summary, it appears that providers who lack resources and time are less confident in their sleep screening practices. In contrast, providers who perceive screening tools to be too long or time consuming are more confident in their ability to screen for sleep problems.

### **Implications of Findings**

The results of this study emphasize the need for pediatric providers to manage sleep problems in primary care settings. Although most pediatric providers in this study reported they

routinely screen for sleep problems, many providers perceive challenging barriers that may decrease their confidence and prevent them from following best practices. Findings from this study led to several important implications. The following sections outline the practice and research implications from this study.

**Implications for Medical Schools, Postgraduate Training, and Continuing Medical Education.** One purpose of this study was to gain information on the current practices of pediatric providers with regard to managing sleep problems in young children with ASD. As previously reported, pediatric providers perceive several barriers to screening for sleep problems during routine exams. In particular, a high percentage of respondents endorsed either not being aware of sleep screening tools or perceiving that the length of sleep screening tools were too long. The results of this study support the need for more training on pediatric sleep medicine. The need for improved sleep education and training is highly prevalent in the related literature (e.g., Faruqui et al., 2011; Mindell et al., 1994; Mindell et al., 2011; Mindell et al., 2013; Owens, 2001). Similarly, the lack of confidence in managing sleep problems in primary care is another possible indicator that pediatric providers do not receive a sufficient amount education and training on sleep disorders. Of note, pediatricians who are formally trained in pediatric sleep are significantly less likely to report barriers than those who have not received formal training (Faruqui et al., 2011). Although there has been a significant increase in the acknowledgment of appropriate practices to manage sleep problems (Mindell et al., 2011), as well as an increase of sleep screening resources designed specifically for primary care settings (Malow et al., 2012; Owens & Dalzell, 2005), there continues to be very little coverage of sleep in medical schools (Faruqui et al., 2011, Mindell et al., 2013; Owens, 2001). One method to improving sleep education at the medical school, postgraduate, and continuing education levels is by increasing

awareness and training on integrated behavioral healthcare (IBH). When systems operate using an IBH model, professionals are able to collaborate with other professionals who have knowledge outside of their scope of practice (e.g., school psychologists, psychiatrists). Through consultation and collaboration, healthcare providers with training and experience in IBH are able to integrate information from a range of domains in order to provide families with comprehensive diagnoses and treatment plans.

**Implications for Pediatricians and Other Pediatric Primary Care Providers.** Despite the recent increase in the acknowledgement of the importance of sleep, in addition to the magnitude of the literature on the benefits of managing sleep problems in young children, many researchers have consistently reported a low incidence of sleep management in pediatric settings (Chervin et al., 2001; Faruqui, et al., 2011; Meltzer et al., 2010; Meltzer et al., 2014; Owens & Dalzell, 2005). As previously stated in Chapter Two, The BEARS (“B = Bedtime Issues, E = Excessive Daytime Sleepiness, A = Night Awakenings, R = Regularity and Duration of Sleep, S = Snoring”) is a simple, free instrument developed by Owens and Dalzell (2005) to assess for symptoms of sleep disorders during routine examinations. This instrument provides pediatric providers with a list of simple questions (e.g. yes or no) that can be quickly asked to parents. Research has shown that the BEARS is an efficient tool for collecting information and identifying sleep concerns during well-child examinations (Owens & Dalzell, 2005). In addition, the Autism Treatment Network (ATN) published a “clinical practice pathway” in order to provide a framework of best practices for pediatricians to reference while working in primary care settings. The ATN Sleep Committee advocates screening for insomnia occur in all patients with ASD. Specifically, the committee stated that screening is most effective when using a short screening tool comprised of insomnia-related questions, such as those from the Children’s Sleep

Habits Questionnaire (CSHQ). If treatment is necessary, behavioral interventions as well as parent education should be considered first line of treatment. Further, pharmacologic agents may be useful on an individual basis, and the effectiveness and tolerance of treatments should be measured through follow-up (Malow et al., 2012). Lastly, pediatric providers should consider promoting healthy sleep habits through the use of technology (e.g., sleep activity tracker such as the Fitbit). By monitoring sleep quality, parents of children with ASD may be more informed of their child's sleep problems, thus increasing the chance of timely identification and treatment.

**Implications for School Psychologists.** School psychologists have the unique opportunity to advance collaboration between educational and medical systems. Although a doctor of medicine is needed to make sleep disorder diagnoses, school psychologists can identify and provide interventions for sleep problems in students who display sleep disorder symptoms at school. The Sleep Disorders Inventory for Students (SDIS; Luginbeuhl et al., 2008) was developed for school psychologists in order determine if sleep disorders may be affecting a student's school performance. Furthermore, school psychologists are in an advantageous position to provide basic sleep education to parents and students. Recent literature has shown that sleep education programs are an effective and economical strategy to increase parent knowledge of sleep disorders, healthy sleep hygiene, consistent bedtime routines, and behavioral treatments (Mindell et al., 2006). Lastly, school psychologists should consider the effects of insufficient sleep on overall functioning at school. When evaluating children for other educational needs, school psychologists should routinely check for sleep problems that may be impacting performance.



## **Delimitations**

The proposed study incorporated several deliberate limitations. First, only pediatric providers who were members of HCMA were included. This excludes all other providers who were not affiliated with HCMA. Next, the exclusion of survey items related to sleep problems in typically developing children in order to reduce the length of the survey. This prevented the researcher from examining the differences in practice between typically developing children and children with ASD. Nevertheless, Dillman and colleagues (2014) state that the length of a survey is often the largest cost experienced by survey respondents, and is commonly the reason for questionnaires not being returned or terminated early. Moreover, Dykema and colleagues (2013) report that a low survey response rate from physicians is common. This delimitation allowed for the opportunity to increase the response rate. Lastly, a delimitation of this study is the relatively small sample size due to the limited number of pediatric physicians associated with the local medical association. This delimitation allowed the researcher to sample local providers, which is less costly than a statewide or national sample.

## **Limitations**

Several threats to the validity of the findings in this study were anticipated. The closed-format survey structure may not have included all important and relevant sleep questions, which may have affected the content validity of the findings. In addition, all data were collected at one time point; therefore, changes over time could not be assessed. Similarly, because the study is voluntary, it is possible that the participants of this study represent providers with a particular interest in sleep disorders and/or ASD. As mentioned in Chapter Three, a low survey response rate among physicians is common. Several scale development recommendations were followed in an attempt to increase the survey response rate. All survey responses were obtained through

self-report and thus subject to socially desirable responding patterns. However, respondents were anonymous, which possibly limited response bias. Although several studies suggest that pediatricians receive very little education and training on sleep problems (e.g., Faruqui et al., 2011; Mindell et al., 1994; Owens, 2001), some participants may have felt inclined to respond falsely. Lastly, this study intended to calculate test-retest reliability using Pearson correlation; however, only two respondents indicated they would be willing to retake the survey one week later. Due to the low number of respondents who chose to participate, test-retest reliability was not able to be calculated.

### **Contributions to the Literature and Future Directions**

The current study has contributed to the existing literature by presenting preliminary data on the current sleep management practices and perceptions of pediatric providers with regard to children ages 2-10 years with ASD. In addition, this study has contributed to the literature by identifying barriers and facilitators to routine sleep screening practices during well-child examinations. The findings from this study have provided recommendations for improved medical education and interdisciplinary collaboration on behalf of this population of children. Lastly, this study has provided preliminary information on the validity of the PSM-ASD survey which could potentially be used to support future studies.

Given that results of this study were preliminary, more research is needed to extend the findings. Future research should examine the perceptions and practices of pediatric providers through qualitative methods (e.g., interviews) in order to gain a deeper understanding of the barriers and facilitators to managing sleep problems in primary care settings. In addition, identifying the perceptions and knowledge of parents of children with ASD may provide additional information necessary to improving sleep practices in this population.

In order to replicate the current findings, future research should conduct this study with a larger, national random sample in order to determine if results from this study can be generalized to the population. One purpose of this study was to pilot test the PSM-ASD survey with pediatric providers. Based on the limited information collected on the instrument's reliability, future studies should continue to assess psychometric properties of the PSM-ASD survey. Given that data were collected at one time point, future studies should consider collecting data across multiple time points to assess changes over time.

## **Conclusion**

Considering the benefits of early identification of childhood sleep problems, the substantial amount of literature on the limited education and training on pediatric sleep, the high prevalence of sleep disorders in children with ASD, the lack of evidence of this type of practice in the professional literature, as well as the availability of psychometrically sound instruments for measuring sleep, the current study aimed to collect data from pediatric providers to investigate their current practices and perceptions on screening, assessing, and treating sleep problems in children with ASD in primary care settings. This study collected data regarding the type of tools used by pediatric providers to screen for sleep problems during well-child examinations, the sleep treatments pediatric providers are most likely to recommend, what pediatric providers perceive as the barriers and facilitators to detecting sleep issues in primary care settings, and pediatric providers' level of confidence in detecting and addressing sleep problems.

Given the amount of literature on the importance of screening for sleep problems in children with ASD, it is encouraging that many providers are providing some form of sleep screening with their patients. However, the vast majority of pediatric providers do not use a sleep

screening tool during routine exams and report low levels of confidence related to their perceived ability to manage pediatric sleep problems in primary care. This relatively low level of confidence may be explained by a number of perceived barriers such as lack of time, resources, and knowledge of sleep screening tools. These results substantiate the need for more training on pediatric sleep medicine, as well as sleep management practices, and demonstrate the need for more awareness of the sleep resources available to providers.

Early identification and treatment of sleep problems may potentially counteract some of the secondary consequences of sleep disturbances such as disruptive behaviors, lack of attention, and learning problems (Moore et al., 2017). Identifying sleep disorders at an early age is likely to increase favorable daytime behaviors and also may have a positive impact on family functioning (Cortesi, 2010). Understanding the current practices of pediatric providers with regard to young children with ASD with sleep problems will help to improve the health outcomes in this population of children.

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## **Appendices**

## Appendix A: Survey Cover Letter

Dear HCMA Member,

Rising rates of children with Autism Spectrum Disorder (ASD) has led to calls for increased involvement by pediatricians in the provision of early identification and intervention services. We are asking for your assistance in expanding the professional literature of pediatricians' current practices and perceptions regarding screening for sleep problems in children ages 2-10 years with ASD during well-child examinations by completing the attached online survey. Our goals in conducting the study are to better understand (a) the type of screening tools used by pediatricians to screen for sleep problems during well-child exams, (b) pediatricians' current practices with regard to addressing sleep problems in children with ASD, (c) factors that facilitate and prohibit pediatricians from providing sleep screening in primary care settings, and (d) pediatricians' level of confidence in detecting and addressing sleep disorders in children with ASD. Findings from this study may ultimately inform medical training and professional development programs.

You are being asked to be part of this study because you work in the role of a pediatrician in a community or academic setting. We would like you to be a participant in this study, regardless of the amount of time you currently spend screening for sleep problems during well-child examinations. Your decision to participate in this study is completely voluntary and you are free to withdraw at any time without penalty.

Participation in the study involves completing the online survey within 2 weeks. **The survey will only take 5-7 minutes to complete.** A returned survey will be considered consent to participate in the study. Please note that data will be reported only in aggregate form and findings may be published; importantly, the responses of individuals will be treated in the strictest confidence.

This study has been approved by the University of South Florida Institutional Review Board as project number #00035935.

Thank you in advance for your time and assistance with this research project. If you have any questions or concerns about the project, please feel free to contact us at the numbers and email listed below. We also invite you to contact us if you would like to obtain the results of the study.

Thank you for your participation.

Sincerely,

Kristin L. Edwards, M.S.  
Principal Investigator  
Doctoral Student  
School Psychology Program  
University of South Florida  
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**Appendix B: Field Test - Additional Items Related to Validity**

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Start of Block: Validity Questions

Thank you for completing the PSM-ASD survey. The following questions are related to the validity of the cover letter and survey. Please answer these questions honestly, as your opinions will help to improve the clarity and accuracy of this research project. Note: the cover letter was included in the initial email you received.

-----

Approximately how long did it take you to complete the survey?

- < 5 minutes
- 5-7 minutes
- 8-9 minutes
- > 10 minutes

-----

Were there any words in the cover letter or survey that you did not understand?

\_\_\_\_\_

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If you received this cover letter and survey by email, would you be likely to participate? If not, what information in the cover letter would make you more willing to take part? Was there anything in the cover letter or survey that made you *not* likely to participate?

\_\_\_\_\_

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Was there any time that you wanted to stop answering during the survey?

No

Yes

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Was there anything on this survey that you felt should have been included and wasn't?

---

Do you have anything else you would like to tell us that you haven't had a chance to mention?

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The final question presented on the next page asks if you are interested in taking the survey again in approximately 5 days in order to determine test-retest reliability of the survey. If you are interested, please enter your email address so we can send you the survey again. *Your responses to this survey will remain anonymous.*

Yes I will take the survey again in one week.

Not interested at this time.

**End of Block: Validity Questions**

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## Appendix C: Initial Email

Dear HCMA Member,

We are asking for your assistance in expanding the professional literature of pediatric providers' current practices and perceptions regarding screening for sleep problems in children ages 2-10 years with ASD during well-child examinations by completing an online survey. Our goals in conducting this research study are to better understand (a) the type of screening tools used by pediatric providers to screen for sleep problems during well-child exams, (b) pediatric providers' current practices with regard to addressing sleep problems in children with ASD, (c) factors that facilitate and prohibit pediatric providers from providing sleep screening in primary care settings, and (d) pediatric providers' level of confidence in detecting and addressing sleep disorders in children with ASD. Findings from this study may ultimately inform medical training and professional development programs.

You are being asked to be part of this study because you work in the role of a pediatric provider in a community or academic setting. You can begin the survey by clicking the link at the bottom of this email. The survey will take approximately 7 minutes to complete. A returned survey will be considered consent to participate in the study. Please note that data will be reported only in aggregate form and findings may be published; importantly, the responses of individuals will be treated in the strictest confidence. You will not be compensated for participating in this study. Potential benefits to participating in this research study include the opportunity to contribute to important research that may enhance the best practices in working with young children with ASD.

This study has been approved by the University of South Florida Institutional Review Board as project number Pro00035935.

Thank you in advance for your time and assistance with this research project. If you have any questions or concerns about the project, please feel free to contact us at the numbers and email listed below. We also invite you to contact us if you would like to obtain the results of the study.

Thank you so much for your participation.

Sincerely,

Kristin L. Edwards, M.S.  
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Doctoral Student  
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## **Appendix D: PSM-ASD Survey (Modified to fit in proposal format)**

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Start of Block: Consent

### **Informed Consent to Participate in Research Information to Consider Before Taking Part in this Research Study**

Pro00035935

Researchers at the University of South Florida (USF) study many topics. To do this, we need the help of people who agree to take part in a research study. This form tells you about this research study. We are asking you to take part in a research study that is called: Sleep Disorders in Children with Autism Spectrum Disorder: An Assessment of Primary Care Pediatrician Practices and Perceptions. The person who is in charge of this research study is Kristin Edwards. This person is called the Principal Investigator.

### **Purpose of the Study**

The purpose of this study is to examine the current practices and perceptions of general pediatricians with respect to managing sleep problems in young children with Autism Spectrum Disorder (ASD). Identification of current sleep screening practices with regard to children with ASD can inform medical training and professional development programs leading to improved patient care. The aim of this study is to gain a better understanding of the sleep management practices of pediatricians in order to identify strategies for maximizing outcomes for children with ASD.

### **Why are you being asked to take part**

We are asking you to take part in this research study because you work in the role of a pediatrician in a community or academic setting in the United States.

### **Study Procedures**

If you take part in this study, you will be asked to complete an online Qualtrics survey investigating your current practices and perceptions on screening, assessing, and treating sleep problems in children with ASD in primary care settings. This survey collects data regarding the type of screening tools used by pediatricians to screen for sleep problems during well-child exams, in addition to pediatricians' familiarity with evidence-based practice for addressing sleep problems in children with ASD, the perceived barriers and facilitators to sleep screening, and pediatricians' level of confidence in detecting and addressing sleep disorders. Data will be reported only in aggregate form and the responses of individuals will be treated in the strictest confidence.

### **Alternatives/Voluntary Participation/Withdrawal**

You have the alternative to choose not to participate in this research study. You should only take part in this study if you want to volunteer; you are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

### **Benefits and Risks**

The present study's direct benefits to participants include a chance to contribute to important research that may enhance their best practices in working with young children with ASD.

This survey will take approximately 5-7 minutes to complete. Thank you for taking the time to complete this brief survey.

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Page Break

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# **Pediatric Sleep Management of Children with Autism Spectrum Disorder Survey**

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(Modified to fit IRB format)

Q1 Do you use a visit documentation form (i.e. intake form or visit checklist) during routine examinations?

Yes

No

*Skip To: End of Block If Do you use a visit documentation form (i.e. intake form or visit checklist) during routine = No*

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Q2 Does your visit documentation form address sleep problems at least once?

Yes

No

End of Block: Consent

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Start of Block: Sleep Screening Practices

Q3 How often do you screen for sleep problems during routine examinations with patients?

- I **almost always** ask at least one question regarding sleep problems.
- I **sometimes** ask at least one question regarding sleep problems.
- I **never** ask questions regarding sleep problems.

*Skip To: Q8 If How often do you screen for sleep problems during routine examinations with patients? = I **never** ask questions regarding sleep problems.*

Q4 Which sleep topic(s), if any, do you ask to screen for sleep problems?  
Please select yes or no for each sleep related question.

	Yes	No
Routine sleep problems (e.g. usual bedtime/wake time)	<input type="radio"/>	<input type="radio"/>
Lack of sleep (e.g. daytime sleepiness, difficulty waking, frequent awakenings)	<input type="radio"/>	<input type="radio"/>
Disturbed sleep (e.g. bedtime resistance/fears, night terrors/nightmares, bedwetting)	<input type="radio"/>	<input type="radio"/>
Family history of sleep problems	<input type="radio"/>	<input type="radio"/>
Sleep related breathing problems (e.g. snoring/breathing issues)	<input type="radio"/>	<input type="radio"/>
Sleep related movement (e.g. frequent leg kicking, teeth grinding)	<input type="radio"/>	<input type="radio"/>
Co-sleeping (e.g. parents sleeping in close proximity to child)	<input type="radio"/>	<input type="radio"/>

If other, please list below.

Q5 What measure(s), if any, do you use to screen for sleep problems?  
Please select yes or no for each measure.

	Yes	No
BEARS Sleep Screening Tool	<input type="radio"/>	<input type="radio"/>
Pediatric Sleep Questionnaire (PSQ)	<input type="radio"/>	<input type="radio"/>
Sleep Disorders Inventory for Students (SDIS)	<input type="radio"/>	<input type="radio"/>
Children's Sleep Questionnaire (CHSQ)	<input type="radio"/>	<input type="radio"/>

If other, please list below.

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*Display This Question:*

*If How often do you screen for sleep problems during routine examinations with patients? = I  
<strong>never</strong> ask questions regarding sleep problems.*

*And How often do you screen for sleep problems during routine examinations with patients? = I  
<strong>sometimes</strong> ask at least one question regarding sleep problems.*

Q6 In what situation(s), if any, would you ask at least one sleep screening question?  
Please select yes or no for each situation.

	Yes	No
If the parent/caregiver brings up a problem	<input type="radio"/>	<input type="radio"/>
If there is a known family history of sleep problems	<input type="radio"/>	<input type="radio"/>
If the child has depression, anxiety, or other mental health diagnosis	<input type="radio"/>	<input type="radio"/>
If the child has ASD	<input type="radio"/>	<input type="radio"/>
If the child has a behavior problem (e.g. oppositional behavior, aggression)	<input type="radio"/>	<input type="radio"/>
If the child is having learning problems (e.g. difficulty learning, low academic achievement)	<input type="radio"/>	<input type="radio"/>
Other: _____	<input type="radio"/>	<input type="radio"/>

End of Block: Sleep Screening Practices

Start of Block: Treatment of Sleep Problems

Q7 In general, which treatments do you recommend for sleep disorders in children **ages 2-10 years with Autism Spectrum Disorder (ASD)**?

*N/A=Not familiar with this treatment*

	Never	Rarely	Sometimes	Often	Very Often or Always	N/A
Prescription Sleep Aides	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Over the counter products (e.g. Benadryl)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Melatonin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behavioral Management (e.g. parent management training, sleep hygiene resources, relaxation techniques)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referral to a sleep specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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If other, please indicate below.

\_\_\_\_\_

End of Block: Treatment of Sleep Problems

Start of Block: Perceived Barriers and Facilitators to Routine Screening for Sleep Problems

Q8

To what extent do you feel each of the following factors presents a **barrier** to your sleep screening practices during routine examinations?

*N/A = Have not personally experienced this factor*

	Not a Barrier	Slight Barrier	Moderate Barrier	Significant Barrier	Extreme Barrier	N/A
Not enough time during exams to address sleep problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Length of sleep screening tools are too long/too time consuming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not aware of sleep screening tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of knowledge about sleep problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of resources and materials (e.g., available diagnostic and/or treatment services for pediatric sleep disorders)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to sleep specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of reimbursement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



If other, please indicate below.

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Q9 To what extent do you feel each of the following factors serves to **enable** your sleep screening practices during routine examinations?

*N/A = Have not personally experienced this factor*

	Not an Enabler	Slight Enabler	Moderate Enabler	Significant Enabler	Extreme Enabler	N/A
Resources and materials (e.g. availability of diagnostic and/or treatment services for pediatric sleep disorders)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Longer routine exams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shorter sleep screening tools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to sleep specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Experience (i.e. years in practice)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal desire to provide sleep screening and treatment recommendations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If other, please indicate below.

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Q10 Please state whether you agree or disagree with the following statements regarding sleep screening.

	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Screening is not needed, as parents/caregivers will indicate if there is a problem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Screening is not necessary because low incidence of sleep problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep problems are not as important as other health issues.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Perceived Barriers and Facilitators to Routine Screening for Sleep Problems

Start of Block: Perceived Confidence of Practices

**Q11 Please indicate your perceived level of confidence in managing sleep problems in children ages 2-10 years with Autism Spectrum Disorder (ASD).**

	Not Confident	Slightly Confident	Somewhat Confident	Moderately Confident	Extremely Confident
I am able to screen children for sleep problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to advise children (or their caregiver) regarding healthy sleep habits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to recommend appropriate treatment to children with sleep problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Perceived Confidence of Practices

Start of Block: Any other comments?

Do you have any other opinions or comments on the topic of managing sleep problems in children with ASD in primary care settings? Please feel free to use the space below.

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End of Block: Any other comments?

Start of Block: Demographics and Background

Q12 What is your gender?

- Male
  - Female
  - Other: \_\_\_\_\_
- 

Q13 What is your age?

- 20-29
  - 30-39
  - 40-49
  - 50-59
  - 60-69
  - >69
- 

Q14 How would you describe your Race/Ethnicity?

- White/ Caucasian
  - Black/ African American
  - Hispanic/ Latino
  - Asian
  - Other: \_\_\_\_\_
-

Q15 What healthcare provider credentials do you currently hold? Check all that apply.

- MD (Doctor of Medicine)
- DO (Doctor of Osteopathic Medicine)
- DNP (Doctor of Nursing Practice)
- CNP (Certified Nurse Practitioner)
- PA (Physician Assistant)
- Other: \_\_\_\_\_



Q16 What is your area of specialty?

- Developmental/Behavioral Pediatrics
  - Family Medicine
  - General Pediatrics
  - Nurse Practitioner
  - Other Pediatric Subspecialty
  - Pediatric Pulmonology
  - Pediatric Psychiatry
  - Pediatric Resident
  - Other: \_\_\_\_\_
- 

Q17 What type of setting do you practice in?

- Community
  - Academia
  - Community and Academia
  - Other: \_\_\_\_\_
-

Q18 Approximately how many children with ASD do you examine per day?

- 5 or less
- 6-10
- 11-20
- 21-30
- 31 or greater

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End of Block: Demographics and Background

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RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX (813) 974-7091

7/23/2018

Kristin Edwards  
Educational and Psychological Studies  
Tampa , FL 33620

RE: **Exempt Certification**

IRB#: Pro00035935

Title: Sleep Disorders in Children with Autism Spectrum Disorder: A Pilot Study of an Assessment of Pediatric Providers' Practices and Perceptions

Dear K. Edwards:

On 7/20/2018, the Institutional Review Board (IRB) determined that your research meets criteria for exemption from the federal regulations as outlined by 45CFR46.101(b):

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

As the principal investigator for this study, it is your responsibility to ensure that this research is conducted as outlined in your application and consistent with the ethical principles outlined in the Belmont Report and with USF HRPP policies and procedures.

Please note, as per USF HRPP Policy, once the Exempt determination is made, the application is closed in ARC. Any proposed or anticipated changes to the study design that was previously declared exempt from IRB review must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant an amendment or new application.

Given the determination of exemption, this application is being closed in ARC. This does not limit your ability to conduct your research project.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in blue ink, appearing to read "Mark Ruiz", is written over a light blue horizontal line.

Mark Ruiz, PhD, Vice Chairperson  
USF Institutional Review Board