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Parent Perceptions of the Effectiveness of Interventions for
Sleep Problems in Children with Autism

Sarah L. Lemmons

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Educational Specialist

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August 2010

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ABSTRACT

Parent Perceptions of the Effectiveness of Interventions for Sleep Problems in Children with Autism

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The purpose of this study was to learn what interventions have been effective in alleviating sleep problems among children with autism spectrum disorders (ASD) according to parent report. This study also investigated resources from which parents received information regarding possible interventions and to what degree these resources were helpful. The participants in this study were 48 parents and caregivers of children with ASD from both the United States and Canada. Background information was attained from participants regarding themselves and their child with ASD. Participants then answered likert-type and open-ended questions regarding their child's sleep problem(s) and the resources they have turned to for help. Eighty five different interventions were reported to treat 25 types of sleep problems. Participants also reported an overall reduction in the severity of sleep problems experienced by their child after intervention.

Keywords: Autism Spectrum Disorders, sleep problems, intervention, children

ACKNOWLEDGMENTS

The process of completing this project would not have been possible without the help and support of many people. First, I'd like to thank my husband, John, for his patience and support throughout graduate school and in our life together. A special thank you goes to my mom for providing the means and encouragement to attain my master's degree, as well as her hard work in recruiting participants for my survey. I would like to thank Tina Dyches for guiding me through the research process and providing ideas and support. I would also like to thank Ellie Young for her time, ideas, and support. A big thank you to Melissa Allen Heath for being more than generous with her time and working hard on my stats and formatting with me. I am grateful to the organizations and people who published and recruited participants for this research. And finally, thank you to the parents of children with autism who participated in this study, without whom this would not have been possible.

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Introduction

Although sleep is commonly regarded as a time of rest and recovery from the stresses of everyday life, research reveals that sleep is more than that. It is a dynamic activity, during which many vital health processes take place. Sleep is essential to maintain mood, memory, and cognitive performance. It also plays an important role in the normal functioning of the endocrine and immune systems, and studies have shown a link between sleep duration and a variety of serious health problems (Phillips & Gelula, 2006).

The sleep-wake cycle consists of approximately eight hours of sleep and 16 hours of wakefulness and is controlled by two internal influences: sleep homeostasis and circadian rhythms. In homeostasis the body maintains a consistent state of internal condition, including blood pressure, internal body temperature, and pH balance. Throughout the day, the homeostatic drive for sleep increases until a maximum state is reached, typically in the late evening. This happens through an increase in levels of adenosine in the body. As the amount of adenosine increases, so does the need for sleep. During sleep, the level of adenosine decreases (Phillips & Gelula, 2006). Certain drugs, such as caffeine, block the adenosine receptor, therefore inhibiting this process (American Academy of Sleep Medicine [AASM], 2005). Circadian rhythms are the cyclical changes, such as fluctuations in body temperature, hormone levels, and sleep that occur over a 24-hour period. These internal 24-hour rhythms in physiology consist of a group of neurons in the hypothalamus of the brain called the suprachiasmatic nucleus (SCN). Therefore, the homeostatic system tends to make us sleepier as time goes on throughout the waking period, regardless of whether it's night or day, while the circadian system tends to keep us awake as long as there is daylight, prompting us to sleep as soon as it becomes dark (Phillips & Gelula, 2006).

Sleep affects how we look, feel, and perform on a daily basis, and it can have a major impact on our overall quality of life. If sleep is cut short or interrupted, the body doesn't have time to complete all of the phases needed to repair muscle, consolidate memory, and release hormones regulating growth and appetite. Then we wake up less prepared to concentrate, make decisions, or engage fully in daily activities (AASM, 2005).

Statement of Problem

An extensive amount of research has been published regarding sleep problems experienced by children with autism. Much of this research also includes possible preventive and intervention measures; however, information on the effectiveness of interventions for these disorders is often lacking. Any existing information on interventions is defined using differing terms across studies; is difficult to locate, as it is not found in one place; and is written to a professional audience. Also, parents may not actively seek out advice on intervention strategies because they believe children outgrow sleep problems. Without knowledge regarding effective intervention strategies, parents are less likely to implement interventions that could positively impact their child's sleep quality, thus decreasing parent-child conflict and reducing parents' stress.

Statement of Purpose

The purpose of this study was to gain insight from parents of children with autism regarding their views on effective and ineffective preventative and intervention strategies for specific sleep problems commonly found among children with autism. This study also investigated which resources parents had used to gain insight into their child's sleep problem and how helpful these resources have been.

Research Questions

This study will investigate parents' perceptions regarding the following questions.

According to parent report,

1. What specific interventions are effective for reducing or eliminating specific sleep problems?
2. What specific interventions are not effective for reducing or eliminating specific sleep problems?
3. Who provides support for sleep problems in children and adolescents with autism?

Review of Literature

Individuals experience different sleep disorders and sleep problems. This review of literature will review specific sleep disorders and their associated interventions, then illustrate sleep problems experienced by children, and finally define autism and common sleep problems among children with autism.

Types of Sleep Problems

A *sleep disorder* is a condition that interferes with the initiation and maintenance of normal sleep that is considered to be a problem for the individual, significant in its severity, chronicity, frequency, and impairment of daytime functioning (Owens & Witman, 2004). Problems regarding sleep can be highly disruptive to the entire family and are among the most common concerns that parents bring to their physicians (Thiedke, 2001). There are four major classifications of sleep disorders: (a) primary sleep disorders (b) sleep disorders related to another mental disorder; (c) sleep disorders due to a general medical condition; and (d) substance-induced sleep disorders.

Primary sleep disorders. *Primary sleep disorders* arise from internal abnormalities in sleep-wake generating or timing mechanisms (American Psychiatric Association [APA], 1994). They are divided into two categories (a) dyssomnias and (b) parasomnias.

Dyssomnias. *Dyssomnias* are disorders of initiating sleep, maintaining sleep, or excessive sleepiness and are characterized by abnormalities in the amount, quality, or timing of sleep (APA, 1994). Complaints from those suffering from dyssomnias include an inability to fall asleep or excessive daytime sleepiness (Mindell, 1993). Dyssomnias include bedtime problems, excessive daytime sleepiness, awakenings during the night, sleep-disordered breathing, and nocturnal eating and/or drinking (Donaldson & Owens, 2006).

Bedtime problems. *Bedtime problems* occur as a result of poor limit setting, ineffective routines, or poor sleep habits and include limit-setting sleep disorder, insomnia, and adjustment sleep disorder. *Limit-setting sleep disorder* involves difficulty in initiating sleep, typically characterized by stalling or refusing to go to bed (Diagnostic Classification Steering Committee [DCSC], 1990). It is estimated that 5% to 10% of children experience this sleep disorder (Mindell, 1993; AASM, 2005). Children, especially those between the ages of two and six years, may refuse to go to bed despite being physiologically ready (Sheldon, Dahl, Kryger, & Ferber, 2005). Bedtime resistance may represent a mismatch between the child's circadian preference for a later bedtime and parental expectations, or it may be related to the child's nighttime fears (Donaldson & Owens, 2006; Mindell, 1993).

Bedtime problems may also be exacerbated by parents who wish to avoid conflicts with their child, lack knowledge regarding appropriate limit-setting, or are too tired to set firm limits. Ineffective strategies are then often used to avoid the bedtime conflict including: sleeping in the child's bed, allowing the child to sleep in a location other than the bed, or punishing the child physically (Donaldson & Owens, 2006). Inconsistent bed times also add to limit-setting problems. Interventions that have been successfully used are graduated extinction, established bedtime routines, positive reinforcement, systematic ignoring (elimination of parental attention after bedtime), earlier bedtimes, token reinforcement, and relaxation training. Studies on the effectiveness of medications have found them to be of limited to moderate value only when in use. Once removed, their effectiveness dissipates (Mindell, 1993; Owens & Witman, 2004).

People of any age may experience difficulty falling or staying asleep. *Insomnia* is characterized by significant difficulty initiating or maintaining sleep, or of restless or light sleep, which causes negative daytime effects (Donaldson & Owens, 2006). Common complaints of

those suffering from insomnia are difficulty falling asleep and intermittent wakefulness during sleep. Insomnia is often associated with increased physiological or psychological arousal at nighttime in combination with negative conditioning for sleep. It is further exasperated through a vicious cycle of frustration of lack and quality of sleep, leading to anxiety regarding sleep, psychophysiological insomnia, which further increases the insomniatic symptoms (APA, 1994). This type of insomnia is more prevalent in adolescents and adults than in young children. As many as 30% of adolescents experience a form of insomnia, usually described as poor sleep (Mindell & Owens, 2003).

Intervention strategies for insomnia include relaxation, Cognitive Behavioral Therapy (CBT), medication, and diet or food supplements. There are many types of relaxation strategies, including progressive muscle relaxation, visual imagery, deep breathing, and meditation. Progressive muscle relaxation is done by tensing different muscle groups or body parts as tightly as possible and then completely relaxing them. Visual imagery is using the imagination to create a place or activity that is calming or peaceful. Concentrating on this activity or place using the five senses will make the imagery more real and affective. Deep breathing involves taking deep, consistent, slow and repetitive breaths. Meditation involves focusing on a word, phrase, or symbol to quiet thoughts and focus the mind (Kemp, De Benedictis, Segal, & Barston, 2007).

Cognitive Behavior Therapy, which involves confronting and altering beliefs and behaviors about sleep, can eliminate or reduce delusions about sleep and teach positive sleep behaviors. CBT uses stimulus control therapy, paradoxical intention, and sleep restriction to help individuals to replace their current ways of thinking about sleep (Kemp et al., 2007). In *stimulus control therapy*, the individual restricts the use of their bedroom to the sole purpose of sleeping. Non-sleep related activities must occur elsewhere. *Paradoxical intention therapy*

recommends that an individual do the opposite of the desired behavior. Instead of going to sleep, the individual would try to stay awake night after night. Thus, by focusing on doing something other than sleeping, fears they have associated with sleeping will dissolve. In sleep restriction therapy, the amount of time spent awake while in bed is decreased to reinforce the relationship between bed and sleep (Kemp et al., 2007).

Medications are also used for the intervention of insomnia. *Gamma-Aminobutyric acid* (GABA) is the primary inhibitory neurotransmitter and the activation of GABA receptors induces sleep. GABA also acts as a relaxing agent. Successfully used medications for the intervention of insomnia include benzodiazepines (temazepam, flurazepam, estazolam, and triazolam), antidepressants, antihistamines, and barbiturates. Barbiturates are effective short-term interventions but are rarely used because of their likelihood for tolerance. Antidepressants and antihistamines are both effective because they contain sedative properties (Kemp et al., 2007).

Specific foods and supplements have also been shown to reduce symptoms of insomnia. Foods or supplements containing tryptophan and L-tryptophan have been shown to be helpful. Tryptophan is changed in the brain to serotonin, which encourages relaxation and sleepiness. Foods high in carbohydrates may also increase the production of serotonin (Kemp et al., 2007).

Adjustment sleep disorder is a form of insomnia that is related to stress, resulting in emotional arousal (DCSC, 1990). Examples of stressors that may affect sleep include family conflicts, traumatic events, or major life changes such as moving, parental separation or divorce, or the death of a family member. Individuals experiencing this problem will present symptoms of insomnia and may also be excessively sleepy during the day. Symptoms include irritability, lethargy, tearfulness, or anxiety, and begin within three months of the onset of the stressor

(AASM, 2005). Individuals experiencing adjustment sleep disorders may also experience impairments in social and educational functioning (Donaldson & Owens, 2006). These problems typically resolve naturally over time with the removal of the stressor or with improved psychological adaptation to the stressor (AASM, 2005).

Excessive daytime sleepiness. *Excessive Daytime Sleepiness* (EDS) may present itself in a variety of ways in childhood that may not always be intuitively recognized by an observer. Symptoms of EDS include appearing extremely overtired during the day, napping excessively, or having difficulty getting up in the morning. Individuals may also present with mood behavior (such as hyperactivity, impulsivity, or aggression), attention, or learning aptitude (Donaldson & Owens, 2006).

Narcolepsy is characterized by excessive sleepiness, often manifesting itself as repeated episodes of naps or lapses into sleep of short duration throughout the day (DCSC, 1990). Narcolepsy occurs in approximately .03-.16% of the population, with onset typically occurring at adolescence (Mindell, 1993). Narcolepsy may be a cause of daytime sleepiness but is rarely diagnosed in children (Donaldson & Owens, 2006). Hallmark symptoms of narcolepsy include (a) sleep attacks that are sudden, dramatic, and irresistible, and which typically endure less than one hour; (b) cataplexy, a sudden partial or complete loss of muscle tone triggered by emotions; (c) sleep paralysis, the perceived inability to move while falling asleep; and (d) visual and auditory hallucinations that occur at the beginning or end of the sleep period (Brooks & Mignot, 2002). There is no known cure for narcolepsy, so intervention for narcolepsy focuses on management of the disorder, often involving the use of medications such as tricyclic antidepressants or stimulants (Mindell, 1993).

Awakenings during the night. *Awakenings during the night* involve an inability to self-regulate or reinitiate sleep once awakened and must occur during most nights. Three types of awakenings during the night are sleep-onset association disorder, restless legs syndrome, and periodic limb movement disorder. *Sleep-onset association disorder* is primarily found in children between the ages of six months and three years with a prevalence rate of approximately 15-20% and occurs when sleep onset or the transition back to sleep once aroused is impaired by the absence of certain associations, objects, or circumstances, at bedtime, such as being fed or rocked to induce sleep (AASM, 2005; DCSC, 1990; Donaldson & Owens, 2006). Behavioral interventions have been successful in intervention of sleep-onset association disorder and include a positive bedtime routine and graduated extinction (Mindell, 1993).

Restless leg syndrome (RLS) is characterized by uncomfortable sensations that lead to an intense urge to move the legs and is exacerbated by inactivity (APA, 1994). Symptoms of RLS tend to peak at the time of sleep onset, making falling asleep difficult. RLS has only recently been diagnosed in children, but it is known to affect approximately 10% of the adult population (AASM, 2005).

Periodic limb movement disorder (PLMD) is a movement disorder characterized by repeated leg twitching, jerks, or kicking every 20-60 seconds during lighter stages of sleep (APA, 1994). These movements are disruptive to sleep and may persist for minutes to hours; however, individuals with PLMD are not aware of these movements (Donaldson & Owens, 2006). The only recognized symptom is excessive daytime sleepiness, and a child's caregiver may describe the child's sleep as restless.

Sleep-disordered breathing. *Sleep-disordered breathing* or *obstructive sleep apnea (OSA)* is a condition that involves repetitive episodes of obstructed airflow during sleep, often

causing a reduction in the oxygen level in the blood (Marcus, 2001). These episodes cause frequent arousals and brief awakenings throughout the night; however, most people experiencing this disorder are unaware of these occurrences (Mindell, 1993). The age range of diagnosis of this disorder is between 2 and 15 years with a mean age at diagnosis of 7 (Donaldson & Owens, 2006; Mindell, 1993). The prevalence rate among all individuals is estimated to be 1% to 3% (Guilleminault, Palayo, Leger, Clerk, & Bician, 1996). Enlarged tonsils and adenoids are the most common underlying cause of OSA in children. Children with facial or oral anomalies, morbid obesity, neuromuscular conditions, or genetic syndromes such as Down syndrome have an increased incidence rate of OSA (Donaldson & Owens, 2006). The most common symptom of OSA is loud snoring, and it is usually accompanied by noticeable pauses in breathing sounds. Other symptoms include restless sleep, nocturnal sweating, abnormal sleep positions, daytime mouth breathing, poor speech, excessive daytime sleepiness, morning headaches, and difficult awakenings (Donaldson & Owens, 2006; Mindell, 1993). The most common form of intervention for OSA is surgery to remove the airway obstructions. Tonsillectomy or adenoidectomy relieves symptoms in about 70% of cases (Mindell, 1993). Other interventions include weight loss, use of medications, or use of nasal Continuous Positive Airway Pressure (CPAP).

Nocturnal eating or drinking. *Nocturnal eating or drinking syndrome* is similar to sleep-onset association disorder and “is characterized by recurrent awakenings, with the inability to return to sleep without eating or drinking” (DCSC, 1990, p. 101). This disorder is most common among infants and young children. The predominant intervention strategy for this disorder is the gradual removal of the eating or drinking behavior. This disorder occurs less often in children over the age of three than other dyssomnias (Mindell, 1993).

Parasomnias. *Parasomnias* are characterized by abnormal behavior or physiological events occurring in association with sleep, specific sleep stages, or sleep-wake transitions (APA, 1994). *Parasomnias* are further defined as undesirable physical events or experiences that occur during sleep, within sleep, or during arousals from sleep; they include sleep-related movements, behaviors, emotions, perceptions, dreaming, and interactions with the autonomic nervous system (Zaiwalla, 2008). A typical complaint of those suffering from *parasomnias* is unusual behavior during sleep (APA, 1994). *Parasomnias* include nightmare disorder, sleep terrors, sleepwalking (somnambulism), bed-wetting (nocturnal enuresis), and teeth grinding (sleep bruxism). *Parasomnias* are episodic and a reflection of central nervous system immaturity (Thiedke, 2001). As a result, *parasomnias* are more common in children and are typically outgrown over time.

In *parasomnias*, the sleep-wake cycle is disrupted by the activation of physiological systems—such as the autonomic nervous system, motor system, or cognitive processes—at inappropriate times. *Parasomnias* are characterized by an abnormal polysomnography that measures multiple electrophysiological parameters during sleep. Parameters often measured include electroencephalographic (EEG) activity (brain activity), electrooculographic activity (eye movement), and electromyographic activity (muscle movement) (APA, 1994). For the diagnosis of a *parasomnia* to be made, the child must also experience clinically significant distress or impairment, including social distress. Individuals may avoid situations during which others may become aware the disorder (APA, 1994). Common triggers of *parasomnias* include fever, sleep deprivation, emotional factors including stress and excitement, hypnotic medication, sudden environmental noise, and intrinsic triggers for arousals such as a signal to pass urine (Zaiwalla, 2008).

Nightmare disorder. *Nightmare disorder* is the repeated occurrences of frightening dreams that lead to fully alert awakenings from sleep, causing the individual significant distress that cannot be attributed to another mental disorder, direct physiological effects of a substance, or other medical condition (APA, 1994). Nightmares typically occur during REM sleep in an elaborate dream sequence that is anxiety provoking. It often results in difficulty returning to sleep and is more likely to occur during the second half of the night because of longer REM sleep stages occurring during this time. During a nightmare, mild autonomic arousal such as sweating, tachycardia, or tachypnea may be present. However, movements and vocalizations are not typical in nightmare disorder because of the loss of skeletal muscle tone, which needs to be present to move, during REM sleep.

Intervention strategies for nightmares have focused on anxiety reduction, often combined with other behavioral strategies such as systematic desensitization, response prevention, and reinforcement (Mindell, 1993). For most families, reassurance that nightmares are part of normal child development is beneficial (Thiedke, 1994).

Sleep terrors. *Sleep terrors*, also referred to as night terrors, share some common features with nightmare disorder. Both include awakenings or partial awakenings with fearfulness and autonomic activation; however, sleep terrors are differentiated by several clinical attributes. Sleep terrors typically produce only single images or no dream at all (APA, 1994). During a sleep terror episode, the child is difficult to awaken or comfort. He or she may resist being held or touched, or may even perform more elaborate muscle movements such as punching or fleeing. These behaviors appear to be attempts at self-protection, or flight, and may result in injury. Following a sleep terror, the individual will partially awaken and be disoriented, confused, and only partially responsive but with significant autonomic arousal, high EEG

activity, increased muscle tone, and increased heart rate, often more than 120 beats per minute (DCSC, 1990). The individual will typically wake with a panicky scream or cry and will not recall the event in the morning. Usually only one instance of sleep terrors will occur during a given night, although instances of several episodes occurring at intervals throughout the night cannot be ruled out (APA, 1994).

Stress is a common precursor to sleep terrors, and increased stress can lead to increased episodes; therefore, attempts should be made to alleviate whatever stress may be occurring in the environment. Steps should also be taken to ensure that the individual is receiving adequate rest and reassurance (Mindell, 1993). For those whose night terrors are especially disruptive, diazepam (Valium), an anti-anxiety medication, or other benzodiazepines have been used with some success (Thiedke, 2001). Factors that increase the likelihood of sleep terror episodes include alcohol or sedative use, sleep deprivation, sleep-wake schedule disruptions, fatigue, fever, and physical or emotional stress (APA, 1994).

Sleepwalking. The central feature of *sleepwalking disorder* is the occurrence of repeated episodes of complex motor movements that are initiated within the first few hours of sleep and includes rising from bed and walking. Characteristics of sleepwalking disorder are reduced alertness and responsiveness, a blank stare, and relative unresponsiveness to communication; however, the individual's heart rate and respiratory rate may increase at the onset of the episode. If awakened during the episode or upon waking in the morning, the individual will have limited recall of the events of the episode. He or she and may initially appear confused or have difficulty regaining their orientation (APA, 1994).

There are a variety of behaviors possibly included in sleepwalking episodes. In confusional arousals or mild episodes, the individual may only sit up in bed or play with the bed

covering. However, in more typical occurrences of sleepwalking, the individual will get out of bed and may walk into other rooms or even leave the building. Persons may also participate in an activity during an episode, such as eating or using the bathroom. Typically, behaviors performed while sleepwalking are routine and of low complexity (APA, 1994). During an episode, there is also a risk of injury, possibly resulting from bumping into objects or walking down stairs. The risk of injury is further increased if sleepwalking co-occurs with episodes of sleep terrors, particularly those that involve fleeing or striking out (APA, 1994). Individuals may talk or even answer questions during an episode of sleepwalking, but will do so with poor articulation and without truly carrying on a conversation.

A typical episode of sleepwalking lasts from several minutes to half an hour. Termination of an episode can be spontaneous and will be followed by a brief period of confusion. In other instances, the individual may return to bed and sleep normally until rising in the morning. Sometimes the individual may awaken in a place other than where they initiated sleep the night before. Awakening an individual during an episode of sleepwalking is typically very difficult; however, the person may respond to direction to return to bed, doing so with reduced levels of alertness. The presence of either internal (e.g., a full bladder) or external (e.g., noises) stimuli can increase the likelihood of a sleepwalking episode. Psychosocial stressors, alcohol or sedative use, fever, and sleep deprivation can also contribute to an increase of sleepwalking episodes (Mindell, 1993). An association between migraine headaches and sleepwalking disorder has also been found (APA, 1994).

Sleepwalking carries a high potential for risk. Interventions should include taking steps to prevent harm and avoid dangerous situations, such as having the individual's bed on the ground level of the home and making sure that all windows and doors are secured. Another

intervention that various studies have proven effective is scheduled awakenings. To effectively use this intervention, parents need to track the time that episodes of sleepwalking occur over several nights. Once a pattern has been established, parents then wake the individual 15 minutes prior to the time that episodes have been occurring, making sure that the person is fully awake for 15 minutes before allowing him to return to sleep. Use of this technique has been shown to extinguish occurrences of sleepwalking in more than 80% of children (Thiedke, 2001).

Bed-wetting or nocturnal enuresis. *Nocturnal enuresis* is when persistent bed-wetting occurs after age 5 and is divided between a primary condition, when the child has never been persistently dry through the night, and a secondary condition, when the child again starts bed wetting after at least a year of continence (Thiedke, 2001). In most cases of bed-wetting, a strong family history is present. Boys are more likely to experience sleep enuresis. Also, children who have developmental delays are more likely to be enuretic at age six because achieving continence is maturational (Thiedke, 2001). Children who are enuretic have also been found to have a lower functioning bladder capacity; that is, the volume of urine a bladder can hold before starting to empty is perceived by the individual to be less than normal. Actual capacity, however, is the same.

Behavior, external, and medical interventions are often used in intervention of sleep enuresis. Behavioral interventions for bed-wetting include limiting the intake of fluids, particularly caffeine, in the evening and waking the child to use the bathroom at the time the parents retire. These two interventions are often tried prior to seeking a physician's help. Bed-wetting alarms, in which a bell rings when bed-wetting occurs, are also common non-medical interventions because they produce high cure rates (as high as 75% have been reported) and have few side effects with low rates of relapse (Thiedke, 2001). In some cases, a physician may

prescribe tricyclic antidepressants; however, on withdrawal from the medication, few children stay dry. Another medication that has been prescribed to treat bed-wetting is desmopressin (DDVAP), which replaces the hormone that reduces urine production during sleep. The success rate and withdrawal factors of this intervention are equivalent to those of antidepressants (Mindell, 1993).

Sleep bruxism. *Sleep bruxism (teeth grinding)* involves grinding or clenching the teeth during sleep. A recent estimated prevalence rate of bruxism among 3-17 year olds is 15% (Lagerge, Tremblay, Vitaro, & Montplaisir, 2000). Bruxism may lead to dental problems. Abnormal wear on the teeth, periodontal tissue damage, and headaches or jaw pains may all be related to sleep bruxism (Mindell, 1993). Possible interventions for bruxism include dental intervention, such as teeth guards, or stress management approaches.

Sleep disorder related to another mental disorder. *Sleep disorder related to another mental disorder* includes insomnia related to another mental disorder and hypersomnia related to another mental disorder. The essential feature of these disorders is the presence of either insomnia or hypersomnia that is judged to be related temporally and causally to another mental disorder. Sleep disturbances are common features of other mental disorders, often a mood or anxiety disorder. The diagnosis of insomnia or hypersomnia related to another mental disorder is made only when the sleep disturbance is a predominant complaint and is sufficiently severe to warrant independent clinical attention (APA, 1994).

Sleep disorder due to a general medical condition. *A sleep disorder due to a general medical condition* consists of a disturbance in sleep that is severe enough to warrant independent clinical attention and is due to a general medical condition (APA, 1994). There must be evidence that the sleep disturbance is a direct consequence of a general medical condition in the

history, physical examination, or laboratory findings and that the sleep disorder is not better explained by another mental disorder. There are four types of sleep disorders due to a general medical condition: (a) insomnia type, in which the patient feels that sleep is not restful or has trouble sleeping or falling asleep; (b) hypersomnia type, when the main complaint is of excessively long sleep or daytime sleepiness; (c) parasomnia type, when abnormal events occur during sleep or sleep transitions; and (d) mixed type, in which the patient shows multiple symptoms but no one symptom clearly is dominant (APA, 1994).

Substance induced sleep disorder. Substance induced sleep disorder must present a sleep disturbance that is severe enough to warrant independent clinical attention and be caused by the direct physiological effects of a substances. There are four types of this sleep disorder. They are the same types as listed above for those due to a general medical condition: insomnia, hypersomnia, parasomnia, and mixed types (APA, 1994). Onset of this disorder may occur either during intoxication or withdrawal of a substance. Intoxication from alcohol, cocaine, caffeine, or amphetamines and related stimulants all result in the insomnia type of this sleep disorder, with withdrawal from these substances often resembling excessive daytime sleepiness. Sedatives and opioids lead to the hypersomnia type. Sedative-hypnotic drugs can aggravate breathing-related sleep disorder and may cause either daytime sleepiness or withdrawal insomnia (APA, 1994).

Sleep Problems in Children

Sleep problems are common during childhood, especially in younger children and in children with developmental disabilities (Polimeni, Richdale, & Francis, 2005). The National Institute of Health (NIH) estimates that as many as 15% of all children may have a significant sleep disorder that is negatively impacting either their academics, behaviors, social-emotional

development, health, safety, or a combination of these (NIH, 2001). Results from a 1999 study suggest that 20–25% of children and adolescents will develop a sleep disorder (Mindell, Owens, & Carskadon, 1999). Of children with a correctable sleep disorder, perhaps only 1–3% are being referred, accurately diagnosed, and treated (Rosen, Zozula, Jahn, & Carson, 2001). Sleep problems in children typically fall into the dyssomnias and parasomnias categories, with the most prevalent form of sleep problems being parasomnias (Mindell, 1993). The most prevalent parasomnia among children is nocturnal enuresis, otherwise known as bed-wetting (Thiedke, 2001). Other common parasomnias in children include nightmares, sleep terrors, and sleepwalking.

Nightmares often begin between three and six years old in 10–50% of children and are typically outgrown. Nightmare disorder is more likely to occur in children that are exposed to severe psychosocial stressors and are reported more in females than males by a ratio of 2–4:1. Sleep terrors occur in up to 6.5% of children, usually begin in children between the ages of four and 12, reduce or spontaneously eliminate when adolescence is reached, and are more prevalent in boys (Jaffa, Scott, Hendriks, & Shapiro, 1993; Zaiwalla, 2008; APA, 1994). Children with sleep terror disorder frequently have a family history of either sleep terrors or sleepwalking.

Sleepwalking occurs in approximately 10–30 % of children, but the prevalence of sleepwalking disorder is much lower, about 1–5%. Sleepwalking disorder is equally likely to occur in boys and girls and can occur at any time after the child is able to walk, most commonly between 4 and 8 years (APA, 1994). Prevalence of sleepwalking occurs by age 12 and disappears spontaneously during early adolescence (around age 15). There is a familial link with sleepwalking. Approximately 10–20% of children who sleepwalk have an immediate family

member who also sleepwalks. The occurrence of sleepwalking further increases to as much as 60% when both parents have a history of the disorder (APA, 1994).

Comparisons between populations. Studies have been conducted to determine the types and prevalence of sleep disorders among children. Prevalence rates of common sleep disorders among children were found in a study of sleep problems in typically developing children (Spruyt, O'Brien, Cludts, Verleye, & Ferri, 2005). Participants, caregivers of 3,045 children ages 6–13 ($M=9.21$ years), completed questionnaires based on the Heath-Behavior Questionnaire which regarded sleep-wake patterns, sleep environment, and sleep behaviors indicative of sleep disorders. The participants were selected from 10 urban schools and 17 rural schools in Belgium and consisted of equal numbers of males and females. The sample represented all socioeconomic groups. Results indicated the following prevalence rates in typically developing children: bruxism (4.27%), nightmares (3.97%), excessive daytime sleepiness (3.68%), sleep terrors (3.65%), sleepwalking (2.27%), periodic limb movement disorder (1.90%), restless legs syndrome (1.28%), and sleep apnea (0.85%) (Spruyt et al., 2005).

A study conducted by Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, and Hansen (2008) compared sleep problems reported by parents of 529 children; of these children, 303 were diagnosed as having autism, 63 as having developmental delays (DD) but not autism, and 163 as typically developing (TD). Children's ages ranged from 2 years old to 5 years old. The sample included 88.1% male in the autism group, 73.0% male in the DD group, and 82.2% male in the TD group. The ethnicity profile for the TD group and the autism group were similar with 47–51% white, 31.9–32.3% Hispanic, and 16.5–20.2% being classified as other. The DD group had a higher percentage of Hispanic respondents (44.4%). Results from the autism group are included in the following section on sleep problems among children with autism. Prevalence

rates of sleep problems within the TD group were as follows: any perceived sleep problems (31.9%), sleep onset (31.9%), and night waking (1.8%). The most common reported sleep onset problems were limit setting sleep disorder (15.9%), going to bed at different times (12.9%), and difficulty falling asleep (8.6%). Of the TD group, 1.8% reported waking up screaming approximately two hours after going to sleep, and 0.6% reported having nightmares. More sleep problems were perceived among the DD group than the TD group, with 46.0% reporting some type of sleep problem. Of the DD group, 46.0% reported problems with sleep-onset and 3.2% with frequent night waking. The most common reported sleep onset problems were going to bed at different times (31.7%), trouble falling asleep (19.0%), sleeping better in places other than own bed (17.5%), resisting bed time (15.9%), sleeping less than other children of the same age (9.5%), and throwing tantrums at bedtime (9.5%).

Children with Autism. *Autism* is a pervasive developmental disorder with symptoms that are manifested along a continuum, from mild to severe. It is one of the autism spectrum disorders (ASD), which also include Asperger syndrome, and Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS). Autism is diagnosable in early childhood (with symptoms manifested prior to age three) and is characterized by marked abnormalities in communication and social interactions, as well as a restricted and socially atypical range of interests (Richdale, 1999). Typical characteristics of autism include avoiding cuddling or making eye contact; not responding to voices or other sounds; not talking or using language properly; rocking back and forth; spinning or banging his or her head; staring at parts of an object, such as the wheels of a toy car; not understanding hand gestures or body language; not pretending or playing make-believe games; being very concerned with order, routine or ritual; having a flat facial expression or using a monotone voice; injuring himself or herself; or being

unafraid of danger (American Academy of Family Physicians, 2005). Other characteristics include poor play skills with stereotypic activity, restlessness with attention deficits, seizures, and abnormal response to stimuli (Gillberg & Coleman, 1996).

The Centers for Disease Control and Prevention report that 1 in 150 children are diagnosed with autism at the age of eight (The Centers for Disease Control and Prevention [CDC], 2009). Autism is the fastest growing developmental disorder, being diagnosed at an increasing rate of 10–17% a year, and occurring in all racial, ethnic, and social groups, and is four times more likely to affect boys than girls. While there is no known single cause for autism, it is generally accepted that it is caused by abnormalities in brain structure or function. Currently, there are no effective means to prevent autism, no fully effective interventions, and no universally accepted cure (Autism Speaks [AS], 2009).

Approximately two-thirds of school age children with autism are likely to experience some type of sleep disturbance (Richdale & Schreck, 2009). Among children with autism, 3% of visits to the doctor are specifically for seeking help for a sleep problem (American Academy of Pediatrics, 2008). Unlike typically developing children, whose sleep problems are predominantly parasomnias, children with autism are more likely to suffer from dyssomnias, problems with initiating and maintaining sleep (Mindell, 1993; Richdale 1999, 2001). This may include problems with irregular sleep-wake patterns, long sleep latencies, sleep onset, early and night waking, poor sleep routines, shortened night sleep, alterations in sleep onset and wake times, night walking, irregular sleep patterns, behavioral problems at bedtime, unusual sleep routines, and settling difficulties (Richdale, 1999, 2001).

Cotton and Richdale (2006) found that compared to children with other disabilities (Down syndrome, Prader-Willi syndrome, and non-specific intellectual disability) and a control

group of TD children, children with autism had the highest percentage of sleep problems (73.0%). In the control group, only 10.9% reported experiencing sleep problems (Cotton & Richdale, 2006). The problems most frequently reported by the parents of children with autism were difficulty settling at bedtime and sleep maintenance.

In 2004, Williams, Sears, and Allard surveyed 210 families of children with documented diagnoses of autism. The survey consisted of Likert-type questions with responses ranging from “never a problem” to “always a problem.” The age of the children ranged from 2 to 16, with a mean age of 8.4 years, and the group included 169 males and 32 females. To determine the frequency of sleep problems, the researchers investigated those responses that were reported as “always” or “frequently.” Based on this survey, the most commonly reported sleep problems were difficulty falling asleep (53% of children), restless sleep (40%), unwillingness to fall asleep in own bed (40%), frequent awakenings (34%), and difficulty arousing from sleep (32%). These common sleep problems likely reflect problems with the sleep-wake cycle. The least frequently reported sleep problems were sleepwalking (1%), morning headaches (1%), crying during sleep (2%), apnea (3%), and nightmares (4%) (Williams et al., 2004).

Researchers found that of 303 children with autism, 52.5% were reported to have frequent sleep problems, 51.2% reported sleep onset problems, and 9.9% reported night waking problems. Having trouble falling asleep (24.4%), going to bed at different times (22.1%), and resisting going to bed at night (21.8%) were the most common problems reported (Krakowiak et al., 2008).

In contrast to some previous studies, a 1999 study of 22 children with autism ages 3–12 years found that when sleep was measured by actigraphy (monitoring of the sleep-wake cycles through a sensor worn on the wrist), despite earlier morning waking, there were no significant

differences between the sleep patterns or duration of sleep in children with autism and healthy controls (Hering, Epstein, Elroy, Iancu, & Zelnik, 1999). In a similar study, Schreck and Mulick found no differences in total duration of sleep per night or in total duration of naps per day as a function of age or group classification (autism, mental retardation and developmental disabilities, pervasive developmental disorder not otherwise specified, and control). Although no difference in quantity of sleep was found, researchers did find a significant difference in the quality of sleep and sleep behavior as reported by the parents of the participants, with parents of children with autism reporting more sleep problems than any other group (Schreck & Mulick, 2000).

Researchers suggest many different interventions to treat sleep problems in children with autism. Richdale (1999) reports that the most frequently used interventions to treat sleep problems in children with autism are behavioral and medical. Common behavioral interventions include applied behavior analysis (in which the behavior is analyzed using behavior assessment to determine the function of the behavior within the environment; the behavior is replaced with a new behavior that serves the same function but in an acceptable way) and cognitive behavior therapy. Common medical interventions include (a) melatonin, (b) multi-vitamin and mineral supplements, (c) anti-depressants, and (d) anti-psychotics. Other interventions for treating sleep problems in children with autism include (a) assistance dogs (b) massage, (c) social stories, (d) special diets, and (e) changes in the sleep environment (American Academy of Pediatrics, 2008; Research Autism, 2008). However, there is a lack of information regarding the effectiveness of these interventions (Polimeni et al., 2005).

Effects on Daily Functioning. Sleep problems may interfere with aspects of a TD child's or child with autism's daily functioning and have been linked with cognitive, verbal, and attention impairments; self-help; and behavior problems, including injury-prone behavior

(Krakowiak et al., 2008). Children with sleep problems may also experience problems related to health, mood, behavior, academic performance, overall quality of life, social-emotional development, and safety (Richdale, 1999). Specifically, children who are excessively sleepy during the day may have trouble concentrating at school and may also be considered a behavior problem in the classroom (Mindell, 1993). Kahn et al. (1989) found that 21% of preadolescents who were identified as poor sleepers had failed at least one year of school. These children also experienced more achievement difficulties than children without sleep difficulties despite spending an equal amount of time on homework (Mindell, 1993). Some sleep problems interfere with social functioning; for example, an older child who continues to be enuretic will avoid situations in which he or she will not be sleeping at home. Poor sleep has also been linked to weakened immune systems, making children more prone to infections (Owens, 2006).

Sleep problems also have an impact on the family. Sleep disturbances increase the parenting burden and family stress. According to a 2007 study, mothers of typically developing preschool students with a parent-reported sleep problem also experience poor general health (Martin, Hiscock, Davey, & Wake, 2007). Of parents who report that their child has a sleep disturbance, 80% report that their sleep is also disrupted (Polimeni et al., 2005). These parents are more likely to experience stress, depression, or poor marital relationships than those whose children have developmental disabilities without a sleep disorder (Chavin & Tinson, 1980; Quine, 1992). Family stress was associated with poorer sleep quality in school-age children with typical development and in children with developmental disabilities (El-Sheikh, Buckhalt, Mize, & Acebo, 2006).

Method

Research Design

This research was initiated to investigate parental perceptions of the effectiveness of interventions for sleep problems among children with autism. This study was designed as an exploratory study (Creswell, 2003; Grinnell & Unrau, 2008) using survey methodology and requiring quantitative and qualitative responses to provide a foundation for future research. Quantitative data are presented as descriptive statistics. Participants' open-ended responses to survey questions were reduced, summarized, and categorized in a simplistic manner.

Participants

The sample consisted of parents of children and adolescents with autism. The sample was a convenience sample, where participants were selected, in part, at the convenience of the primary researcher. Therefore, this sample does not represent the general population. Participants were recruited through multiple resources: the Utah Parent Center; Clear Horizons Academy, a school for children with autism; Nebo school district; Dr. Mickle South, a private provider of services to children with autism and their families; and two early intervention providers, Kids on the Move and Kids Who Count. A representative from each school or organization was sent a letter describing the research and asked that they include an announcement in their newsletter or send an email out to parents requesting parent participation. For example, the Utah Parent Center, founded by parents in 1984, offers information to parents that will encourage them to help their children live more productive lives in community settings. The center included an announcement in their electronic newsletter regarding this study and requesting parent participation. Additional participants were recruited through personal contacts,

an open invitation posted on autism-blog.com, and an invitation sent via Facebook, a social networking website.

The sample ($N = 48$) was composed of parents and caregivers of children with autism: 43 mothers (89.6%), four fathers (8.3%), and one grandparent (2.1%). The mean age of participants was 38.50 with an age range of 27 to 58 and a standard deviation of 7.38 years. Participants reported residing in two countries (U.S. and Canada) and represent six states and one province: Utah ($n=30$, 62.3%), Alabama ($n=8$, 16.7%), New York ($n=3$, 6.3%), Texas ($n=3$, 6.3%), Arizona ($n=1$, 2.1%), California ($n=1$, 2.1%), North Carolina ($n=1$, 2.1%), and Alberta, Canada ($n=1$, 2.1%).

The sample was 95.8% Caucasian ($n = 46$) and 2.1% Hispanic or Latino ($n = 1$). One participant did not list their ethnicity (2.1%). The participants provided information regarding their highest level of education: 19 had completed some college (39.6%), 13 had earned a bachelor's degree (27.1%), eight had graduate degrees (16.7%), five had an associate's degree (10.4%), three had high school diplomas (6.3%) (see Table 1).

Information provided by participants indicated that 58.3% of the children were diagnosed with autism ($n=28$), 29.2% with Asperger syndrome ($n=14$), and 12.5% with pervasive developmental disorder—not otherwise specified (PDD-NOS) ($n=6$). Three participants reported their child as having a co-morbid diagnosis: autism with apraxia ($n=1$, 2.1%), Asperger syndrome with sensory processing disorder ($n=1$, 2.1%), and Asperger syndrome with depression ($n=1$, 2.1%). The participants' children were 83.3% male ($n=40$) and 16.7% female ($n=8$) with a mean age of 10.21 years (range 3–21 years). 10 participants did not state their child's age. The mean of children's age when they started having sleep problems was 1.69 years of age, with an age range of birth to 13 years.

Table 1
Demographic Characteristics of Participants

Demographic Information	<i>n</i>	%
Relationship to child		
Father	4	8.3
Mother	43	89.6
Grandparent	1	2.1
Ethnicity		
White	46	95.8
Hispanic	1	2.1
Unknown	1	2.1
Location		
Utah	30	62.3
Alabama	8	16.7
New York	3	6.3
Texas	3	6.3
Arizona	1	2.1
California	1	2.1
North Carolina	1	2.1
Alberta, Canada	1	2.1
Level of Education		
High school diploma	3	6.3
Some college	19	39.6
Associate's degree	5	10.4
Bachelor's degree	13	27.1
Graduate degree	8	16.7

Note. *N*=48.

Measures

Data were collected from all participants using a web-based survey (see Appendix A). Prior to finalizing the survey, an online pilot test was conducted with a convenience sample of five parent volunteers associated with the primary investigator. Volunteers were parents and caregivers of children with autism. The primary investigator interviewed parent volunteers by phone to gather information on their experience completing the survey. Their feedback assisted in streamlining the survey to ensure understanding and ease of responding. Participants were asked the following questions: Did you have any difficulty completing the survey? Do you have

suggestions to improve the survey? Were any questions hard to understand? Were any questions offensive? Please offer any other suggestions.

The final survey consisted of 30 questions. The first section comprised 13 demographic questions. Demographic questions included both multiple-choice and fill-in-the-blank responses. The second section of the survey had 17 Likert-type and open-ended questions. The survey included three areas of interest: demographic questions about the parent/caregiver, demographic questions about the child with ASD, and questions about sleep problems and intervention information.

The adult questions included role of the caregiver (mother, father, relative: please explain, or other caregiver: please explain); age (fill in the blank); ages of the dependant living in the home (fill in the blank); ethnicity (7 selections); county and state of residence (fill in the blank); and highest level of completed education (ranges of education were offered).

Child-based questions requested information about the diagnosis (multiple choice); age (fill in the blank); gender (M/F); educational setting (multiple choice); level of academic achievement (multiple choice); medications (Y/N and list); medications' affect on sleep (Y/N and explain); age of child at the onset of the sleep problem (fill in the blank); current relevance of the sleep problem (Y/N); description of the child's sleep environment (open-ended); and official diagnosis of a sleep problem (Y/N and explain).

The Likert-type and open-ended questions included three areas of interest: (1) the nature of the child's sleep disorder/problem; (2) intervention for the sleep problem that was found to be most effective, including where parents obtained information and support; and (3) intervention for the sleep problem that was least effective, including where they obtained information and support.

Procedures

Upon receiving Institutional Review Board (IRB) approval, the primary researcher worked with the various program coordinators to include a description of the research in their electronic newsletters, through their email distribution lists, or in paper form, along with a link to the survey. Interested parents or caregivers were given the opportunity to click on the hotlink and complete the survey via web-based survey software, Qualtrics. The survey's initial page included an informed consent (Appendix A) detailing the study's purpose, risks, and benefits. The informed consent also provided contact information for the primary investigator, thesis chair, and BYU's IRB Chair. After reviewing the informed consent, participants had the option of clicking an "I agree" button to access the survey login page. Appendix B contains the survey. The survey was available online to parents for 30 days after the initial announcement.

Data Analysis

Research data were collected using a web-based survey. The demographic and Likert-scale questions were analyzed quantitatively and described with descriptive statistics, including percentages, means, standard deviations, and ranges. Several open-ended questions required the participant to enter responses in their own terms. The open-ended questions were analyzed for specific content. Common themes, particularly children's sleep problems and interventions, were coded and summarized descriptively. The primary researcher then coded these items into themes. Coding was checked for accuracy on all surveys ($N=48$) by a secondary researcher. Inter-rater agreement was above 90% on all categories. On items where disagreements occurred, the researchers discussed and resolved points of disputed coding.

Results

Parents and caregivers of children identified with ASD responded to questions regarding their child's sleeping problems. In this section, results summarize participants' concerns and interventions they utilized to address these problems. Additionally, parents reported where they received support regarding their child's sleep problems and rated the effectiveness of this support. Fewer participants than expected identified their child as having a diagnosed sleep disorder ($n=5$, 10.4%); however, all parents ($N=48$) reported their child as having at least one sleep-related problem. Therefore, the data were analyzed to address parents' concerns regarding sleep problems affecting their child.

Parents reported a total of 25 different sleep problems. Of the problems reported by participants, 66.7% were dyssomnia-like problems, 28.3% were parasomnia-like problems, and 5.1% were other problems affecting their child's ability to sleep. The majority of participants ($n=34$, 70.8%) reported their child as experiencing multiple sleep problems. The following are selections of descriptions of problems that were given by participants to illustrate the variance of problems experienced by their children. The parent of an 11-year-old boy with autism discussed the history of her son's sleeping problems:

From birth, [my son] woke through out the night. When the autism hit at 19 months there was a change in his sleeping pattern. He couldn't fall asleep easily. Once he did fall asleep, he would only sleep for an hour or two and then awaken. He would stay in bed [and] rock, laugh hysterically, bang his head, [and] bite himself. It was so loud at times that it would awaken the rest of the household.

A mother of a three-year-old boy with autism described her son's struggles with sleep starting at a young age:

He has rarely taken naps since he was 1. He likes to drink juice or something if he wakes up at night. Sometimes he has night terrors and will raise up his arms/body and cry and then lay back down (not awake during this). His props are our ears and/or moles which he rubs to soothe himself. When he does take a nap, he will sleep too much or too late in the

day and then stay up too late. He is still in diapers and will wet through his diaper often. He does get out of bed and so far he has not gone out of the house, just to another bed. He likes to touch someone else with his feet or hands.

A 13-year-old boy with Asperger Syndrome was reported to have multiple problems with sleep:

As an infant our son had difficulty falling asleep, even when obviously tired. He has always slept VERY deeply and we suspect his sleep does not follow “normal” sleep patterns. For example, although he had difficulty falling asleep, once asleep we could go into his room, turn on the light, change his diaper, including using cold wipes, change his pajamas, and tuck him back in bed all without waking him. He also did not sleep a “normal” length of time, usually waking in the very early hours of the morning, around 3:00 or 4:00am, ready to get up and play. He rarely took naps during the daytime, even as a baby. When he was little he also periodically suffered from night terrors, which were probably more upsetting to us than to him since he never remembered them afterward. When he was younger he needed his pacifier to fall asleep. When he was about four years old his pacifiers all “got lost” and he started chewing on the edge of his sheets, blankets, pillows, etc. He wet the bed frequently until he was about ten or eleven.

Participants also reported using a broad spectrum of interventions (n=82) in an attempt to reduced or eliminate their children’s sleep problems, sometimes using multiple interventions to alleviate individual sleep problems. The following are excerpts from participants that illustrate the various interventions that were implemented. The mother of an 11-year-old boy with autism reported her son’s sleep history:

When he was about 4–5, he wasn’t on any kind of medication yet, and he literally would sleep for an hour or two at night. That’s it. He wouldn’t stay in his room, so his “bed” was the living room couch, where he’d just hang out an[d] watch Noggin. That lasted a few years. He has been on Risperdal, Abilify, and no, Geodone, which not only improve[d] his behavior (e.g. no choking strangers at the grocery store), but we make sure to give them at a time of day where the tired/dizzy side effect is also effective at getting him to sleep. We’ve been lucky with the Geodone that he actually seems to be able to sleep ALL NIGHT, rather than just for a few hours. The other night there was a miscommunication between my husband and I, and he [the child] never got his dose. We figured it out when it was 2:30am and he was still going strong, with no signs of fatigue.

The parent of a 13-year-old boy with Asperger Syndrome reported using interventions to try and alleviate the child’s sleep problems:

After a great deal of trial and error and sleepless nights we discovered that loud television static helped him fall asleep. Interestingly, no other “white” noise source seemed to be as

effective, including radio static. We also discovered that he slept best when wrapped very snugly in a blanket, and as he got older, with pillows on the sides as well as under his head.

Several participants expressed frustration in trying to resolve their child's sleep problems.

The following descriptions were given by parents. The mother of a nine-year-old boy with autism discusses how her interventions have failed:

[My son] is difficult to get to bed, won't stay in bed, occasionally reward systems work for short periods. We start the bedtime routine at about 8:30 for him and it usually takes until 11:00 or later until he is finally down for the night, although it is not unusual for me to wake up at 2:00 or 3:00 a.m. and find him in another room reading a book or to find evidence of a midnight feast on the kitchen table after we thought he was fast asleep. Sometime [he] has a hard time waking up in the morning, but not always. He gets his concerta pill at 6:30 and usually falls back asleep until it kicks in at about 7:30 a.m. We give it to him early in hopes that it will wear off earlier so he can fall asleep sooner at night. [His sleep problems] seem to have worsened. We used to be able to get him to sleep by staying in his room with him but that strategy no longer works.

A two-year-old boy with autism's mother stated, "...while taking out naps did help his nighttime sleep, it destroyed his ability to cope with everyday life during the day." The mother of a ten-year-old girl with autism reported frustrations with interventions that are commonly recommended and her daughter's sleep problems:

She has a set routine for bed but it doesn't seem to help any. Typical calming things don't seem to make a difference (bath, soft music, reading to wind down, etc.) She seems too alert and too awake at night, like her mind can't slow down and stop. She used to wake up multiple times a night for long amounts of time but that has stopped. If she does wake up, she can't go back to sleep for hours. She has always had trouble staying in bed because she's still so wound up, even if she hasn't had more than 2-3 hours of sleep the night before. No toy, blanket, etc. makes any difference. When she was younger, she would wake up screaming for a few months until we discovered it was reflux and related to what she was eating. Since she's become potty trained, she is waking up less at night. She has had sleep issues since she developed autism and it has been very problematic for the family.

Sleep Problems and Effectiveness of Associated Interventions

The survey results are organized according to when the sleep problem occurred, the child's type of sleep problem, and interventions implemented to address specific sleep problems. The sleep problems were categorized into four types: bedtime delays, internal difficulties achieving restful sleep, nighttime behaviors and physical ailments, and waking and alertness. Interventions reported by parents were categorized into the following types of interventions: (a) medical and pharmaceutical, (b) environmental, (c) change in routine, (d) dietary change, (e) behavioral, (f) physiological, and (g) psychological.

Of the seven types of interventions used, environmental interventions were used the most frequently, 57 times by 31 participants. Participants used medical and pharmaceutical interventions 53 times ($n=27$), changes in routine 48 times ($n=25$), physiological interventions 30 times ($n=21$), behavioral interventions 20 times ($n=17$), dietary interventions 19 times ($n=15$), and psychological interventions were used four times ($n=5$). Overall, participants reported that Dietary interventions were the most effective at reducing sleep problems ($M=1.95$, $n=19$). See table 2 for information regarding the effectiveness of other types of interventions. Specifically, participants reported using the following three interventions most frequently: (a) bedtime routine ($n=17$, $M=2.35$), (b) unspecified medication ($n=12$, $M=2.08$), and (c) melatonin ($n=11$, $M=2.45$). All types of interventions were reported to reduce sleep problems. Appendix D contains additional information regarding all interventions reported and their overall effectiveness. Tables containing information regarding the effectiveness of specific interventions for specific sleep problems are located in Appendix C.

Table 2

Parents' Perceptions of Overall Effectiveness of Types of Interventions in Treating Sleep Problems

Intervention type	<i>n</i> Participants reporting intervention	Occurrence of Interventions of this type	<i>M</i> ^a	<i>SD</i>
Environmental	31	57	2.14	0.72
Medical and Pharmaceutical	27	53	2.21	0.88
Change in Routine	25	48	2.27	0.65
Physiological	21	30	2.10	0.59
Behavioral	17	20	2.35	0.75
Dietary	15	19	1.95	0.71
Psychological	4	5	2.00	0.71

Note. *N*=46. Intervention types are listed according to the number of participants who reported using the intervention type starting with the most frequent. ^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Table 3 shows the overall effectiveness parents reported regarding interventions' impact on specific types of sleep problems. The table also includes the number of parents reporting sleep problems within each category. According to participants' reports, as a whole, all sleep problems were reduced through intervention.

Bedtime delays. Eleven participants expressed that their children had problems that led to a delay in getting to bed. These problems were bedtime refusal, overstimulation, and an unusual bedtime routine. The largest proportion of these problems was related to bedtime refusal.

Bedtime refusal. Eight participants reported their child experienced bedtime refusal. The most frequently used interventions to help resolve bedtime refusal were environmental (*n*=7), changes in routine (*n*=5), physiological (*n*=4), medical and pharmaceutical (*n*=2), and dietary (*n*=1). Parents did not report using behavioral or psychological interventions (see Table 4). One parent reported that eliminating red-40, a food dye, had a positive impact on his child's sleep.

Table 3

Parents' Perceptions of Overall Interventions' Effectiveness in Treating Specific Sleep Problems

Sleep problem	M^a	SD	n Participants reporting problem
Bedtime delays			
Bedtime refusal	2.06	.64	8
Overstimulation	2.22	.83	3
Unusual sleep routine	1.50	.70	1
Internal difficulties achieving restful sleep			
Nighttime awakening	2.23	.65	11
Sleep latency	2.28	.58	8
Sleep latency and nighttime awakening	2.78	1.09	3
Insomnia	2.33	1.53	3
Nightmares	2.44	.53	3
Night terrors	1.71	.49	5
Nighttime behaviors and physical ailments			
Not staying in bed	1.90	.91	12
Nighttime activity, disturbing others	2.31	.75	7
Nighttime activity, not disturbing others	2.00	.00	1
Nighttime eating and drinking	2.00	.00	1
Bed wetting	2.25	.91	9
Teeth grinding	2.00	.00	1
Sleepwalking and sleep talking	2.50	.71	1
Leaving house	2.50	.71	1
Physical pain preventing sleep	2.25	.50	2
Harming self	2.00	1.41	1
Restless legs	2.00	.00	1
Unusual sleeping positions	1.00	.00	1
Seizures	1.00	.00	1
Waking and alertness			
Abbreviated sleep time	2.21	.43	6
Difficulty waking	1.67	.58	3
Excessive daytime sleepiness	2.33	.82	7

Note. $N=46$.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Table 4
Bedtime Refusal: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.50	.71	2
Melatonin	3.00	.00	1
Unspecified medication	2.00	.00	1
(2) Environmental	2.43	.53	7
Parents in the child's room	2.00	.00	1
Remove stimulating materials	2.00	.00	1
Unspecified environmental change	3.00	.00	3
Weighted blanket	2.00	.00	1
White noise	2.00	.00	1
(3) Change in routine	1.80	.45	5
Bedtime routine	2.00	.00	1
Scheduled awakenings	2.00	.00	1
Unspecified change in routine	1.50	.71	2
Visual schedule	2.00	.00	1
(4) Dietary change	1.00	.00	1
Eliminate red-40	1.00	.00	1
(5) Behavioral –none reported	.00	.00	0
(6) Physiological	1.67	.58	4
Increase daytime physical activity	2.00	.00	1
Massage	2.00	.00	2
Relaxation/relaxing activity	1.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Eight parents reported this problem as challenging in their child with ASD (bedtime refusal). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Environmental ($n=7$, $M=2.43$) and medical and pharmaceutical ($n=2$, $M=2.5$) interventions resulted in a reduction of bedtime refusal. Physiological intervention ($n=4$, $M=1.67$) and change in routine ($n=5$, $M=1.80$) were the most successful in reducing bedtime refusal overall.

Relaxation, a physiological intervention, eliminated bedtime refusal for one participant. The physiological interventions of increasing daytime activity and massage reduced bedtime refusal. Bedtime routine, scheduled awakenings, a visual schedule, and an unspecified routine were all changes in routine that reduced bedtime refusal. Environmental interventions that reduced bedtime routine included having parents in the child's room, removing stimulating materials, using a weighted blanket, and adding white noise. An unspecified medication was also found to reduce bedtime refusal (see Table 4).

Overstimulation. *Overstimulation* occurs when a child experiences increased physiological or psychological arousal (DCSC, 1990). Three participants reported their child experienced overstimulation. The most frequently used interventions to help resolve overstimulation at night were medical or pharmaceutical ($n=5$), then changes in routine ($n=2$), physiological ($n=1$), and environmental ($n=1$). Parents did not report using dietary change, behavioral or psychological interventions. Medical and pharmaceutical interventions were reported to have a mean success rate of 2.20 ($n=2$), an overall reduction in overstimulation. Change in routine resulted in some decrease in overstimulation ($n=2$, $M=2.5$).

An unspecified medication was reported to eliminate the problem of overstimulation; however, this type of intervention was only used by one participant. Using melatonin, darkening the child's room, changing bedtime routine, and increasing daytime activity were all found to reduce overstimulation. An unspecified change in routine and medical and pharmaceutical interventions and taking L-Tyrosine or magnesium were reported to have no effect on

overstimulation. One participant listed two interventions: “bought all sleep problem books” and “asked [the] doctor.” These means of gaining information regarding the sleep problem and possible interventions were not interventions by themselves; therefore, these items were not coded as interventions.

Unusual sleep routine. One parent of a ten-year-old boy with PDD-NOS described her child’s most challenging problem as having an unusually long sleep routine.

The most challenging [sleep problem] has been following his rituals, getting him to bed, to go to sleep, and then to stay asleep in his own room. Sometimes when he wakes it is hours to get him back to sleep. He has a very specific way the night must go and that is it. If all the rituals are not followed, he will not go to sleep.

Gradually changing the bedtime routine eliminated the problem. Another intervention used by this participant was positive reinforcement which reduced the problem.

Internal difficulties achieving restful sleep. Thirty-one participants expressed that their child had internal difficulties making the achievement of restful sleep difficult. These problems were categorized into six problems: (a) nighttime awakening, (b) sleep latency, (c) a combination of nighttime awakening and sleep latency, (d) insomnia, (e) nightmares, and (f) night terrors. The largest portion of these problems was related to nighttime awakening.

Nighttime awakening. Nighttime awakenings involved an inability to self-regulate sleep once awakened, possibly resulting in multiple awakenings throughout the night (DCSC, 1990). Nighttime awakening problems were reported by 11 participants. The most frequently used interventions to help resolve nighttime awakening were medical and pharmaceutical ($n=13$), then changes in routine ($n=9$), physiological ($n=5$), environmental ($n=4$), and dietary ($n=4$). Parents did not report using behavioral or psychological interventions (see Table 5). All types of interventions used were successful in reducing nighttime awakenings overall.

Table 5
Nighttime Awakening: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.15	.80	13
Benadryl	2.00	.00	1
L-Tyrosine	3.00	.00	1
Magnesium	2.00	1.41	2
Melatonin	2.00	1.00	3
Sleep Aid	2.50	.71	2
Zantac	2.00	.00	1
Trazodone	3.00	.00	1
Unspecified medication	1.50	.71	2
(2) Environmental	2.00	.82	4
Earmuffs	1.00	.00	1
Keep child warm	3.00	.00	1
Sleep with parents	2.00	.00	1
White noise	2.00	.00	1
(3) Change in routine	2.44	.53	9
Bedtime routine	2.60	.55	5
Change nap schedule	2.00	.00	2
Stay up later	3.00	.00	1
Turn on movie/TV	2.00	.00	1
Unspecified change in routine	2.00	.00	1
(4) Dietary change	2.25	.50	4
Eliminate red-40	2.00	.00	1
Eliminate gluten, casein, and sugar	2.00	.00	1
Snack prior to bedtime	3.00	.00	1
Unspecified dietary change	2.00	.00	1
(5) Behavioral –none reported	.00	.00	0
(6) Physiological	2.20	.45	5
Attending to toileting needs	2.00	.00	1
Increase daytime physical activity	2.50	.71	2
Limit daytime sleeping	2.00	.00	2
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. 11 Parents reported this problem as challenging in their child with ASD (awakening during night). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

The use of earmuffs eliminated nighttime awakening; however, this intervention was only reported by one participant. Medical and pharmaceutical interventions that reduced nighttime awakening were Benadryl, magnesium, melatonin, unspecified sleep aids, Zantac, and unspecified medication. Sleeping with parents, turning on a movie or TV, and white noise were environmental interventions that reduced nighttime awakening. Changes in routine that reduced nighttime awakening involved bedtime routine, nap schedule, and an unspecified change in routine. The dietary interventions of eliminations of red-40, gluten, casein, and sugar, and an unspecified dietary change reduced nighttime awakening. Three physiological interventions reduced nighttime awakening: attending to toileting needs, increasing daytime activity, and limiting day time sleeping. Using L-Tryosine or Trazodone, keeping the child warm, staying up later, and having a snack prior to bed were reported to have no effect on nighttime awakening (see Table 5).

Sleep latency. *Sleep latency* is the amount of time that passes between when the child gets in bed and falls asleep. When this is an extended period of time, it is a sleep latency problem. This problem was reported by three participants. Parents reported the most frequently used interventions to help resolve a sleep latency problem were medical and pharmaceutical ($n=10$) and environmental ($n=10$). Physiological ($n=7$), change in routine ($n=5$), dietary ($n=1$), behavioral ($n=1$), and psychological ($n=1$) interventions were also used (see Table 6). All types of interventions used resulted in reducing the child's sleep latency problem except for behavioral ($M=3.00$), used by one participant, which had no change. The use of a combination of melatonin and hydroxyzine ($n=1$, $M=1.00$) was the only intervention reported to eliminate a sleep latency problem; however, multiple interventions were reported to reduce sleep latency (see Table 6). An unspecified sleep aid ($n=1$, $M=4.00$) was reported to increase sleep latency.

Table 6
Sleep Latency: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency of specific interventions
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	
(1) Medical and pharmaceutical	2.30	.82	10
Ciproheptadine	2.50	.58	4
Combination melatonin and hydroxyzine	1.00	.00	1
Melatonin	2.00	.00	2
Unspecified medication	2.00	.00	1
Unspecified sleep aid	4.00	.00	1
Vitamin D	2.00	.00	1
(2) Environmental	2.30	.48	10
Barrier around bed	2.00	.00	1
Darken room	2.00	.00	1
Electric blanket	2.00	.00	1
Isolated room	2.00	.00	1
Moved room	2.00	.00	1
Turn on movie or tv	2.00	.00	1
Weighted blanket	3.00	.00	1
White noise	2.67	.58	3
(3) Change in routine	2.20	.45	5
Bedtime routine	2.00	.00	4
Unspecified change in routine	3.00	.00	1
(4) Dietary change	2.00	.00	1
Full stomach at bedtime	2.00	.00	1
(5) Behavioral	3.00	.00	1
Unspecified behavior intervention	3.00	.00	1
(6) Physiological	2.29	.00	7
Increase physical activity during the day	2.00	.00	2
Lavender soap	3.00	.00	1
Limit daytime sleep	2.00	.00	1
Relaxation	2.00	.00	2
Unspecified physiological intervention	3.00	.00	1
(7) Psychological	2.00	.00	1
Reduce anxiety	2.00	.00	1

Note. *N*=46. Eight parents reported this problem as challenging in their child with ASD (sleep latency). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nighttime awakening and sleep latency. Three participants reported that their child had a challenging sleep problem with a combination nighttime awakening and sleep latency problem. The most frequently reported type of intervention was medical and pharmaceutical; however, this type of intervention was reported to increase the nighttime awakening and sleep latency problem ($n=4$, $M=3.50$). Specifically, two participants reported that melatonin ($n=2$, $M=4.00$) increased this problem. Removing gluten and casein ($n=1$, $M=1.00$) from the child's diet was reported to eliminate a nighttime awakening and sleep latency problem; however, this specific intervention was only reported by one participant. Using tryptophan, removing stimulating objects, and making an unspecified change in routine were all reported to reduce nighttime awakening and sleep latency.

Insomnia. Two participants reported their child as having insomnia. One parent said the following regarding the sleep problem experienced by her 19-year-old son with autism:

He has difficulty falling asleep. He is often sleepy during the day and seems to get his best sleep in the early morning hours. If we try to wake him in the morning so he can go to sleep easier at night it makes things worse until he isn't sleeping at all. He has gone three nights in a row before with very little if any sleep. He doesn't respond to sleeping medications, in fact, it seems to make the problem worse.

The environmental intervention of moving the child's bedroom was the only intervention reported to eliminate insomnia. An unspecified medication ($n=1$, $M=4.00$) was reported to increase insomnia while an unspecified dietary change ($n=1$, $M=2.00$) reduced insomnia.

Nightmares. Three participants reported that their child was having nightmares. The most frequently used type of intervention was environmental ($n=6$). Psychological ($n=2$) and change in routine ($n=1$) were also reported. Environmental interventions ($n=6$, $M=2.33$) were reported to be the most successful in reducing nightmares. Ambient light, moving the furniture, moving the child's bedroom closer to the parents' room, removing stimulating objects, and counseling were

all reported to reduce the child's nightmares. Darkening the child's bedroom, practicing cognitive processing with a parent, and using props or bedtime routines resulted in no change in the occurrence of nightmares.

Night terrors. Five children were reported by participants as experiencing night terrors. All types of interventions reported either eliminated or reduced the night terrors. No medical and pharmaceutical or psychological interventions were reported. Specifically, increasing daytime sleep and ignoring the behavior were reported to eliminate night terrors; however, these interventions were only reported by one participant. A parent in the child's room, an unspecified change in routine, a limit on sugar before bed, and relaxation were all reported to reduce night terrors.

Nighttime behaviors and physical ailments impacting sleep. Twenty-one participants expressed that their child had problems in 13 areas included in nighttime behaviors and physical ailments that impact sleep. This type of sleep problem had the most variance and frequency of reported problems. These problems were (a) not staying in bed, (b) nighttime behaviors that disturbed others, (c) nighttime behaviors that did not disturb others, (d) nighttime eating and drinking, (e) bed wetting, (f) teeth grinding, (g) sleepwalking and sleep talking, (h) leaving the house, (i) experiencing physical pain that prevented sleep, (j) harming self, (k) having restless legs, (l) having unusual sleep positions, and (m) experiencing seizures. The largest reported portion of these problems was not staying in bed ($n=12$).

Not staying in bed. Twelve participants reported their child experienced problems staying in bed. The father of an eight-year-old boy with autism described his son's problem:

My son has never slept the entire night. He will become violent if he is kept up past 8:00 p.m. He sleeps for a few hours, usually wets himself, gets up and takes his clothes off, then moves from the bed where he began the night. He will end up anywhere, in a closet,

[on the] sofa, under the piano, or in the car. There isn't anywhere he won't sleep, but in his bed. He will go back to sleep then get up a few hours later and get food.

The most frequently used interventions to help resolve this problem were environmental ($n=7$), then behavioral ($n=5$), medical and pharmaceutical ($n=2$), changes in routine ($n=2$), physiological ($n=2$), and psychological ($n=2$). Parents did not report using dietary changes (see Table 7). Medical and pharmaceutical intervention was reported to eliminate the problem of the child not staying in bed; however, this type of intervention was only reported by two participants. Psychological ($n=2$, $M=1.50$) and environmental ($n=7$, $M=1.57$) interventions were the most successful in reducing the behavior of a child not staying in bed overall. Physiological ($n=2$, $M=2.00$) and behavioral ($n=5$, $M=2.40$) interventions also resulted in a reduction of the problem (see Table 7).

Taking an unspecified medication, placing a barrier around the child's bed, using an electric blanket or props, sleeping in a made bed, and sleeping with parents eliminated not staying in bed. Moving furniture, positive reinforcement, punishment, relaxation, and social stories were all reported to reduce not staying in bed. Bedtime routine and visual schedule were reported to have no effect on not staying in bed. An unspecified environmental change increased not staying in bed (see Table 7).

Nighttime behavior, disturbing others. Seven participants reported their child experienced problems that disturbed others. The most frequently used interventions to help resolve nighttime activities that disturb others were environmental ($n=4$), and then medical and pharmaceutical ($n=3$), behavioral ($n=3$), changes in routine ($n=1$), dietary change ($n=1$), and physiological ($n=1$). Parents did not report using psychological interventions. Medical and pharmaceutical ($n=3$, $M=1.33$) interventions were reported to have the greatest overall effect on reducing nighttime behavior that was disturbing to others. Environmental ($n=4$, $M=2.75$), dietary

Table 7
Not Staying in Bed: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	M^a	SD	Reported frequency of specific interventions
(1) Medical and pharmaceutical	1.00	.00	2
Unspecified medication	1.00	.00	2
(2) Environmental	1.57	1.13	7
Barrier around bed	1.00	.00	1
Electric blanket	1.00	.00	1
Moved furniture	2.00	.00	1
Prop	1.00	.00	1
Sleeping in made bed	1.00	.00	1
Sleeping with parents	1.00	.00	1
Unspecified environmental change	4.00	.00	1
(3) Change in routine	3.00	.00	2
Bedtime routine	3.00	.00	1
Visual schedule	3.00	.00	1
(4) Dietary change – none reported	.00	.00	0
(5) Behavioral	2.40	.55	5
Positive reinforcement	2.33	.58	3
Punishment	2.00	.00	1
Unspecified behavior intervention	3.00	.00	1
(6) Physiological	2.00	.00	2
Relaxation	2.00	.00	2
(7) Psychological	1.50	.71	2
Social Stories	1.50	.71	2

Note. $N=46$. 12 Parents reported this problem as challenging in their child with ASD (will not stay in bed). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

change ($n=1$, $M=2.00$), behavioral ($n=3$, $M=2.67$), and physiological ($n=1$, $M=2.00$) interventions also resulted in a reduction of the problem behavior (see Table 7). No change in nighttime behavior that disturbed others was reported as a result of change in routine ($n=1$, $M=3.00$).

Zantac ($n=2$, $M=1.00$) was reported by two participants to eliminate nighttime activity that disturbed others. Taking clonidine, isolating the child's room from others, eating more before bed, establishing rules, and increasing physical activity during the day were all reported to reduce nighttime activity that disturbed others. Placing the child to sleep in a "cloth tube," using bedtime routine, and self-soothing were reported to have no effect on nighttime activity disturbing others.

Nighttime behavior, not disturbing others. Reported examples of nighttime activities that did not disturb others were finding the child reading or rocking in a chair when he or she should have been asleep. Only one participant reported this as a problem for their child. Two interventions were used that reduced this problem: an unspecified medication ($n=1$, $M=2.00$) and use of the toilet before bed ($n=1$, $M=2.00$).

Nighttime eating and drinking. One participant reported this as a problem for their child. Two interventions were used that reduced this problem: locking the food up ($n=1$, $M=2.00$) and setting good snacks out ($n=1$, $M=2.00$)

Bed wetting. Nine participants reported their child experienced problems with bed wetting. The most frequently used types of interventions to help resolve bed wetting were changes in routine ($n=9$), and then dietary ($n=5$), environmental ($n=4$), and medical and pharmaceutical ($n=2$). Parents did not report using behavioral, physiological, or psychological interventions (see Table 8). Dietary ($n=5$, $M=2.00$) and medical and pharmaceutical ($n=2$, $M=2.00$) interventions were reported to have the greatest overall effect on bed wetting.

Table 8
Bed Wetting: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.00	.00	2
Alternative medical treatment	2.00	.00	1
Unspecified medication	2.00	.00	1
(2) Environmental	2.50	1.00	4
Unspecified environmental change	1.00	.00	1
Use of diapers	3.00	.00	3
(3) Change in routine	2.33	1.00	9
Scheduled awakenings	2.80	.84	5
Using the toilet before bed	1.75	.96	4
(4) Dietary change	2.00	1.00	5
Limit fluid intake before bed	2.00	1.00	5
(5) Behavioral –none reported	.00	.00	0
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Nine parents reported this problem as challenging in their child with ASD (bed wetting). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Environmental ($n=3$, $M=2.50$) and change in routine ($n=9$, $M=2.33$) also resulted in a reduction of the problem behavior (see Table 8).

Using the toilet before bed ($n=4$, $M=1.75$) and an unspecified environmental change ($n=1$, $M=1.00$) were reported have the greatest effect on reducing bed wetting. Using alternative medical treatment ($n=1$, $M=2.00$), limiting fluids before bed ($n=5$, $M=2.00$), and scheduled awakenings ($n=5$, $M=2.80$) all reduced bed wetting. The use of diapers was reported to have no effect on bed wetting (see Table 8).

Teeth grinding. One participant reported teeth grinding as a sleep problem for their son with ASD, who has ground his teeth to the point of breaking one. Only one intervention was reported, bedtime routine ($M=2.00$). This intervention reduced teeth grinding.

Sleepwalking and sleep talking. One participant listed both sleepwalking and sleep talking together as a challenging problem for the child with ASD. Only one type of intervention was reported, medical and pharmaceutical. The interventions included removal of the tonsils ($M=2.00$) which reduced the problem and an unspecified medication ($M=3.00$) that was reported to have no change in the occurrence of sleepwalking and talking.

Leaving the house. One participant described a challenging sleep problem for their child with ASD as leaving the house during the night, although other participants stated they were concerned about this being a future or potential problem. The participant that reported this problem stated that their eight year old boy with autism will “get up at night to get food. I have locked the pantry but then he goes to the neighbors houses at 3:00 a.m. to eat their food.” One intervention reduced the problem, punishment ($n=1$, $M=2.00$). A second intervention, having alarms and locks on the doors ($n=1$, $M=3.00$) created no change in the occurrence of the problem.

Physical pain preventing sleep. Two participants regarded physical pain to be a sleep problem. One child with ASD was kept awake by itchy skin caused by an allergic reaction; the other child had an orthopedic problem resulting in aches and pains in the legs and feet. Both participants used medical and pharmaceutical ($n=2$, $M=2.50$) and environmental ($n=2$, $M=2.00$) interventions. Keeping the room at a temperature to keep the child warm ($n=2$, $M=2.00$) helped to reduce physical pain preventing sleep. An unspecified allergy medicine ($n=1$, $M=2.00$) also helped reduce the problem. Tylenol ($n=1$, $M=3.00$) had no effect on the problem.

Harming self. One parent reported a child causing self harm as a sleep problem. The 11 year old boy with autism would bite himself and bang his head. Positive reinforcement ($n=1$, $M=3.00$) had no change on the problem; however, a removing gluten and casein from the diet ($n=1$, $M=1.00$) eliminated the sleep problem.

Restless legs. One participant reported restless legs as a sleep problem for their child with ASD. Only one intervention was reported, bedtime routine ($M=2.00$). This intervention reduced restless legs.

Unusual sleeping positions. Multiple participants described their child's sleeping positions as unusual, including lying upside down in a chair, folded in half, and squished in a corner with the child's head pressed against the wall. However, when asked which problems were considered challenging, only one participant listed unusual sleeping positions. Moving the furniture ($n=1$, $M=1.00$) eliminated this problem

Seizures. Although seizures are not a sleep-specific problem, they can interfere with sleep. One participant listed seizures as a sleep problem for their child with ASD. An unspecified medication ($n=1$, $M=1.00$) was used as a medical and pharmaceutical intervention that eliminated the problem

Waking and alertness. Fourteen participants expressed that their child had problems of waking and alertness. Sleep problems of waking and alertness include abbreviated sleep time, difficulty waking, and excessive daytime sleepiness.

Abbreviated sleep time. *Abbreviated sleep time* occurs when a child wakes at an early hour and either does not require additional sleep or will not go back to sleep. Six participants reported their child as having an abbreviated sleep time. The most frequently used interventions to help resolve an abbreviated sleep time were medical and pharmaceutical ($n=3$), environmental ($n=3$), behavioral ($n=3$), physiological ($n=3$), and changes in routine ($n=2$). Parents did not report using dietary, or psychological interventions (see Table 9). All types of interventions were reported to reduce the problem with behavioral interventions ($n=3$, $M=2.67$) being the least effective overall.

Taking Benadryl ($n=1$, $M=2.00$), melatonin ($n=1$, $M=2.00$), or an unspecified anxiety medication ($n=1$, $M=2.00$); darkening the room ($n=1$, $M=2.00$); turning on a movie or TV ($n=2$, $M=2.00$); following a bedtime routine ($n=1$, $M=2.00$); setting a later bedtime ($n=1$, $M=2.00$); establishing rules ($n=1$, $M=2.00$); increasing physical activity ($n=1$, $M=2.00$); and limiting daytime sleeping ($n=1$, $M=2.00$) all reduced the problem of abbreviated sleep time. Ignoring the behavior and using negative reinforcement or relaxation before bed were reported to have no effect on abbreviated sleep time (see Table 9).

Difficulty waking. Children who have difficulty waking were described by their parents as being an abnormally heavy sleeper. One parent said of her eight-year-old son with autism, “In the morning for school his alarm will be going off just inches away from his ear but it doesn’t wake him up. I have to go in and pull his covers off, take his clothes off his body, [and] turn on the light to get him to wake up.” Three participants reported their child with ASD as having

Table 9
Abbreviated Sleep Time: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.00	.00	3
Benadryl	2.00	.00	1
Melatonin	2.00	.00	1
Unspecified anxiety medication	2.00	.00	1
(2) Environmental	2.00	.00	3
Darken room	2.00	.00	1
Turn on movie or TV	2.00	.00	2
(3) Change in routine	2.00	.00	2
Bedtime routine	2.00	.00	1
Later bed time	2.00	.00	1
(4) Dietary change –none reported	.00	.00	0
(5) Behavioral	2.67	.58	3
Ignore behavior	3.00	.00	1
Establish rules	2.00	.00	1
Negative reinforcement	3.00	.00	1
(6) Physiological	2.33	.58	3
Increase physical activity during the day	2.00	.00	1
Limit day time sleeping	2.00	.00	1
Relaxing activity before bed	3.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Six parents reported this problem as challenging in their child with ASD (abbreviated sleep time). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

difficulty waking. Turning the light on to wake the child ($n=1$, $M=2.00$) and scheduled awakenings ($n=1$, $M=2.00$) reduced the problem. One participant reported that ignoring the problem eliminated it.

Excessive daytime sleepiness. Children experiencing excessive daytime sleepiness appeared extremely overtired during the day, or may have had difficulty getting up in the morning (Donaldson & Owens, 2006). Seven participants reported their child as having a problem with excessive daytime sleepiness. The most frequently used interventions to help resolve excessive daytime sleepiness were changes in routine ($n=5$), and then physiological ($n=3$), medical and pharmaceutical ($n=2$), environmental ($n=2$), behavioral ($n=2$), and dietary change ($n=1$). Parents did not report using psychological interventions. Medical and pharmaceutical ($M=2.00$), change in routine ($M=2.00$), dietary ($M=2.00$), and behavioral ($M=2.00$) interventions were reported to have the greatest overall effect on excessive daytime sleepiness. Environmental ($M=3.00$) and physiological ($M=3.00$) were reported to have no change on excessive daytime sleepiness. Changing to home schooling ($M=1.00$) and ignoring the behavior ($M=1.00$) were reported to eliminate excessive daytime sleepiness. A mental activity, such as reading, was reported to increase excessive daytime sleepiness (see Table 10).

Resources for Sleep Problems and Parent Ratings of Helpfulness

The third research question addressed the source of support and information about sleep problems in children and adolescents with autism. Parents were asked to report on whom or where they turned to for help and support when they had concerns about their child's sleep problem (see Table 11). The most reported people or places that participants sought support were from their child's pediatrician ($n=32$, 66.7%), family ($n = 31$, 64.4%), friends ($n = 25$, 52.1%), another parent of a child with ASD ($n=20$, 41.7%), and the internet ($n=19$, 39.6%).

Table 10

Excessive Daytime Sleepiness: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	2.00	.00	2
Antacid	2.00	.00	1
C-PAP	2.00	.00	1
(2) Environmental	3.00	.00	2
Increase darkness	3.00	.00	2
(3) Change in routine	2.00	.71	5
Change to home schooling	1.00	.00	1
Earlier bed time	3.00	.00	1
Later bed time	2.00	.00	1
Unspecified change in routine	2.00	.00	1
Wake child earlier	2.00	.00	1
(4) Dietary change	2.00	.00	1
Limit food intake before bed	2.00	.00	1
(5) Behavioral	2.00	1.41	2
Ignore behavior	1.00	.00	1
Positive reinforcement	3.00	.00	1
(6) Physiological	3.00	1.00	3
Increase physical activity during the day	2.00	.00	1
Mental activity	4.00	.00	1
Reduce day time sleeping	3.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Seven parents reported this problem as challenging in their child with ASD (excessive day time sleepiness). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

None of the participants reported seeking support from a charter preschool, charter school K–12, or a private school K–12. Only one participant sought help from the Utah Parent Center (2.1%) or an alternative medical source (2.1%). Two participants sought help from a behavior specialist (4.2%) or a private preschool (4.2%). Logically, parents would seek help from those resources with which they are most familiar with or that are the most readily available to them. Therefore, participants whose children do not attend a private or charter school seek alternative medical care or enlist the care of a behavior specialist would not be likely to use these resources to resolve their child's sleep problems.

Parents reported the helpfulness of each resource. On a scale of one (not helpful) to five (helpful), parents were also asked to rate the effectiveness of resources that helped them address their child's sleep problems (see Table 11). Although more parents reported seeking help from their child's pediatrician ($n=32$, 66.7%) than any other source, parents rated the pediatrician's helpfulness as indifferent ($n=32$, $M=3.06$). Other resources that were referred to most frequently received the following ratings: family ($n=31$, $M=2.87$), friends ($n=25$, $M=2.84$), another parent of a child with ASD ($n=20$, $M=3.75$), and the internet ($n=19$, $M=3.85$). Two of the resources most frequently used, family and friends, had the two lowest scores in terms of helpfulness when compared with participants' ratings of all of the resources (see Table 11). The resources that received the highest amount of helpfulness scores were doing research ($n=2$, $M=4.50$), meeting with behavior specialist ($n=2$, $M=4.50$), talking with a parent from a support group ($n=7$, $M=4.14$), using an alternative medical provider ($n=1$, $M=4.00$), attending a private preschool ($n=2$, $M=4.00$), visiting the Utah Parent Center ($n=1$, $M=4.00$), and talking with another parent of a child with ASD ($n=20$, $M=3.75$). Additional information regarding the helpfulness of resources can be found in Appendix E.

Table 11
Support for Parents of Children with ASD and Sleep Problems: Who Provides Support and How Helpful is that Support?

Source of Support	<i>N</i>	Percent ^a	<i>M</i> ^b	<i>SD</i>
Self (research)	2	4.2	4.50	0.71
Family	31	64.4	2.87	1.26
Friends	25	52.1	2.84	1.21
Another parent of a child with ASD	20	58.3	3.75	1.32
Pediatrician	32	66.7	3.06	1.31
Mental health counselor	16	33.3	3.25	1.34
Medical specialist	14	29.2	3.50	1.40
Sleep disorder specialist	4	8.3	3.00	1.41
Behavior Specialist	2	4.2	4.50	0.71
Alternative Medicine	1	2.1	4.00	0.00
Birth-to-3 Provider	7	14.6	3.57	1.40
District Preschool	3	6.3	3.67	0.58
Charter Preschool	0	0.0	0.00	0.00
Private Preschool	2	4.2	4.00	0.00
District School K-12	5	10.4	3.20	1.79
Charter School K-12	0	0.0	0.00	0.00
Private School K-12	0	0.0	0.00	0.00
Utah Parent Center	1	2.1	4.00	0.00
Internet	19	39.6	3.58	1.17
Parent Support Group	7	14.6	4.14	1.46

Note. *N*=48.

^a Percentages are based on a total of *N*=48. ^bNot Helpful =1; Somewhat Not Helpful =2; Indifferent =3; Somewhat Helpful =4; and Helpful=5.

When the participants were asked what would be helpful to them and their families, participants expressed concern about a lack of knowledgeable resources to help resolve their child's sleep problem. One parent of a ten-year-old boy with PDD-NOS stated that there needed to be "more information out there on the internet, given to doctors and teachers about the kinds of problems our kids have. Most give advice for 'normal kids' that just does not work for our situations." A mother of an eight-year-old boy with autism requested,

Researched based solutions. There is an abundance of information out there about sleep problems. In my experience, most of it is anecdotal. It's difficult to sort through practices or solutions that have been researched and tested, as opposed to what one parent or medical professional believes will work. Like many issues related to autism, there is a lack of scientific, research backed solutions for many of these issues.

Another participant, the parent of a ten-year-old girl with autism, said,

I think sleep issues are a BIG problem with children with autism and more studies need to be done. I think many pediatricians, like our first two, simply told us to live with it and wouldn't do anything for us. Until we went to a doctor who only worked with children with autism we couldn't find any support. Luckily we found someone who treats kids with ASD and has a child with ASD himself, so he was willing to work with us.

Several parents also expressed an interest in being able to discuss their child's sleep problems with other parents who have children with autism, either in person or a website forum. In doing so, participants would be able to learn what interventions have been successful for other children struggling with the same sleep problems.

Discussion

The purpose of this study was to investigate parents' perceptions of the effectiveness of interventions for treating sleep problems in their children with autism. A web-based survey was used to obtain data regarding parents' perspectives on sleep problem interventions. This study serves as a foundation in understanding the many sleep problems children with ASD experience and what specific interventions parents believe have been successful or unsuccessful in reducing or eliminating those problems. Through gaining a better understanding of what interventions have proven successful, it is hoped that researchers will be able to better serve the needs of parents whose children have both autism and a sleep problem. This study also creates a foundation for future research.

Research among children with autism and a sleep problem suggested that these children are more likely to suffer from dyssomnia-type sleep problems than parasomnia-type sleep problems, specifically; children with autism are likely to have difficulty settling at bedtime and with sleep maintenance (Cotton & Richdale, 2006; Mindell, 1993; Richdale, 1999, 2001). Participants in this study reported 66 dyssomnias and 28 parasomnias, confirming the findings of previous studies. The sleep problems that participants in this study reported most frequently were the dyssomnia type problems of not staying in bed ($n=12$), nighttime awakening ($n=11$), bedtime refusal ($n=8$), and sleep latency ($n=8$). Bedwetting ($n=9$) and night terrors ($n=5$) were the most frequently reported parasomnias.

Research indicated that the most frequently used interventions to treat sleep problems in children with autism are behavioral and medical (Richdale, 1999). If routine changes had been included in behavioral interventions in this study as they were in Richdale's (1999) study, then behavior interventions would have been the most frequently reported type of intervention,

increasing from a total of 20 usages of interventions to 68 usages, partially confirming previous findings. With interventions categorized as they were, participants in this study reported using environmental ($n=57$) and medical ($n=53$) most frequently. Environmental interventions may have been reported most frequently by participants, in part, because of their ease of use or availability. Many environmental interventions, such as moving the furniture or turning on a white noise machine, required little follow-through or behavior change on the part of the parent. Also, parents were likely to have access to the materials required to implement the intervention, thus making this type of intervention easier to implement.

Medical interventions were the second most frequently reported intervention in this study. Of the participants reporting in this study, 66.7% ($n=32$) had turned to their pediatrician for help to resolve their child's sleep problem. A child's doctor could have prescribed a medication or other medical intervention because the doctor was knowledgeable about and comfortable with these interventions. Also, much like environmental interventions, medical interventions would require little behavior change on the part of the parent. Presumably, the goal of a medical intervention was that the procedure or medication would fix the problem.

Very few participants reported using psychological interventions—four participants reported using a total of five interventions. Possible causes for the under usage of this type of intervention included a lack of knowledge regarding this type of intervention or limited access to professionals who could assist parents with psychological interventions. Also, the specific intervention of seeking professional counseling can be very costly and may not have been within families' budgets to attain.

Previous research included bedtime routine as a frequently used behavioral intervention (Richdale, 1999). In this study, bedtime routine was included with routine change interventions.

However, bedtime routine ($n=15$) was the most frequently reported intervention in this study as well. Other interventions that research indicated to treat sleep problems in children with autism were also reported by participants in this study: (a) special diets ($n=18$), (b) melatonin ($n=11$), (c) multi-vitamin and mineral supplements ($n=4$), (d) massage ($n=2$), (e) social stories ($n=2$), (f) cognitive behavior therapy ($n=1$), (g) assistance dogs ($n=1$), and (h) anti-depressants ($n=1$) (Research Autism, 2008).

It is estimated that only 1–3% of children with a correctable sleep disorder are being referred, accurately diagnosed, and treated (Rosen et al., 2001). Participants in this study reported that five of their children (10.4%) had been diagnosed with a sleep disorder. Thirty-two participants (66.7%) had turned to their child's pediatrician for help regarding sleep problems, but only 14 had sought the help of a medical specialist and even fewer had been to a sleep specialist ($n=4$) regarding their child's sleep problem. More participants in this study had sought the help of a medical professional in trying to resolve their child's sleep problem than research suggested; however, participants primarily sought the help of their pediatrician whose helpfulness was rated as being indifferent by participants overall. More often than in previous studies that included typically developing children, participants in this study might have sought the help of a medical professional because they went in to the doctor more frequently than parents or caregivers of typically developing children. This possibly gave parents and caregivers of children with autism and a sleep problem increased opportunities to discuss their child's sleep problem and a more involved working relationship with the child's caregiver, making it easier to collaborate and discuss sensitive topics.

Limitations

Findings from this study may not generalize to all children with ASD who struggle with sleep problems for several reasons. Participating parents may be more representative of parents who have extra time and energy to complete a survey or have a computer and internet service in their home. The questionnaire was available online and parents who are technically savvy could participate. To attempt to alleviate this potential problem, a paper questionnaire was made available upon request; however, no parent requested a paper copy. Additionally, parents who participated in this research study may have elected to do so because of a greater self-efficacy in successfully addressing their challenging situations.

Furthermore, this survey was not translated and so parents whose primary language was not English would not likely have participated, thus excluding a large portion of the general population. The majority of the participants, 95.8% ($n=46$), reported their ethnicity as White. Also, 45 participants reported their highest level of college as at least some college with 26 (54.1%) having completed an associate's degree or higher. This may have led to a higher average socio-economic standing than the general population. This would affect both the resources and types of interventions participants would have access to in seeking help for their child's sleep problem. Also, scores with an n smaller than 30 should be considered with caution because they represent the opinion of only a few participants; as a result, they are not likely to generalize to a larger population.

Parents may not have accurately answered the survey questions, leading to the possibility that the child's true sleep disorder was misrepresented. Interventions previously or currently used by parents may not have been implemented with integrity, therefore influencing and possibly leading to inaccurate findings of the intervention's level of effectiveness. The

assumption was made that parents were accurate in their description of their child's sleep problem and of the interventions used, and that interventions were implemented with integrity. Two parents did not link interventions to a specific sleep problem. Therefore, their information was not included in data analysis. Other parents listed interventions but did not include specific details to clarify their responses. For instance, several parents listed "medication" as an intervention but did not identify the type of medication used to treat the specific sleep problem.

Implications for Future Research and Practice

This study investigated a broad range of sleep problems in children with ASD and did not gather the depth of information and insight that would be most helpful to parents struggling with a child's specific sleep problem. Future research projects should identify a narrower spectrum of specific sleep problems and gather a greater depth of information regarding those targeted interventions. This narrower focus would create a larger amount of information on a tighter topic of research specific to children identified with ASD.

In gathering information about children with ASD who struggle with sleep problems, future research efforts should closely monitor treatment integrity and collect data across time regarding response to intervention. This research study assumed that parents reported the problems accurately, that interventions were implemented correctly, and that parents were accurate in their assessment of the change in the problem due to the intervention.

As professionals working in the school system, educators and other school personnel need to be aware of the variety of sleep problems experienced by children with ASD and the effects these problems have on daytime functioning. School personnel can better serve the students they work with by being a resource to students' parents. To do this, teachers and other school professionals need to be educated on effective intervention strategies to treat specific

sleep problems. Professionals working in the schools can then help parents to resolve their child's sleep problems by providing information on specific interventions and reporting back to parents regarding their child's school behavior. School professions should also be aware of other resources to help parents whose children have ASD and sleep problems so that parents will know of other resources through which to seek treatment for sleep problems.

School psychologists should also help parents and medical professionals by helping to identify potential sleep problems. Much like the screening instruments school psychologists use to help in the identification of attention and behavior problems, a screening instrument such as the Sleep Disorders Inventory for Students (SDIS) should be used to help parents and medical professionals identify sleep problems (Luginbuehl, Bradley-Klug, Ferron et al., 2008). This particular instrument not only identifies potential sleep problems but also provides possible interventions for those problems.

Conclusions

The purpose of this study was to learn what specific interventions have been effective in alleviating specific sleep problems among children with autism spectrum disorders (ASD) according to parent report. This study also investigated where or from whom parents are receiving information regarding possible interventions and to what degree these resources have been helpful. Forty-eight parents or caregivers of children with ASD from both the United States and Canada participated in this research. Participants gave background information about themselves and their child with ASD, and then answered Likert-type and open-ended questions regarding their child's sleep problem(s) and the resources they have turned to for help.

Participants reported using 82 different interventions to treat 25 types of sleep problems. Overall, parents reported a reduction in each sleep problem following intervention. When

seeking help to resolve their child's sleep problem, parents reported using 16 different resources. Of these resources, the most helpful overall were a behavior specialist, personal research, and parent support groups.

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APPENDIX A

Participation and Consent to be a Research Subject

Background

This research study is being conducted by Sarah Lynn Lemmons, a graduate student at Brigham Young University, to gain insight from parents of children with autism regarding the sleep problems their child is or has experienced as well as the parents' views of the effectiveness of specific interventions for those sleep problems. You were asked to participate because you are a parent or caregiver of a child with autism.

Study Procedure

After consenting to participate, you will be led to a questionnaire that will take approximately 30 minutes to complete. Questions will include details about you and your child, the type of sleep problem(s) experienced by your child including when your child first experienced a sleep problem, your views on the effectiveness and ineffectiveness of interventions tried, and where you have received support regarding your child's sleep problem(s).

Risks/Discomforts

There are few risks associated with the study. Sometimes when family members answer questions regarding various aspects of family life, unpleasant memories or frustrations may be recalled.

Benefits

There are no direct benefits to participants. However, it is hoped that through your participation, researchers will learn more about what parents of children with autism have found to be effective and ineffective interventions for sleep problems. While completing the survey, parents and caregivers may realize the improvement in sleep their child with autism has achieved.

Confidentiality

All information provided will remain confidential and will only be reported as group data with no identifying information. All data reported on the questionnaire will be kept in a password-protected computer and website, and only those directly involved with the research will have access to the data. After the research is completed, the questionnaires will be destroyed.

Compensation

Ten randomly selected participants who provide home addresses will receive a popular children's book featuring a character with disabilities.

Voluntary Participation

Participation in this research study is voluntary, without penalty or loss of benefits. Also, participation will not affect your participation with the organization through which you were recruited for this research. You have the right to withdraw at anytime or refuse to participate entirely without consequence.

Questions about the Research

If you have questions regarding this study, you may contact the primary investigator, Sarah Lynn Lemmons, at (801) 357-9481, sarahlynnlemmons@gmail.com; or the thesis chair, Dr. Tina T. Dyches, Ed.D. at (801) 422-5045.

Questions about your Rights as Research Participants

You can contact the Institutional Review Board office at Brigham Young University at (801) 422-3841, irb@byu.edu (A-285 ASB, Brigham Young University) for answers to questions you might have about research and your rights as a research participant.

You must agree to the below statement in order to take this survey.

I have read and understood the above consent and desire of my own free will to participate in this study. I understand that no penalties will result from non-participation or withdrawal. I am at least 18 years old.

APPENDIX B

SURVEY

Please answer the questions as thoroughly as you can. Thank you for your participation!

Survey Questions

Information about adult caregiver of child with an autism spectrum disorder (ASD):

1. Are you the:

Mother? _____

Father? _____

Relative? _____ (please explain)_____

Other Caregiver? _____ (please explain)_____

2. Your Age: _____

3. What are the ages of the dependents living in your home: _____

4. Your dominant ethnicity:

White

Black or African-American

Asian

American Indian or Alaskan Native

Native Hawaiian or Other Pacific Islander

Hispanic or Latino

Other race _____

5. Where do you live? (Please include county and state)

County

State

6. What is your highest level of completed education?

Did not graduate from high school

GED

Graduated high school

Some college

Associate's degree

Bachelor's degree

Graduate degree

Other (please specify) _____

Information about your child with ASD:

1. Child's Diagnosis?

Autism

Asperger Syndrome

- Rett Syndrome
- Childhood Disintegrative Disorder
- Pervasive Developmental Disorder – Not Otherwise Specified
- Other_____

2. Child's age _____

3. Child's gender: M/F

4. Where was your child educated during the past school year? (check all that apply)

- Regular classroom full-time
- Regular classroom part-time
- Resource room full-time
- Resource room part-time
- Self-Contained room (e.g., life skills, small group)
- Self-Contained room for children with ASD
- Self-Contained school for children with ASD
- Self-Contained school for children with disabilities
- Home
- Hospital
- Other: _____

5. On average, at what level does your child achieve in school academically?

- Infant level
- Toddler level
- Preschool level
- K-3 level
- 4-6 level
- 7-9 level
- 10-12 level

Describe: _____

6. Does your child take any medications? Y/N Please list:

7. Do any of these medications affect your child's sleep? Please explain.

Sleep Problem Questions

1. Does your child currently have problems sleeping or did he/she have problems sleeping in the past?
2. How old was your child when he/she began having sleep problems? _____
3. Please describe your child's sleeping environment.
 - a. Where does your child with sleep problem(s) sleep most of the time?

- b. Do other people sleep in the room with your child with sleep problem(s)? Y/N, if so, please explain.
- c. Please describe any other information regarding your child's sleeping environment that you feel impacts your child's sleep.
4. Please list and describe the sleep problems your child has experienced or is currently experiencing. Examples of sleep problems include but are not limited to insomnia, ineffective routines, excessive daytime sleepiness, narcolepsy, awakening during the night, restless legs syndrome, eating or drinking during sleep, nightmare disorder, sleep terrors, sleepwalking, bed-wetting, teeth grinding, taking a long time to fall asleep once in bed, difficult to get to bed, won't stay in bed, needs props to fall asleep (such as a certain toy, blanket, pacifier).
5. Have any of your child's sleep problems changed over time? If so, please explain.
6. Which of your child's current sleep problems was/is the most challenging for your family?
7. Has your child seen a healthcare provider regarding sleep problems? Y/N
8. Has your child been diagnosed as having a sleep disorder? If so, please explain.
9. Who/where have you turned for help regarding your child's sleep problem? How helpful have these resources been? (Please indicate whether or not you have referred to the resources listed below and rate their amount of helpfulness.)

		How helpful was this resource?				
		Received help from?		Not Helpful		Helpful
	Yes/No	1	2	3	4	5
Family	Yes/No	1	2	3	4	5
Friends	Yes/No	1	2	3	4	5
Another parent with a child diagnosed with ASD	Yes/No	1	2	3	4	5
Pediatrician	Yes/No	1	2	3	4	5
Mental Health Counselor	Yes/No	1	2	3	4	5
Medical Specialist	Yes/No	1	2	3	4	5
Sleep Disorder Specialist	Yes/No	1	2	3	4	5
Birth-to-3 Provider	Yes/No	1	2	3	4	5
District Preschool	Yes/No	1	2	3	4	5
Charter Preschool	Yes/No	1	2	3	4	5
Private Preschool	Yes/No	1	2	3	4	5
District School K-12	Yes/No	1	2	3	4	5
Charter School K-12	Yes/No	1	2	3	4	5
Private School K-12	Yes/No	1	2	3	4	5
Support Group (list type of group) _____	Yes/No	1	2	3	4	5
Utah Parent Center	Yes/No	1	2	3	4	5
Internet	Yes/No	1	2	3	4	5

Other (list) _____	Yes/No	1	2	3	4	5
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Please answer the following questions using the table(s) below for each sleep problem your child has experienced, beginning with the most challenging problem:

Sleep Problem #1 (most challenging problem): _____

What interventions have been helpful/not helpful in reducing/eliminating your child's sleep problem(s)? Interventions may include but are not limited to environmental, behavioral, or medical interventions, such as using CPAP machine, establishing a bedtime routine, using positive reinforcement, conducting relaxation training, taking medications (please be specific), changing the diet (please describe if applicable), scheduling awakenings, setting bed-wetting alarm, or using social stories.

Then, rate how your child's sleep problem changed for each intervention.

Include a response regarding who and/or where you learned of each intervention.

Intervention	Change in Sleep Problem	Learned of Intervention from:
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	

Sleep Problem #2 (next most challenging problem): _____

What interventions have been helpful/not helpful in reducing/eliminating your child's sleep problem(s)? Interventions may include but are not limited to environmental, behavioral, or medical interventions, such as using CPAP machine, establishing a bedtime routine, using positive reinforcement, conducting relaxation training, taking medications (please be specific), changing the diet (please describe if applicable), scheduling awakenings, setting bed-wetting alarm, or using social stories.

Then, rate how your child's sleep problem changed for each intervention.

Include a response regarding who and/or where you learned of each intervention.

Intervention	Change in Sleep Problem	Learned of Intervention from:
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	

Sleep Problem #3: _____

What interventions have been helpful/not helpful in reducing/eliminating your child's sleep problem(s)? Interventions may include but are not limited to environmental, behavioral, or medical interventions, such as using CPAP machine, establishing a bedtime routine, using positive reinforcement, conducting relaxation training, taking medications (please be specific), changing the diet (please describe if applicable), scheduling awakenings, setting bed-wetting alarm, or using social stories.

Then, rate how your child's sleep problem changed for each intervention.

Include a response regarding who and/or where you learned of each intervention.

Intervention	Change in Sleep Problem	Learned of Intervention from:
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	
	Eliminated/Reduced/No Change/Increased	

10. Additional sleep problems, interventions tried, changes in sleep problem, and where you received information regarding this intervention:

11. What would be helpful to you and your family to help solve your child's sleep problem(s)?

12. Other feedback.

APPENDIX C
**Tables of Sleep Problems and Effectiveness of Associated
Interventions
And Support Resources for Parents**

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Bedtime Refusal: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	2.50	.71	2
Melatonin	3.00	.00	1
Unspecified medication	2.00	.00	1
(2) Environmental	2.43	.53	7
Parents in the child's room	2.00	.00	1
Remove stimulating materials	2.00	.00	1
Unspecified environmental change	3.00	.00	3
Weighted blanket	2.00	.00	1
White noise	2.00	.00	1
(3) Change in routine	1.80	.45	5
Bedtime routine	2.00	.00	1
Scheduled awakenings	2.00	.00	1
Unspecified change in routine	1.50	.71	2
Visual schedule	2.00	.00	1
(4) Dietary change	1.00	.00	1
Eliminate red-40	1.00	.00	1
(5) Behavioral –none reported	.00	.00	0
(6) Physiological	1.67	.58	4
Increase daytime physical activity	2.00	.00	1
Massage	2.00	.00	2
Relaxation/relaxing activity	1.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Eight parents reported this problem as challenging in their child with ASD (bedtime refusal). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Overstimulation: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions	
(1) Medical and pharmaceutical	2.20	1.10	5	
L-Tyrosine	3.00	.00	1	
Magnesium	3.00	.00	1	
Melatonin	2.00	1.41	2	
Unspecified medication	1.00	.00	1	
(2) Environmental	2.00	.00	1	
Darken room	2.00	.00	1	
(3) Change in routine	2.50	.71	2	
Bedtime Routine	2.00	.00	1	
Unspecified change in routine	3.00	.00	1	
(4) Dietary change – none reported	.00	.00	0	
(5) Behavioral – none reported	.00	.00	0	
(6) Physiological	2.00	.00	1	
Increase physical activity	2.00	.00	1	
(7) Psychological –none reported	.00	.00	0	

Note. *N*=46. Three parents reported this problem as challenging in their child with ASD (overstimulation). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Unusual Sleep Routine: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical –none reported	.00	.00	0
(2) Environmental –none reported	.00	.00	0
(3) Change in routine	1.00	.00	1
Gradual routine change	1.00	.00	1
(4) Dietary change –none reported	.00	.00	0
(5) Behavioral	2.00	.00	1
Positive Reinforcement	2.00	.00	1
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (extended bedtime routine). The participant reported two interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nighttime Awakening: Parental Report of Effectiveness of Interventions

Interventions: Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.15	.80	13
Benadryl	2.00	.00	1
L-Tyrosine	3.00	.00	1
Magnesium	2.00	1.41	2
Melatonin	2.00	1.00	3
Sleep Aid	2.50	.71	2
Zantac	2.00	.00	1
Trazodone	3.00	.00	1
Unspecified medication	1.50	.71	2
(2) Environmental	2.00	.82	4
Earmuffs	1.00	.00	1
Keep child warm	3.00	.00	1
Sleep with parents	2.00	.00	1
White noise	2.00	.00	1
(3) Change in routine	2.44	.53	9
Bedtime routine	2.60	.55	5
Change nap schedule	2.00	.00	2
Stay up later	3.00	.00	1
Turn on movie/TV	2.00	.00	1
Unspecified change in routine	2.00	.00	1
(4) Dietary change	2.25	.50	4
Eliminate red-40	2.00	.00	1
Eliminate gluten, casein, and sugar	2.00	.00	1
Snack prior to bedtime	3.00	.00	1
Unspecified dietary change	2.00	.00	1
(5) Behavioral –none reported	.00	.00	0
(6) Physiological	2.20	.45	5
Attending to toileting needs	2.00	.00	1
Increase daytime physical activity	2.50	.71	2
Limit daytime sleeping	2.00	.00	2
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Eleven parents reported this problem as challenging in their child with ASD (awakening during night). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Sleep Latency: Parental Report of Effectiveness of Interventions

Interventions:			
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.30	.82	10
Ciproheptadine	2.50	.58	4
Combination melatonin and hydroxyzine	1.00	.00	1
Melatonin	2.00	.00	2
Unspecified medication	2.00	.00	1
Unspecified sleep aid	4.00	.00	1
Vitamin D	2.00	.00	1
(2) Environmental	2.30	.48	10
Barrier around bed	2.00	.00	1
Darken room	2.00	.00	1
Electric blanket	2.00	.00	1
Isolated room	2.00	.00	1
Moved room	2.00	.00	1
Turn on movie or tv	2.00	.00	1
Weighted blanket	3.00	.00	1
White noise	2.67	.58	3
(3) Change in routine	2.20	.45	5
Bedtime routine	2.00	.00	4
Unspecified change in routine	3.00	.00	1
(4) Dietary change	2.00	.00	1
Full stomach at bedtime	2.00	.00	1
(5) Behavioral	3.00	.00	1
Unspecified behavior intervention	3.00	.00	1
(6) Physiological	2.29	.00	7
Increase physical activity during the day	2.00	.00	2
Lavender soap	3.00	.00	1
Limit daytime sleep	2.00	.00	1
Relaxation	2.00	.00	2
Unspecified physiological intervention	3.00	.00	1
(7) Psychological	2.00	.00	1
Reduce anxiety	2.00	.00	1

Note. *N*=46. Eight parents reported this problem as challenging in their child with ASD (sleep latency). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Sleep Latency and Nighttime Awakening: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	3.50	.52	4
Melatonin	4.00	.00	2
Unspecified medication	4.00	.00	1
Tryptophan	2.00	.00	1
(2) Environmental	2.00	.00	1
Removal of stimulating objects	2.00	.00	1
(3) Change in routine	2.00	.00	1
Unspecified change in routine	2.00	.00	1
(4) Dietary change	2.00	1.41	2
Removal of gluten and casein	1.00	.00	1
Unspecified Dietary change	3.00	.00	1
(5) Behavioral	3.00	.00	1
Positive reinforcement	3.00	.00	1
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Three parents reported this problem as challenging in their child with ASD (sleep latency and nighttime awakening). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Insomnia: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	4.00	.00	1
Unspecified medication	4.00	.00	1
(2) Environmental	1.00	.00	1
Moved bedroom	1.00	.00	1
(3) Change in routine –none reported	.00	.00	0
(4) Dietary change	2.00	.00	1
Unspecified dietary change	2.00	.00	1
(5) Behavioral –none reported	.00	.00	0
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (insomnia). The participant reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nightmares: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical – none reported	.00	.00	0
(2) Environmental	2.33	.52	6
Ambient light	2.00	.00	1
Darkened room	3.00	.00	1
Moved furniture	2.00	.00	1
Moved bedroom closer to parents	2.00	.00	1
Prop	3.00	.00	1
Removed stimulating objects	2.00	.00	1
(3) Change in routine	3.00	.00	1
Bedtime routine	3.00	.00	1
(4) Dietary change –none reported	.00	.00	0
(5) Behavioral - none reported	.00	.00	0
(6) Physiological – none reported	.00	.00	0
(7) Psychological	2.50	.71	2
Cognitive processing with parent	3.00	.00	1
Counseling	2.00	.00	1

Note. *N*=46 Three parents reported this problem as challenging in their child with ASD (nightmares). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Night Terrors: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency of specific interventions
Major categories and specific types	<i>M</i> ^a	<i>SD</i>		
(1) Medical and pharmaceutical – none reported	.00	.00		0
(2) Environmental	2.00	.00		1
Parent in the child's room	2.00	.00		1
(3) Change in routine	2.00	.00		1
Unspecified change in routine	2.00	.00		1
(4) Dietary change	2.00	.00		1
Limit sugar before bed	2.00	.00		1
(5) Behavioral	1.00	.00		1
Ignore behavior	1.00	.00		1
(6) Physiological	1.67	.58		3
Increase daytime sleep	1.00	.00		1
Relaxation	2.00	.00		2
(7) Psychological –none reported	.00	.00		0

Note. *N*=46. Five parents reported this problem as challenging in their child with ASD (night terrors). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Not Staying in Bed: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	1.00	.00	2
Unspecified medication	1.00	.00	2
(2) Environmental	1.57	1.13	7
Barrier around bed	1.00	.00	1
Electric blanket	1.00	.00	1
Moved furniture	2.00	.00	1
Prop	1.00	.00	1
Sleeping in made bed	1.00	.00	1
Sleeping with parents	1.00	.00	1
Unspecified environmental change	4.00	.00	1
(3) Change in routine	3.00	.00	2
Bedtime routine	3.00	.00	1
Visual schedule	3.00	.00	1
(4) Dietary change – none reported	.00	.00	0
(5) Behavioral	2.40	.55	5
Positive reinforcement	2.33	.58	3
Punishment	2.00	.00	1
Unspecified behavior intervention	3.00	.00	1
(6) Physiological	2.00	.00	2
Relaxation	2.00	.00	2
(7) Psychological	1.50	.71	2
Social Stories	1.50	.71	2

Note. *N*=46. Twelve parents reported this problem as challenging in their child with ASD (will not stay in bed). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nighttime Behavior, Disturbing Others: Parental Report of Effectiveness of Interventions

Interventions:			
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	1.33	.58	3
Clonidine	2.00	.00	1
Zantac	1.00	.00	2
(2) Environmental	2.75	.50	4
Cloth tube around child	3.00	.00	1
Isolate room from others	2.00	.00	1
Return child to own bed	3.00	.00	1
Weighted blanket	3.00	.00	1
(3) Change in routine	3.00	.00	1
Bedtime Routine	3.00	.00	1
(4) Dietary change	2.00	.00	1
Eat more before bed	2.00	.00	1
(5) Behavioral	2.67	.58	3
Established rules	2.50	.71	2
Self soothing	3.00	.00	1
(6) Physiological	2.00	.00	1
Increase physical activity during the day	2.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Seven parents reported this problem as challenging in their child with ASD (nighttime activity-disturbing others). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nighttime Behavior, Not Disturbing Others: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>		of specific interventions
(1) Medical and pharmaceutical	2.00	.00		1
Unspecified medication	2.00	.00		1
(2) Environmental –none reported	.00	.00		0
(3) Change in routine	2.00	.00		1
Use of toilet before bed	2.00	.00		1
(4) Dietary change –none reported	.00	.00		0
(5) Behavioral –none reported	.00	.00		0
(6) Physiological –none reported	.00	.00		0
(7) Psychological –none reported	.00	.00		0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (nighttime activity – not disturbing others). The participant reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Nighttime Eating and/or Drinking: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>		of specific interventions
(1) Medical and pharmaceutical –none reported	.00	.00		0
(2) Environmental	2.00	.00		1
Lock food up	2.00	.00		1
(3) Change in routine –none reported	.00	.00		0
(4) Dietary change	2.00	.00		1
Set good snacks out	2.00	.00		1
(5) Behavioral –none reported	.00	.00		0
(6) Physiological –none reported	.00	.00		0
(7) Psychological –none reported	.00	.00		0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (nighttime eating and/or drinking). The participant reported two interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Bed Wetting: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	M^a	SD		of specific interventions
(1) Medical and pharmaceutical	2.00	.00		2
Alternative medical treatment	2.00	.00		1
Unspecified medication	2.00	.00		1
(2) Environmental	2.50	1.00		4
Unspecified environmental change	1.00	.00		1
Use of diapers	3.00	.00		3
(3) Change in routine	2.33	1.00		9
Scheduled awakenings	2.80	.84		5
Using the toilet before bed	1.75	.96		4
(4) Dietary change	2.00	1.00		5
Limit fluid intake before bed	2.00	1.00		5
(5) Behavioral –none reported	.00	.00		0
(6) Physiological –none reported	.00	.00		0
(7) Psychological –none reported	.00	.00		0

Note. $N=46$. Nine parents reported this problem as challenging in their child with ASD (bed wetting). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Teeth Grinding: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	M^a	SD		of specific interventions
(1) Medical and pharmaceutical – none reported	.00	.00		0
(2) Environmental – none reported	.00	.00		0
(3) Change in routine	2.00	.00		1
Bedtime routine	2.00	.00		1
(4) Dietary change – none reported	.00	.00		0
(5) Behavioral – none reported	.00	.00		0
(6) Physiological – none reported	.00	.00		0
(7) Psychological –none reported	.00	.00		0

Note. $N=46$. One parent reported this problem as challenging in their child with ASD (teeth grinding). The participant reported a single intervention for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Sleepwalking and Talking: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types		<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical		2.50	.71	2
Tonsils removed		2.00	.00	1
Unspecified medication		3.00	.00	1
(2) Environmental – none reported		.00	.00	0
(3) Change in routine – none reported		.00	.00	0
(4) Dietary change – none reported		.00	.00	0
(5) Behavioral – none reported		.00	.00	0
(6) Physiological – none reported		.00	.00	0
(7) Psychological –none reported		.00	.00	0

Note. *N*=46. One Parent reported this problem as challenging in their child with ASD and listed both sleepwalking and talking together. The parents reported two interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Leaving the House: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types		<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical –none reported		.00	.00	0
(2) Environmental		3.00	.00	1
Alarms and locks		3.00	.00	1
(3) Change in routine –none reported		.00	.00	0
(4) Dietary change –none reported		.00	.00	0
(5) Behavioral		2.00	.00	1
Punishment		2.00	.00	1
(6) Physiological –none reported		.00	.00	0
(7) Psychological –none reported		.00	.00	0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (leaving the house at night). The parents reported two interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Physical Pain Preventing Sleep: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical	2.50	.71	2
Tylenol	3.00	.00	1
Unspecified allergy medication	2.00	.00	1
(2) Environmental	2.00	.00	2
Warm room temperature	2.00	.00	2
(3) Change in routine – none reported	.00	.00	0
(4) Dietary change – none reported	.00	.00	0
(5) Behavioral – none reported	.00	.00	0
(6) Physiological	2.00	.00	1
Wearing supportive shoes during the day	2.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Two parents reported this problem as challenging in their child with ASD (physical pain preventing sleep). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Harming Self: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical –none reported	.00	.00	0
(2) Environmental –none reported	.00	.00	0
(3) Change in routine –none reported	.00	.00	0
(4) Dietary change	1.00	.00	1
Eliminate gluten and casein	1.00	.00	1
(5) Behavioral	3.00	.00	1
Positive reinforcement	3.00	.00	1
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (excessive day time sleepiness). The parent reported two interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Restless Legs: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical –none reported	.00	.00	0
(2) Environmental –none reported	.00	.00	0
(3) Change in routine	2.00	.00	1
Bedtime routine	2.00	.00	1
(4) Dietary change –none reported	.00	.00	0
(5) Behavioral –none reported	.00	.00	0
(6) Physiological –none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. One parents reported this problem as challenging in their child with ASD (restless legs). The parents reported a single intervention for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Unusual Sleep Position: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical – none reported	.00	.00	0
(2) Environmental	1.00	.00	1
Moved furniture	1.00	.00	1
(3) Change in routine – none reported	.00	.00	0
(4) Dietary change – none reported	.00	.00	0
(5) Behavioral – none reported	.00	.00	0
(6) Physiological – none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. One parent reported this problem as challenging in their child with ASD (unusual sleep position). The parent reported a single intervention for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Seizures: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types		<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical		1.00	.00	1
Unspecified medication		1.00	.00	1
(2) Environmental – none reported		.00	.00	0
(3) Change in routine – none reported		.00	.00	0
(4) Dietary change – none reported		.00	.00	0
(5) Behavioral – none reported		.00	.00	0
(6) Physiological – none reported		.00	.00	0
(7) Psychological –none reported		.00	.00	0

Note. *N*=46. One parents reported this problem as challenging in their child with ASD (excessive day time sleepiness). The parent reported a single intervention for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Abbreviated Sleep Time: Parental Report of Effectiveness of Interventions

Interventions:			
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	Reported frequency of specific interventions
(1) Medical and pharmaceutical	2.00	.00	3
Benadryl	2.00	.00	1
Melatonin	2.00	.00	1
Unspecified anxiety medication	2.00	.00	1
(2) Environmental	2.00	.00	3
Darken room	2.00	.00	1
Turn on movie or TV	2.00	.00	2
(3) Change in routine	2.00	.00	2
Bedtime routine	2.00	.00	1
Later bed time	2.00	.00	1
(4) Dietary change –none reported	.00	.00	0
(5) Behavioral	2.67	.58	3
Ignore behavior	3.00	.00	1
Establish rules	2.00	.00	1
Negative reinforcement	3.00	.00	1
(6) Physiological	2.33	.58	3
Increase physical activity during the day	2.00	.00	1
Limit day time sleeping	2.00	.00	1
Relaxing activity before bed	3.00	.00	1
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Six parents reported this problem as challenging in their child with ASD (abbreviated sleep time). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Difficulty Waking: Parental Report of Effectiveness of Interventions

Interventions:			Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>	of specific interventions
(1) Medical and pharmaceutical –none reported	.00	.00	0
(2) Environmental	2.00	.00	1
Turn on light to wake child	2.00	.00	1
(3) Change in routine	2.00	.00	1
Scheduled awakenings	2.00	.00	1
(4) Dietary change–none reported	.00	.00	0
(5) Behavioral –none reported	1.00	.00	1
Ignore behavior	1.00	.00	1
(6) Physiological–none reported	.00	.00	0
(7) Psychological –none reported	.00	.00	0

Note. *N*=46. Three parents reported this problem as challenging in their child with ASD (difficulty waking). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

Excessive Daytime Sleepiness: Parental Report of Effectiveness of Interventions

Interventions:				Reported frequency
Major categories and specific types	<i>M</i> ^a	<i>SD</i>		of specific interventions
(1) Medical and pharmaceutical	2.00	.00		2
Antacid	2.00	.00		1
C-PAP	2.00	.00		1
(2) Environmental	3.00	.00		2
Increase darkness	3.00	.00		2
(3) Change in routine	2.00	.71		5
Change to home schooling	1.00	.00		1
Earlier bed time	3.00	.00		1
Later bed time	2.00	.00		1
Unspecified change in routine	2.00	.00		1
Wake child earlier	2.00	.00		1
(4) Dietary change	2.00	.00		1
Limit food intake before bed	2.00	.00		1
(5) Behavioral	2.00	1.41		2
Ignore behavior	1.00	.00		1
Positive reinforcement	3.00	.00		1
(6) Physiological	3.00	1.00		3
Increase physical activity during the day	2.00	.00		1
Mental activity	4.00	.00		1
Reduce day time sleeping	3.00	.00		1
(7) Psychological –none reported	.00	.00		0

Note. *N*=46. Seven parents reported this problem as challenging in their child with ASD (excessive day time sleepiness). Parents reported multiple interventions for this problem.

^aScores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem; 4=increased problem.

APPENDIX D

Parent Reported Interventions and Effectiveness Across Sleep Problems

Parents' Perceptions of Overall Effectiveness of Specific Interventions in Treating Sleep Problems

Intervention type	<i>n</i>	<i>M^a</i>	<i>SD</i>
Environmental	31	2.14	0.72
Darken room	5	2.40	0.55
Unspecified environmental intervention	5	3.00	1.10
White noise	5	2.40	0.56
Diapers	3	3.00	0.00
Keep child warm	3	2.33	0.58
Move furniture	3	1.67	0.58
Moved room	3	1.67	0.58
Remove stimulating materials	3	2.00	0.00
Turn on movie or TV	3	2.00	0.00
Weighted blanket	3	2.67	0.58
Barriers around bed	2	1.50	0.71
Electric blanket	2	1.50	0.71
Isolate room	2	2.00	0.00
Parent in child's room	2	2.00	0.00
Props	2	2.00	1.41
Sleep with parents	2	1.50	0.71
Alarms & locks on doors	1	3.00	0.00
Ambient light	1	2.00	0.00
Earmuffs	1	1.00	0.00
Lock up food	1	2.00	0.00
Return child to bed	1	3.00	0.00
Sleep in a made bed	1	1.00	0.00
Sleep with service dog	1	1.00	0.00
Turn on light to wake child	1	2.00	0.00
Wrapped in cloth tube	1	3.00	0.00
Medical and Pharmaceutical	27	2.21	0.88
Unspecified medication	12	2.17	1.11
Melatonin	11	2.45	1.04
Cyproheptadine	4	2.50	0.58
Magnesium	3	2.33	1.15

Unspecified sleep aid	3	3.00	1.00
Benadryl	2	2.00	0.00
L-Tyrosine	2	3.00	0.00
Zantac	2	1.50	0.71
Alternative medication	1	2.00	0.00
Antacid	1	2.00	0.00
Clonidine	1	2.00	0.00
C-PAP machine	1	2.00	0.00
Melatonin & hydroxyzine	1	1.00	0.00
Removal of tonsils	1	2.00	0.00
Trazodone	1	3.00	0.00
Tryptophan	1	2.00	0.00
Tylenol	1	3.00	0.00
Unspecified allergy medication	1	2.00	0.00
Unspecified anxiety medication	1	2.00	0.00
Vitamin D	1	2.00	0.00
Change in Routine	25	2.27	0.65
Bedtime routine	17	2.35	0.49
Unspecified routine change	9	2.00	0.71
Scheduled awakenings	7	2.57	0.79
Tend to toileting needs	5	1.80	0.84
Stay up later	3	2.33	0.58
Cut out naps	2	2.00	0.00
Visual schedule	2	2.50	0.71
Change to home schooling	1	1.00	0.00
Go to bed earlier	1	3.00	0.00
Turn on movie	1	2.00	0.00
Wake child earlier	1	2.00	0.00
Physiological	21	2.10	0.59
Increase physical activity	9	2.11	0.33
Relaxation/relaxing activity	7	2.00	0.58
Limit daytime sleeping	5	2.20	0.45
Massage	2	2.00	0.00
Increase daytime sleeping	1	1.00	0.00
Lavender soap	1	3.00	0.00
Mental activity	1	4.00	0.00
Potty training	1	2.00	0.00

Unspecified physiological intervention	1	3.00	0.00
Wear supportive shoes during the day	1	2.00	0.00
Behavioral	17	2.35	0.75
Positive reinforcement	7	2.57	0.53
Ignore	4	1.50	1.00
Establish rules	3	2.33	0.58
Punishment	2	2.00	0.00
Unspecified behavior intervention	2	3.00	0.00
Negative reinforcement	1	3.00	0.00
Self soothing	1	3.00	0.00
Dietary	15	1.95	0.71
Limit fluids before bed	5	2.00	1.00
Gluten/casein/sugar free	3	1.33	0.58
Unspecified dietary change	3	2.33	0.58
Eat more before bed	2	2.00	0.00
Eliminate red-40	2	1.50	0.71
Good snacks out at night	1	2.00	0.00
Limit food intake before bed	1	2.00	0.00
Limit sugar	1	2.00	0.00
Snack before bed	1	3.00	0.00
Psychological	4	2.00	0.71
Social stories	2	1.50	0.71
Cognitive processing with parent	1	3.00	0.00
Counseling	1	2.00	0.00
Reduce anxiety	1	2.00	0.00

Note. $N=46$. Interventions are ordered with the most frequently reported first per type of intervention.
 "Scores are based on following scale: 1=eliminated problem; 2=reduced problem; 3=no change in problem;
 4=increased problem.

APPENDIX E

Support for Parents of Children with ASD and Sleep Problems: Who Provides Support and How Helpful is that Support?

Source of Support	Total Responses <i>N</i> ^a (%)	1	2	3	4	5	<i>M</i> ^b (SD)
		Not Helpful <i>n</i> (%)	Somewhat Not Helpful <i>n</i> (%)	Indifferent <i>n</i> (%)	Somewhat Helpful <i>n</i> (%)	Helpful <i>n</i> (%)	
Self (research)	2 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	4.50 (0.71)
Family	31 (64.4)	6 (19.4)	7 (22.6)	4 (12.9)	13 (41.9)	1 (3.2)	2.87 (1.26)
Friends	25 (52.1)	6 (24.0)	2 (8.0)	8 (12.0)	8 (12.0)	1 (4.0)	2.84 (1.25)
Another parent of a child with ASD	20 (58.3)	1 (5.0)	3 (15.0)	2 (10.0)	8 (40.0)	6 (30.0)	3.75 (1.21)
Pediatrician	32 (66.7)	6 (18.8)	5 (15.6)	5 (15.6)	13 (40.6)	3 (9.4)	3.06 (1.32)
Mental health counselor	16 (33.3)	2 (12.5)	3 (18.8)	3 (18.8)	5 (31.3)	3 (18.8)	3.25 (1.34)
Medical specialist	14 (29.2)	1 (7.1)	3 (21.4)	3 (21.4)	2 (14.3)	5 (35.7)	3.50 (1.40)
Sleep disorder specialist	4 (8.3)	1 (25.0)	0 (0.0)	1 (25.0)	2 (50.0)	0 (0.0)	3.00 (1.41)
Behavior Specialist	2 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	1 (50.0)	1 (50.0)	4.50 (0.71)
Alternative Medicine	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)	4.00 (0.00)
Birth-to-3 Provider	7 (14.6)	1 (14.3)	0 (0.0)	2 (28.6)	2 (28.6)	2 (28.6)	3.57 (1.40)
District Preschool	3 (6.3)	0 (0.0)	0 (0.0)	1 (33.3)	2 (66.7)	0 (0.0)	3.67 (0.58)
Charter Preschool	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.00 (0.00)
Private Preschool	2 (4.2)	0 (0.0)	0 (0.0)	0 (0.0)	2 (100.0)	0 (0.0)	4.00 (0.00)
District School K-12	5 (10.4)	1 (20.0)	1 (20.0)	1 (20.0)	0 (0.0)	2 (40.0)	3.20 (1.79)
Charter School K-12	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.00 (0.00)
Private School K-12	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0.00 (0.00)
Utah Parent Center	1 (2.1)	0 (0.0)	0 (0.0)	0 (0.0)	1 (100.0)	0 (0.0)	4.00 (0.00)
Internet	19 (39.6)	1 (5.3)	3 (15.8)	3 (15.8)	8 (42.1)	4 (21.1)	3.58 (1.17)
Parent Support Group	7 (14.6)	1 (14.3)	0 (0.0)	0 (0.0)	2 (28.6)	4 (57.1)	4.14 (1.46)

Note. *N*=48.

^a Percents listed in the Total Responses column are based on the total *N*=48. Percents listed in other columns are based on the number of participants responding, not to the total number of participants (48). ^b Not Helpful =1; Somewhat Not Helpful =2; Indifferent =3; Somewhat Helpful =4; and Helpful=5.