

USING A BEHAVIORAL TREATMENT PACKAGE FOR SLEEP PROBLEMS IN
CHILDREN WITH AUTISM SPECTRUM DISORDERS

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ABSTRACT

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by Rachel M. Knight

This study investigated the effectiveness of using a behavioral treatment package for sleep problems in children diagnosed with autism spectrum disorders. The treatment package consisted of four behaviorally-based treatment components: circadian rhythm management (CRM), positive bedtime routines, white noise, and graduated extinction. A multiple-baseline design across participants was used for three participants. Data were collected using daily sleep diaries completed by parents. These families completed a baseline phase of various lengths followed by one month of intervention which included all four treatment components. One month after formal treatment ended, follow-up data were collected for a period of one week. Additionally, families completed a social validity scale at the conclusion of the study. Results indicated that the treatment package was effective in decreasing the frequency of night awakenings along with sleep onset latency. Parents reported satisfaction with the four intervention components and that their children slept better as a result of this treatment package.

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CHAPTER I

INTRODUCTION

Sleep problems are common, affecting about 25-40% of young children (Owens, 2007). It is possible that these problems may have an even higher prevalence but often go unreported by parents and caregivers (Johnson, 1991) and undiagnosed by physicians (Meltzer, Johnson, Crossette, Ramos, & Mindell, 2010). Despite some controversy over total sleep time recommendations, lack of adequate sleep in the pediatric population has become a major health concern (Matricciani, Olds, Blunden, Rigney, & Williams, 2012). In the *Sleep in America Poll* about 69% of parents reported that their child had problems sleeping a few times per week (National Sleep Foundation, 2004). Wakefulness is the most common sleep problem in young children; other difficulties such as parasomnias and sleep apnea occur but are less prevalent (Meltzer et al., 2010; Richman, 1981). Night waking is more common than bedtime struggle for infants and preschoolers; 15% to 30% of children four years of age and under experience frequent night time waking whereas 6% to 15% experience difficulty settling at bedtime (Kataria, Swanson, & Trevathan, 1987).

There are multiple risk factors associated with sleep problems in young children. These include medical problems such as Caesarian sections, toxicity in the mother during pregnancy (Minde et al., 1993), environmental factors such as parent separation or a recent move (Kataria et al., 1987), and higher levels of stress on family relationships (Kataria et al., 1987; Richman, 1981). Additionally, parent-child difficulties related to insecure attachment or depression and/or anxiety in the mother have been shown to be associated with sleep problems (Benoit, Zeanah, Boucher, & Minde, 1992; Minde et al., 1993). However, these data are correlational and it is not always clear which, if any, are causative. Lack of independent sleep initiation skills and the

ability to self-soothe are also associated with difficulty falling asleep and night awakenings that require parental presence to return to sleep (Benoit, Zeanah, Boucher, & Minde, 1992; Ferber, 2006; Gaylor, Goodlin-Jones, & Anders, 2001; Hiscock & Wake, 2001; Minde et al., 1993).

Another major issue involves associations between sleep disturbances and behavior problems; 30% to 50% of young children with sleep disturbances exhibit anxiety, depression, attention problems, aggression, hyperactivity, excessive crying, and temper tantrums (Gregory, Eley, O'Connor, & Plomin, 2004; Kataria et al., 1987; Richman, 1981). Although sleep problems may not cause difficulties, they may serve as a possible indicator of future behavior and emotional problems. Additionally, sleep problems can negatively impact a child's cognitive and academic performance (Buckhalt, Wolfson, & El-Sheikh, 2009).

Not only are sleep problems prevalent; current research indicates that children with developmental disabilities have even higher rates than typically developing children. Didden and Sigafos (2001) reported prevalence rates for sleep problems in children with developmental disabilities that range from 13% to 86%. In particular, children with autism experience the highest rates; about two-thirds have sleep difficulties (Richdale, 2001). Polimeni, Richdale, and Francis (2005) reported that 73% of children with autism had sleep problems versus 50% of typically developing children. Souders et al. (2009) reported prevalence rates of sleep disturbances in typically developing children at 45% versus 66% in children with autism spectrum disorders (ASD). Similarly, Giannotti et al. (2008) reported 60% prevalence rates of sleep problems in children with autism, with higher rates in children who experienced autistic regression. A recent study by Giannotti, Cortesi, Cerquiglini, Vagnoni, and Valente (2011) provided additional support that children with autism who experienced regression presented with more sleep disorders. However, the relationship between sleep problems and autistic regression

remains unclear. Liu, Hubbard, Fabes, and Adam (2006) found that 86% of children with ASD had at least one sleep problem. Finally, Wiggs and Stores (2004) reported that most children with ASD have severe sleep problems, especially those under age eight.

Although it is clear that sleep problems are highly prevalent and persistent in children with ASD, the etiology of these sleep problems remains uncertain (Richdale & Schreck, 2009). Current research suggests a significant relationship between sleep difficulties and various problem behaviors in children with autism such as language use, attention, social interactions, anxiety, hyperactivity, aggression, and eating habits (Goldman, McGrew, Johnson, Richdale, Clemons, & Malow, 2011). However, the authors recommended further research regarding these relationships in order to determine appropriate treatment plans. Hollway and Aman (2011) reviewed various correlates of sleep disturbances in children with autism spectrum disorders (e.g., intellectual functioning, internalizing behaviors, problem behaviors) and found mixed results. More research is needed to understand the various relationships among ASD, sleep problems, and additional cognitive and behavioral concerns.

Like typically developing children, children with autism experience unusual bedtime routines, difficulty settling at bedtime, more sleep anxiety, irregular sleep-wake patterns, and night wakings (Hoffman, Sweeney, Gilliam, & Lopez-Wagner, 2006; Richdale, 2001). Honomichl, Goodlin-Jones, Burnham, Gaylor, and Anders (2002) provided further support noting that children with pervasive developmental disorders have longer sleep-onset latency, more frequent night wakings, and night wakings of longer duration than typically developing children.

Williams, Sears, and Allard (2004) surveyed 210 families of children with autism and found the most common sleep problem was difficulty falling asleep, noted in 53% of the sample.

Other common problems included restless sleep, unwillingness to sleep in own bed, frequent wakings, and difficulty arousing the child from sleep. These problems suggest troubles with the sleep-wake cycle. Glickman's (2010) review of sleep problems in children with autism also indicates impairments in the sleep-wake cycle. Children with autism appear to have abnormal melatonin and cortisol production, which suggests impairments in circadian rhythms.

Schreck and Mulick (2000) reported that children with autism are more likely to have disoriented awakenings that include sluggishness and confusion. Additionally, they exhibit higher rates of screaming at night, sleep walking, acting out dreams, breathing cessation, and bruxism. Moreover, sleep difficulties may exacerbate symptoms of autism; the fewer hours a child slept per night predicted more severe stereotypic behaviors and social-skill deficits (Schreck, Mulick, & Smith, 2004). Quality of sleep is also important; for example, communication difficulties were significantly related to increased sensitivity to the sleeping environment and periods of screaming during the night. Children who had more night wakings accompanied by screaming were more likely to engage in stereotyped behaviors and to have communication difficulties (Schreck et al., 2004). Although this study does not prove causation, it appears that sleep problems intensify symptoms of autism and, if ameliorated, might lessen some of these symptoms.

Hoffman et al. (2005) provided additional support for the association between sleep problems and intensified symptoms of autism when they replicated and expanded the study by Schreck et al. (2004). Their findings were consistent in that shortened sleep duration was predictive of developmental disturbances, but some additional points were noted. Hoffman et al. (2005) reported that in their sample, parasomnias were strong predictors of developmental disturbances and overall scores on the *Gilliam Autism Rating Scale* (GARS; Gilliam, 1995).

Additionally, sleep-disordered breathing predicted stereotyped behaviors, social-skill deficits, and overall scores on the GARS. Daytime sleepiness was associated with stereotyped behaviors and social interaction difficulties.

There is increasing evidence for severe sleep problems in children with autism, however little research is available regarding evidence-based treatments (Schreck, 2001; Wiggs & Stores, 2004). Children with autism have various types of sleep disorders, but the most common problems are behavioral, just as in the general population (Wiggs & Stores, 2004). Due to the behavioral nature, it seems that behavioral interventions should be the first step to ameliorate these problems.

Melatonin

Although there is little controlled research for behavioral treatments for sleep problems in children with autism, there is some evidence suggesting the efficacy of melatonin. Glickman (2010) reported concerns that children with autism have impairment in circadian rhythms and atypical hormone production, including melatonin and cortisol. Additionally, Johnson, Giannotti, and Cortesi (2009) suggested that children with autism may have abnormal melatonin production and would benefit from supplemental melatonin therapy. Cortesi, Giannotti, Ivanenko, & Johnson (2010) also suggested that melatonin therapy may be effective in decreasing sleep onset latency and waking after sleep onset, as well as increasing total sleep time in children with ASD. Anderson, Kaczmarska, McGrew, and Malow (2008) found melatonin therapy to be effective in treating sleep-onset insomnia and sleep maintenance insomnia in many children with ASD. However, the authors reported a need for more controlled studies on the efficacy and safety of melatonin for these children. Rossignol and Frye (2011) conducted a review and meta-analysis of melatonin usage for sleep problems in children with ASD, which

suggested that melatonin may be a promising treatment, but further controlled research was warranted. Johnson and Malow (2008) also suggested the need for more controlled pharmacotherapy research.

It is difficult to determine the most appropriate and effective treatment plan for sleep problems because each individual case may have multiple contributing factors. Therefore, different treatments continue to be investigated for optimal efficacy. One type will not be effective for all children, thus, it is beneficial to determine multiple methods that have potential to alleviate various sleep problems.

Scheduled Awakenings

One treatment shown to be effective with night wakings is scheduled awakenings. This method requires the parent to awaken the child about 15 minutes before he or she normally wakes and cries. The parent soothes the child back to sleep, perhaps feeding and changing diapers if that is what had been done during spontaneous awakening and crying episodes in the past. Scheduled awakenings would occur nightly; then these awakenings would be spaced and gradually decreased over time until they were no longer needed. Multiple studies have found scheduled awakenings to be more effective than control groups (Mindell, 1999). However, the effectiveness depends on parent adherence to the treatment schedule (Johnson, Bradley-Johnson, & Stack 1981; Johnson & Lerner, 1985; Rickert & Johnson, 1988). One study indicated that scheduled awakenings were effective in treating chronic sleep terrors in children with autism (Durand, 2002).

Extinction

Another well-researched treatment is extinction or letting the child “cry it out.” This involves putting the child to bed and requiring the parent to ignore cries. Parents may first check to make sure that the child is safe (not sick or hurt), but then they must ignore the child’s crying for the remainder of the night (Mindell, 1999). Rickert and Johnson (1988) presented evidence that either extinction or scheduled awakenings were more effective than a control group of infants and toddlers. Wolf, Risley, and Mees (1964) used extinction to eliminate nighttime tantrums in a 3-year-old boy with autism. Additionally, Weiskop, Matthews, and Richdale (2001) found extinction combined with a bedtime routine was effective in treating night wakings and bedtime resistance in a 5-year-old boy diagnosed with autism. In a later study, extinction combined with bedtime routines and reinforcement was effective in treating night waking, co-sleeping, and refusal to fall asleep alone in children with autism (Weiskop, Richdale, & Matthews, 2005).

However, a major difficulty with extinction is parent compliance. Many parents have difficulty following through with this intervention (Johnson, 1991; Mindell et al., 2006; Trilling, 1989). Additional concerns regarding extinction revolve around possible child abuse. Research has shown that shaken baby syndrome is often a result of tension and frustration generated by a baby’s constant crying, especially when caregivers are already under significant stress (American Academy of Pediatrics, 2001). Therefore, letting a child cry it out might not be the best option for some caregivers. Nevertheless, Mindell et al. (2006) showed extinction as an empirically-supported treatment.

Graduated Extinction

In graduated extinction, or the progressive-waiting approach, parents ignore bedtime and night-waking tantrums for progressively longer time intervals (Ferber, 2006). After the designated time interval (5 to 30 minutes), parents are allowed to enter the room, briefly soothe their child, and then leave the bedroom before he or she falls back to sleep. Leaving the room while the child is awake is critical for the child learning to self-soothe. This approach is supported by research with typically developing children (Mindell, 1999; Mindell et al., 2006). Durand, Gernert-Dott, and Mapstone (1996) reported that graduated extinction, when combined with a bedtime routine and scheduled bedtime, was effective in reducing bedtime tantrums in children with autism.

White Noise

White noise also is effective for treating sleep problems. Spencer, Moran, Lee, & Talbert (1989) found white noise useful for improving sleep in neonates. Borkowski, Hunter, & Johnson (2001) found 75 decibel (dB) white noise effective in treating night wakings and bedtime resistance in young children when combined with bedtime routines and a daily schedule. Forquer and Johnson (2005) found 75 dB white noise effective as the sole treatment in decreasing night wakings and sleep latency in toddlers. However, the authors reported a concern that sleep problems may return upon its removal; if parents are comfortable with white noise and it improves their child's sleep there may be no need to fade it out. It is unknown if white noise is effective in treating sleep problems for children with autism.

Positive Bedtime Routines

Positive bedtime routines is an intervention in which four to six calm activities the child enjoys take place close to bedtime, such as reading a book with a parent (Adams & Rickert, 1989). The few studies solely using this treatment are promising and found positive bedtime routines effective (Mindell, 1999; Mindell et al., 2006). Several studies combined positive bedtime routines with other behavioral interventions, and these were effective (Mindell et al., 2006). Additionally, when combined with extinction or graduated extinction, positive bedtime routines were effective in treating sleep problems in children with autism (Durand et al., 1996; Weiskop et al., 2001; Weiskop et al., 2005).

Bedtime Fading

Kuhn and Elliot (2003) suggested bedtime fading as a promising alternative to extinction to treat sleep latency difficulties and bedtime resistance in typically developing children. This procedure consists of adhering to consistent sleep and wake times while delaying bedtimes when the child is more likely to fall asleep quickly. Parents then gradually fade the bedtime earlier over time. This procedure was combined with a positive reinforcement and response cost system to treat long sleep latencies in children with autism (Moon, Corkum, & Smith, 2011). Although effective, it was a case-study design of three children which leads to concerns regarding generalizability and other variables that may have been related to the outcomes.

Circadian Rhythm Management

Finally, another method for treating sleep problems is circadian rhythm management (CRM). These are the body's daily rhythms in behavior and physiological processes that run in cycles of approximately 24 hours and are controlled by the internal biological clock located in

the suprachiasmatic nucleus (SCN) of the hypothalamus (Carlson, 2007; Ferber, 2006; Lu & Zee, 2006). The SCN controls the body's sleep-wake patterns along with body temperature, hormones, blood pressure, and appetite (Carlson, 2007; Ferber, 2006). Different environmental stimuli reset the biological clock of the SCN, which are referred to as zeitgebers. Light acts as a powerful zeitgeber, along with other stimuli such as meals and alarm clocks (Carlson, 2007; Ferber, 2006). Dysynchrony between one's circadian rhythms and the external environment can cause sleep disturbances (Carlson, 2007; Lu & Zee, 2006). For example, if meals and sleep times do not occur at regular times, then rhythms may become disorganized leading to sleepiness and hunger at unpredictable times (Ferber, 2006).

CRM aims to reset the sleep-wake cycle according to the external environment to help regulate feelings of sleepiness and hunger (Ferber, 2006; Lu & Zee, 2006). This method is effective in treating delayed sleep-phase insomnia in adults, using a scheduled sleep and wake time each day (Czeisler et al., 1981). CRM, combined with a systematically delayed bedtime and bedtime routines, also was effective in treating sleep difficulties in an 8-year-old child diagnosed with autism (Piazza, Hagopian, Hughes, & Fisher, 1998). Dahl, Pelham, and Wierson (1991) combined CRM with a behavior modification program including positive bedtime routines to treat delayed sleep phase insomnia in a 10-year-old diagnosed with ADHD. Sadeh (2001) provided further support for CRM, noting that an inconsistent sleep schedule often leads to sleeping problems in children. Maintaining a clear and consistent sleep schedule, along with meal and nap times, should have a positive effect on a child's sleeping patterns and circadian rhythms (Ferber, 2006).

The purpose of the current study was to examine the effectiveness of using a treatment package to ameliorate sleep problems in children with autism, specifically bedtime resistance

and night awakenings. The treatment package consisted of four behaviorally-based treatment components: CRM, positive bedtime routines, white noise, and graduated extinction. Extinction, while shown to be effective, was not included in the treatment package due to parent reluctance to comply with this method, possible response bursts in the form of temper tantrums, and concerns regarding possible child abuse during tantrums or crying episodes as indicated by the American Academy of Pediatrics (2001). Although scheduled awakenings are effective for night wakings and night terrors, this method was not applicable for tantrums that occur immediately after putting a child to bed. Graduated extinction can be used for tantrums that occur at bedtime and for night wakings, so this option was included as opposed to scheduled awakenings or bedtime fading. Finally, melatonin was not employed because behavioral treatments were applied and not drug- or hormone-based methods.

CHAPTER II
METHODOLOGY

Participants

Families of three children with autism between the ages of 4-5 years participated. Please refer to Table 1 for further information. Participants were identified through a Seminar Series on Autism for parents organized by a graduate student and professors in the Psychology Department at Central Michigan University. Seminars covered a variety of topics such as toilet training, applied behavior analysis, and childhood sleep problems. When parents attended seminars, they were requested to sign a form indicating their interest in participating in future research. Parents who agreed to be contacted were called for possible participation. Additionally, flyers were distributed at the Early Intervention Program in the Center for Autism Spectrum Disorders within the Munroe-Meyer Institute in Omaha, NE.

Table 1. *Participant Information*

| | Child A | Child B | Child C |
|---------------------|--|---------------------|--|
| Age in years | 4 | 5 | 5 |
| Gender | Male | Male | Female |
| GARS-2 Autism Index | 124 (120-128) | 89 (85-93) | 98 (94-102) |
| Sleep problem | Night awakenings; Sleep onset latency | Sleep onset latency | Night awakenings; Sleep onset latency |

Note: An autism index of 85 or higher on the GARS-2 indicates a "very likely" probability of autism.

Child A struggled with night awakenings and lengthy sleep onset latency. His mother reported some reactive co-sleeping because he would often enter the parental bed following night awakenings.

Child B's main sleep concern was lengthy sleep onset latency; it often took over an hour to fall asleep. During the parent interview his mother reported that he refused to sleep in his own

bed and often slept on the couch or other places (e.g., a wagon in the living room). Once he did not fall asleep until 7:00AM so she kept him home from therapy and school that day. Child B also had occasional night awakenings.

Child C was diagnosed with high functioning autism. Her mother reported concerns regarding both bedtime resistance and frequent lengthy night awakenings.

Measures

Parents completed the *Gilliam Autism Rating Scale, Second Edition* (GARS-2; Gilliam, 2006) regarding their child's symptoms. An autism index of 85 or higher on the GARS-2 was indicative of a “very likely” probability of autism.

Parents also completed a modified version of Morrell's (1999) sleep questionnaire, which is listed in Appendix A. This survey was used to understand the child's current sleep and eating patterns and to evaluate the type and intensity of the child's sleeping problem.

Sleep diaries recorded every day were used as the primary form of data collection. Please refer to Appendix B. These diaries included information regarding bedtimes, duration of sleep, morning waking times, nap times, meal times, and the frequency and duration of night wakings. Diaries also addressed unusual circumstances such as sleeping away from home, illness, or medical procedures.

Parents completed a social validity scale at the end of the follow-up phase to assess their level of satisfaction with the treatment package as well as its specific components. The questionnaire is displayed in Appendix C.

Apparatus

The white noise generator used was the Obus Forme Sound Therapy Relaxation System. The decibel levels (dB) for each machine were measured and calibrated at Central Michigan University.

Procedure

During the initial contact, parents were given a modified version of Morrell's (1999) sleep questionnaire. If parents indicated that their child was diagnosed with autism and experiencing bedtime resistance or night wakings, they were asked to participate.

Participation was based on the parents' perceptions of the severity of their child's bedtime resistance or night waking. Bedtime resistance was defined as refusal by the child to go to bed, leaving the bedroom multiple times before falling asleep, or taking excessive time to fall asleep at night. Night wakings were defined as wakings in which the child did not soothe him or herself back to sleep; instead parental intervention was required. If parents considered their child's bedtime resistance and/or night wakings problematic, they were included in the study. Additional requirements included that the children did not co-sleep with the parents on a regular basis and were not on medication for sleep problems.

When parents agreed to participate, a meeting was scheduled to explain the study in detail. Next, parents were given the opportunity to provide consent. Refer to Appendices D through J for consent forms. Parents completed the GARS-2 regarding their child's symptoms. The autism index for each child indicated a very likely probability of autism, which is displayed in Table 1.

Families were asked to complete three phases of the study: baseline, intervention, and follow-up. Families were required to agree to use the combination treatment package of CRM,

bedtime routines, white noise, and graduated extinction seven nights a week for the duration of intervention. Each family was compensated \$25 upon completion of baseline, \$50 upon completion of intervention, and an additional \$25 upon completion of the follow-up interview.

Sleep diaries were used for data collection during all three phases of the study. Baseline data were collected for a minimum of one week. Once complete, a second meeting was scheduled to explain the treatment package and distribute white noise generators. The first component of the treatment package was CRM. Parents were instructed to put their child to bed at the same time every night and to wake them up at the same time every morning. Parents also were instructed that upon awakening their child in the morning, he or she should not be allowed to continue to lie in the dark or watch television.

Using Ferber's (2006) recommended guidelines for amount of sleep required for different ages of children and the individual baseline data, both bedtimes and wake times were determined in collaboration with the parents. Parents and the researcher discussed recommended bedtimes and wake times that fit into the families' current schedules. No children took naps as part of their regular schedule so those were not included. Meal times also were determined based on parent input and baseline data.

The second component of treatment was bedtime routines. Parents and children were instructed to complete four to six quiet, calm activities prior to going to sleep. Routines included activities such as brushing teeth, reading a story, and taking a bath. The researcher discussed activities with the families to decide on a bedtime routine based on caretaker and child input. Families were instructed to follow the same routines, in order, seven nights per week throughout treatment.

The third component was use of white noise throughout the night. A white noise generator was provided for each family and parents were instructed to find a place in the child's room where the machine could be plugged in. They were instructed to turn the white noise generator on when they put their child to bed and to turn the device off upon waking the child in the morning. This step was one of the four to six components of the bedtime routine for each child. The machines were marked between 50 to 75 dB; parents were instructed to set the device and check to ensure it was set at the appropriate level for their child. Parents started at 50 dB and then adjusted the volume to a level that was comfortable for their family. They were requested to keep track of the volume level at the end of intervention. All families returned the machines so the dB level could be measured. Families used white noise generators seven nights per week throughout intervention and follow-up phases.

The fourth component was graduated extinction (Ferber, 2006) and was used, if applicable, to each family's situation. This component was utilized to decrease any nighttime tantrums occurring during treatment and follow-up. For example, if a child awoke during the night and cried, parents were requested to use graduated extinction. After the required waiting interval lapsed, parents could enter the room, check to make sure their child was not sick or hurt, and then promptly leave the room while the child was still awake. Parents were requested to follow this procedure for tantrums that occurred immediately after completing routines and putting the child to bed for the night or that occurred when their child woke during the night.

Treatment for each participant lasted one month. Parents were provided with instructions for each treatment component, which are listed in Appendix K. The researcher contacted the parents twice per week to answer questions, promote compliance with the treatment package, and ensure that the sleep diaries were sent. One family chose to e-mail sleep diaries, one family

chose to mail the sleep diaries, and one family chose to drop off the sleep diaries at the Center for Autism Spectrum Disorders at the Munroe-Meyer Institute.

After treatment families were encouraged to continue the use of CRM, bedtime routines, white noise, and graduated extinction. However, families were not required to complete sleep diaries between the end of treatment and before follow-up. One month after formal treatment and data collection ended, parents completed a sleep diary for one week. Subsequently, a follow-up meeting occurred to collect sleep diaries, discuss parents' reactions to treatment, and to return the white noise generators. During this meeting parents also completed a social validity scale to assess their level of satisfaction with the treatment package and its components. Replacement white noise generators were provided for families if they chose to continue to use white noise after the conclusion of the study.

Research Design

A non-concurrent multiple-baseline-across-participants-design was employed (Kazdin, 2011; Richards, Taylor, Ramasamy, & Richards, 1999). Due to enrollment in the study at various times, a non-concurrent baseline design enabled participants to enroll in the study at their convenience. Baseline data were collected for a minimum of one week and until the frequency of night wakings or the duration of sleep latency was stable for each participant. Each additional participant had a longer baseline beyond the first child.

The dependent variables were the number of night wakings, the minutes to fall asleep at night, dB level of white noise chosen by parents at the end of treatment, and scores on the social validity scale. Duration of night awakenings was not reported due to difficulties recording these data.

CHAPTER III
RESULTS

All three children showed some improvement in night wakings during treatment, which is demonstrated in Figure 1. The mean frequencies decreased from 1.2 during baseline to 0.4 during treatment and 0.3 during follow-up. Child A decreased from 1.4 during baseline to 0.7 during treatment, which maintained during follow-up at a mean of 0.6 night awakenings. Child B's rate stayed relatively stable, experiencing only four wakings during the entire month of treatment and one during the follow-up phase. Child C demonstrated a dramatic decrease from 1.9 during baseline to 0.4 occurrences per night during treatment and 0 during follow-up.

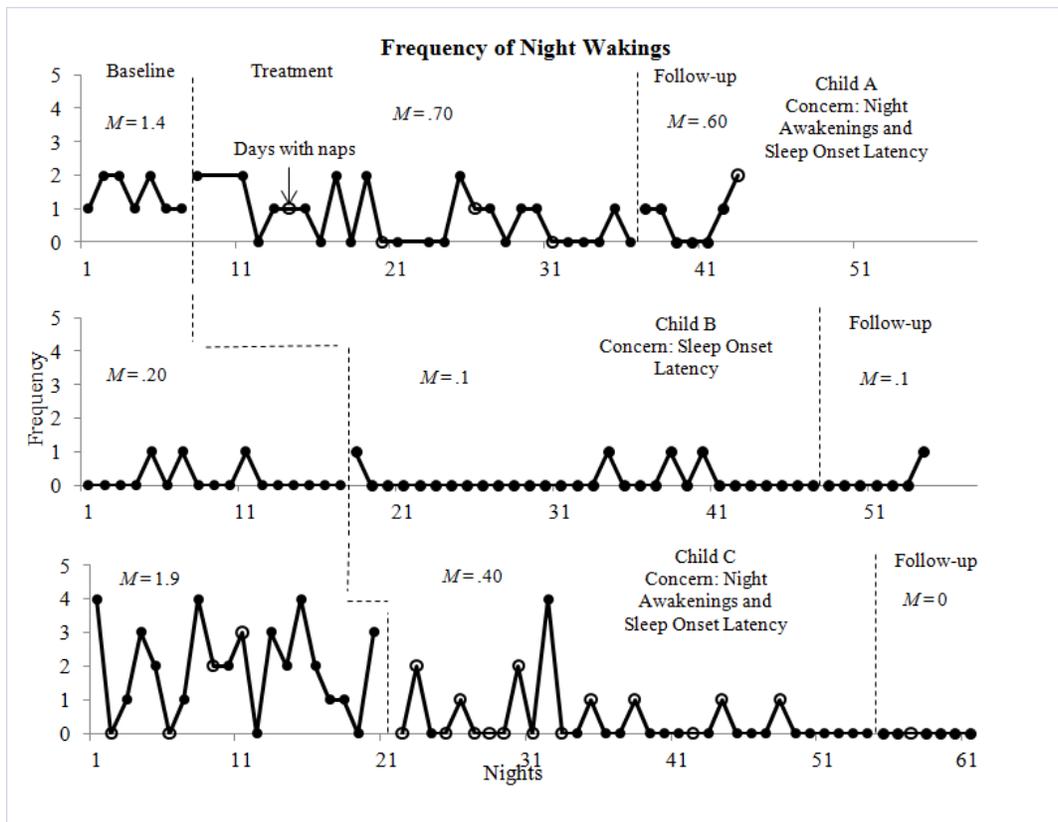


Figure 1. *Frequency of Night Wakings across Children.*

Sleep onset latency is shown in Figure 2. Mean sleep latencies for all children decreased from 73.2 minutes during baseline to 32.9 minutes during treatment and 31.1 during follow-up. Child A's sleep latency averaged 86.4 minutes, with a range of 60 to 135. This decreased during intervention to an average of 38.4 minutes, and it decreased further during follow-up to 26.4 minutes. He took 60 minutes or longer to fall asleep on four nights during treatment although less than the mean during baseline. Child A took naps on two of those days, which were not part of his regular schedule. Additionally, he stayed at his father's house during a third day and was allowed to sleep in longer than usual. Therefore, three of these four days were outside the agreed-to-protocol for CRM and then it took him longer to fall asleep that night. Table 2 depicts Child A's sleep onset latency with and without these deviations in treatment.

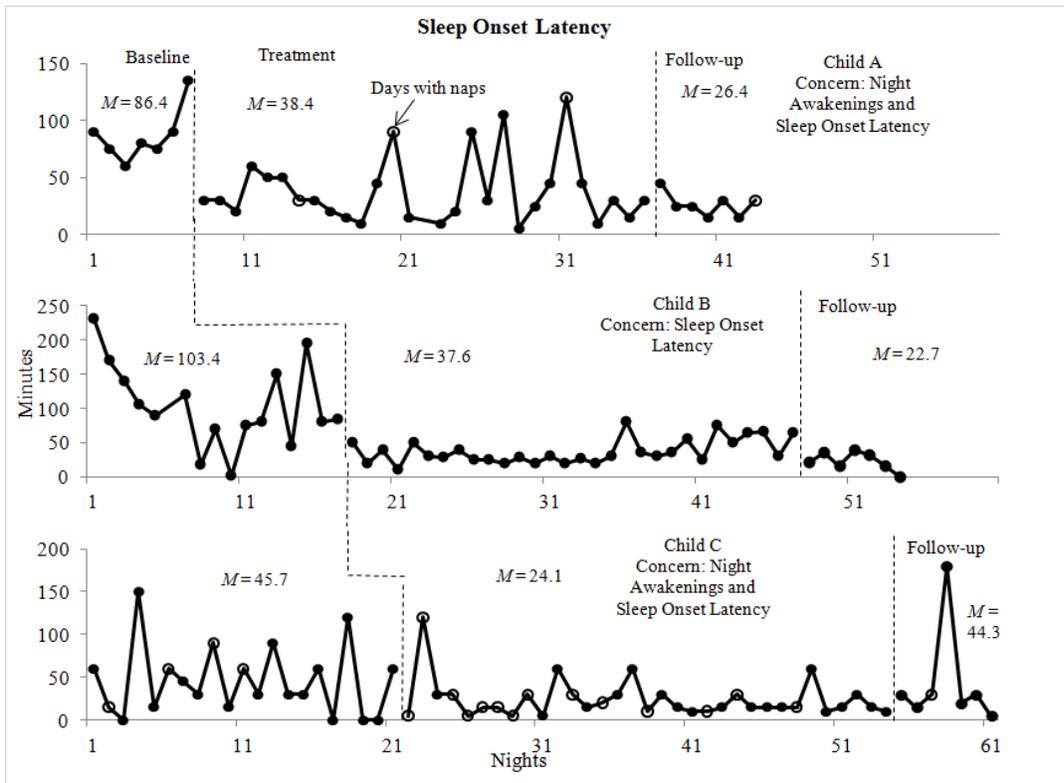


Figure 2. Total Minutes to Fall Asleep Each Night across Children.

Table 2. *Special Circumstances and Mean Sleep Latencies during Treatment for Child A*

| | Minutes |
|---------------------------------------|---------|
| Special Circumstances ($n = 3$ days) | 95 |
| Without Special Circumstances | 31.6 |
| Overall | 38.4 |

Note: Special circumstances included two days with naps and one day of sleeping in late.

Child B's sleep latencies decreased from an average of 103.4 minutes during baseline to 37.6 minutes during intervention. During follow-up he averaged 22.7 minutes to fall asleep at night.

Child C's sleep latencies decreased from about 45 to about 24 minutes during treatment. Due to one lengthy sleep latency during follow-up, her mean increased to about 44 minutes. Parent C reported that night was atypical for her sleep behaviors; all other nights during follow-up were 30 minutes or less. Special circumstances were also noted for Child C throughout intervention, as she often took 30 minute naps during lengthy car rides. It should be noted that there was only one night during which night awakenings occurred for days without naps during the treatment phase.

Parents also marked the white noise generators to indicate the volume level they used throughout treatment. The devices were checked at the end of treatment to determine the decibel levels. Results included 53dB, 65dB, and 71dB, which indicated that parents abided by the recommended decibel level range.

Sleep diaries were analyzed to determine parent compliance during intervention and these results are displayed in Table 3. Compliance was defined as reporting bed times, wake times, and meal times within 30 minutes before or after the scheduled CRM time. Additionally, parents were required to use all steps of the bedtime routines and white noise each night. Parents were requested to use graduated extinction as needed for nighttime tantrums.

Table 3. *Percent of Parent Compliance with the Treatment Package*

| Treatment Component | Parent A | Parent B | Parent C |
|---------------------|----------|----------|----------|
| Wake Times | 78.6 | 93.3 | 100 |
| Bed Times | 89.3 | 100 | 93.9 |
| Meal Times | 83.3 | 94.4 | 98.9 |
| Bedtime Routines | 88 | 100 | 100 |
| White Noise | 100 | 100 | 100 |
| No Naps | 82 | 100 | 60 |

Note: Compliance with wake, bed, and meal times was defined as being within 30 minutes of the scheduled time. Naps were not part of any child's schedule.

Overall, Parent A reported an average of 87% compliance with all components of the treatment package. She reported the highest level of compliance with using white noise every night. Parent A showed the most difficulty with adherence to set wake times, and occasionally she allowed her son to nap, which was not part of his CRM schedule.

Parent B demonstrated high levels of adherence to treatment across bed times, wake times, meal times, and using white noise with an overall average of 98% compliance. She noted some difficulties with wake times when her son woke up prior to his scheduled wake time.

Parent C also reported high levels of compliance with the treatment package with an overall average of 92% compliance. However, Parent C allowed her daughter to nap 40% of the days for about 30 minutes, which were not part of her regular schedule. These naps typically took place in the car after school.

Regarding graduated extinction, Parent A reported it was only necessary to use it on about 1/3 of all nights during intervention. Graduated extinction was not reported on nights when Child A was at his father's house. Parent B reported only having to use graduated extinction during 3 of the 30 nights of intervention. Parent C reported using it almost every night during treatment.

Results from this analysis indicated that white noise was the only treatment component for which all parents reported 100% compliance. Additionally, two parents reported significant difficulties with adherence to no naps for their children's schedules.

As shown in Table 4, all mothers reported satisfaction with the treatment package. Mothers also agreed that they were comfortable following all components of the treatment package and that their children slept better as a result of implementing the treatment package.

The last two questions of the survey were not rated on a Likert scale. Please refer to Appendix C for the full list of questions. Parent A reported that the average time for her child to fall asleep was 30 minutes and the average number of night wakings was 1-3. Parent B reported that the average time for her son to fall asleep was 15 minutes with the average number of night awakenings being 0. Parent C reported that the average time for her child to fall asleep was 15 minutes with the average number of night awakenings being 0-1.

Table 4. *Social Validity Questionnaire*

| Question | Parent A | Parent B | Parent C |
|---|----------|----------|----------|
| I believe that my child falls asleep better now than before this experiment. | 2 | 1 | 1 |
| I believe that the treatment package reduced his/her trouble falling to sleep. | 1 | 1 | 1 |
| I believe that the treatment package has decreased my child's night awakenings. | 1 | 1 | 1 |
| I would recommend the treatment package to others who have a child with sleep problems. | 1 | 1 | 1 |
| I felt comfortable following scheduled wake times for my child. | 2 | 1 | 1 |
| I felt comfortable following scheduled nap times for my child (if applicable). | N/A | N/A | 3 |
| I felt comfortable following scheduled bedtimes for my child. | 2 | 1 | 1 |
| I felt comfortable following scheduled meal times for my child. | 1 | 2 | 1 |
| I felt comfortable using bedtime routines. | 2 | 1 | 1 |
| I felt comfortable using white noise. | 2 | 1 | 1 |
| I felt comfortable using graduated extinction (if applicable). | 1 | 1 | 1 |
| Overall, the treatment package helped my child sleep. | 1 | 1 | 1 |
| I liked the overall experience of participating in this project. | 1 | 1 | 1 |

Note: The Evaluation of Treatment Package (CRM, Bedtime Routines, White Noise, & Graduated Extinction). Research questionnaire was rated using a 5-point Likert scale (1 = Strongly Agree; 5 = Strongly Disagree).

CHAPTER IV

DISCUSSION

Numerous behavioral methods have been studied extensively to promote sleep in typically developing children; however, currently there is little empirical evidence to suggest that these methods would be effective in treating sleep problems in children with autism.

Additionally, the current body of literature suggests that sleep problems are more prevalent and severe in children with ASD. This study aimed to address this gap between the prevalence of sleep problems in children with ASD and the lack of empirical evidence available for treatment. Additionally, although melatonin has some empirical evidence for its efficacy in treating sleep onset insomnia and sleep maintenance, it is unknown if this hormone is useful for bedtime resistance and tantrums. Also, long-term effects of melatonin are unknown and should be researched.

This experiment examined the efficacy of using a combined treatment package consisting of four behavioral components that have empirical support for treating sleep problems of typically developing children: CRM, bedtime routines, white noise, and graduated extinction. Results indicated that this behavioral treatment package was effective in reducing sleep latency and the frequency of night awakenings in young children diagnosed with ASD. Child A demonstrated improvements in both night awakenings and sleep latencies from baseline through follow-up. However, there was a rising trend for night awakenings at the end of follow-up. Child A took a brief nap on this last follow-up day which was not part of his regular schedule, and it may have contributed to sleep difficulties that night. Child B did not demonstrate difficulties in night awakenings during baseline, and these remained stable throughout treatment and follow up. However, his sleep latencies decreased substantially from baseline through

follow-up. Additionally, Child B's mother reported that he currently sleeps in his own bed every night since beginning intervention, something he did not do on any night prior to treatment. He was sleeping in various locations in the household before and during baseline such as the living room couch. She reported using graduated extinction during the first few nights of treatment to address this behavior. Child C demonstrated improvements in both night wakings and sleep latencies from baseline to the end of treatment. She continued to improve during follow-up; however, she had one night with lengthy sleep latency. Her mother documented that she had a difficult day at school and throughout the evening. No other special occurrences were noted for this day. Child C demonstrated sleep latencies of 30 minutes or less for the other 6 nights of follow-up.

Analyses of the sleep diaries indicated that parents generally adhered to treatment recommendations. Parents reported the highest levels of compliance with using the white noise consistently each night. Additionally, parents reported high levels of compliance with bedtime routines. However, parents reported some difficulties with adherence to treatment, and following a schedule without naps proved to be the most challenging for parents. Additional difficulties in adherence were noted such as staying at another caretaker's home without implementation of treatment, medical procedures interrupting meal times, and holidays or special occasions when intervention was suspended. For example, Parent A reported that several of the changes in her child's schedule were due to spending time at his father's house, which occurred about 2 days per week. According to parent report and documentation in the sleep diaries, Child A's father did not always adhere to the CRM guidelines. Additionally, Parent C reported that her child often took naps during long drives, but the naps were brief and typically lasted about 30 minutes. However, car rides provide constant stimulation (i.e., noise, motion), which may have

induced sleep during this time, making it difficult for Parent C to ensure her child was awake. Brackbill (1973) reported that using constant stimulation such as noise, motion, and touch reduces arousal levels in infants both behaviorally and physiologically. These variables may have impacted Child C's napping behavior. However, data from the three sleep diaries suggest that this treatment package can fit comfortably into a family's schedule most of the time.

The social validity questionnaire indicated that the mothers felt the treatment package was effective in reducing their children's sleep problems. Despite the fact that sleep problems were not completely eliminated for all children, the improvements were very important to parents. Each mother provided additional comments on the questionnaire. Child A's mother reported, *"Overall I think this has helped and made the sleeping experience 90% better. I appreciate all the help and think that we are doing better from the treatment package that was offered to us."* Parent B commented, *"Thank you so much! This study made a huge impact on our lives for the better."* Parent C reported, *"I think this will work for any child as long as they stick with it. I love it! I'm so grateful I got your number!"* Parent C also recommended the treatment package to other parents.

These data suggest this behavioral intervention package is effective for treating sleep problems in children with ASD. However, there are some limitations to this study. First, because of the small sample size in the non-concurrent multiple-baseline-across-participants-design, results may not generalize to larger populations. Though the results are promising, some children with ASD may need additional intervention and other areas may need to be assessed. For example, some children may exhibit daytime behavior concerns such as noncompliance or the bedroom environment may require evaluation. These may need to be targeted first or in

concert with this treatment package to facilitate efficacy. Additionally, a non-concurrent multiple-baseline was used due to enrollment in the study at various times.

Although sleep diaries are valid methods for this research topic (Sadeh, 2008), there are some concerns. Sleep diaries are subject to error as parents may over- or underestimate the number and length of night awakenings, especially if they retrospectively complete the diaries the following morning. Also, sleep diaries only consist of information of which parents are aware (Sadeh, 2008). If a child lies quietly awake in bed, parents may not be aware, which is why actigraphy typically documents more night awakenings than parent report methods (Sadeh, 1994). However, these awakenings would typically not be considered problematic by parents since they do not include tantrums (Schreck & Mulick, 2000; Schreck et al., 2004).

Although sleep diaries are subject to error, parent perceptions of their children's night awakenings and sleep latencies during follow-up were fairly similar to the children's actual means. If one night was removed from follow-up for Child C, which was noted as atypical, then all parent estimates were within 10 minutes of their children's average sleep latencies. In terms of night awakenings, Parents B and C were highly accurate in their estimates, whereas Parent A reported an overestimate of night awakenings when compared to her child's follow-up mean. Parent A estimated about 1-3 awakenings per night, but her son's average was 0.6 night awakenings. Parent A's estimation could have been related to the increasing trend in the data at the end of the follow-up phase.

Another limitation in this study, due to single-parent households and scheduling difficulties, only one caregiver completed sleep diaries for each of the three families, making it difficult to measure inter-observer reliability. Future research may benefit from a combination of data collection methods such as actigraphy and sleep diaries (Sadeh, 2008; Sadeh, 2011).

Actigraphy is helpful in providing objective data, especially because parents tend to overestimate assumed sleep time (Sadeh, 2011). However, sleep diaries appear reliable to measure sleep onset, and they can provide additional information about sleep habits that is useful for editing actigraph data, such as if a child is being rocked during sleep. Parent report also provides information regarding special circumstances that may impact a child's sleep and behavior (e.g., illness, vacations, etc.). Sleep diaries could be used to elucidate actigraph data and provide descriptive information regarding a child's sleep habits. Additionally, parent report can be useful to determine adherence to treatment, which would not be provided using actigraphy alone. For example, showing that Parent A reported 87% compliance with the treatment suggests that treatment effects may have been even stronger if adherence could have been improved.

Despite these limitations, the results suggest that behavioral treatments have promise as effective strategies for treating various sleep problems in children with ASD. Additionally, parents reported satisfaction with the treatment package; buy-in from parents is crucial when implementing interventions for young children because parents are typically responsible for managing the sleep schedules. Results from the social validity questionnaire suggest that mothers are comfortable implementing the various components of the behavioral treatment package and feel that the treatment was effective. However, since only mothers completed sleep diaries and the satisfaction surveys, paternal adherence as well as perceptions of the treatment package are unknown.

This study provided further evidence for behavioral treatments for sleep problems in children with ASD, and it also expanded on the previous studies by including a follow-up phase, white noise, and a multiple baseline design as much of the current literature is based on case-

study designs. However, long-term follow-up phases would be beneficial to determine lasting stability of behavioral interventions for sleep problems.

Future research regarding additional types of behavioral treatment methods would be beneficial (e.g., scheduled awakenings, extinction). Additionally, this study utilized a treatment package combining four different methods. It would be beneficial to determine if components of the treatment package would be effective when utilized individually or in various combinations, as well as which are most effective and least intrusive for families. Strategies for combining various treatments and the order of implementation also would be important to investigate. Finally, studies comparing or combining melatonin with behavioral treatment packages may prove to be highly efficacious. Additionally, long-term follow-up for the treatment package in this study was not completed, which would be beneficial to investigate.

Examining the various behavioral interventions for sleep problems in children with ASD is important, but it also would be helpful to investigate the effectiveness of this and other behavioral treatment packages in children with other co-morbid disorders such as Attention-Deficit/Hyperactivity Disorder (ADHD) or various genetic disorders. Determining appropriate and effective behavioral interventions for sleep problems in children with various emotional, behavioral, and/or genetic disorders will be helpful not only to these children, but for their families as well. Such research is critical for their well-being and our understanding of ways to ameliorate challenging behaviors.

APPENDICES

APPENDIX A

USING A BEHAVIORAL TREATMENT PACKAGE FOR SLEEP PROBLEMS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS

- I. Hello, is Ms./Mrs. _____ there?
A. Yes, proceed to II.
B. No, 1.) Ask person if there is a more convenient time to get a hold of the mother or caregiver then record answer under III.
2.) Leave a message on the answering machine. *Hi this is _____ from the Psychology Department at Central Michigan University. I was calling in regards to our sleep study. I will try and reach you at a better time.*

- II. My name is _____ from the Psychology Department at Central Michigan University. I am calling about sleep study for children with autism. We received your contact information from the Seminar Series on Autism provided by the Psychology Department at CMU. On the sign-in sheet at the Seminar Series, you indicated that you would be interested in being contacted about research participation. We are following up to learn whether you might still be interested in participating in a study of a treatment for sleep problems in children with autism.

Has your child been diagnosed with autism?

1. ___ no 2. ___ yes 3. ___ Don't know/ Not Sure

(If yes) Who made the diagnosis? _____

Do you think that your child has any sleeping difficulties? (If yes, please specify severity.)

1. ___ no 2. ___ yes 3. ___ Don't know/ Not Sure

(If yes) Do you consider the sleep problem to be _____ mild _____ moderate _____ severe?

- III. (If yes) We will begin with an over- the- phone survey with some general questions about your child's sleeping & eating habits. It will last between 10 and 15 minutes and is confidential. After completing the survey, we may call you back to participate in our study to possibly solve your child's sleep problems and an opportunity to earn _____ dollars. Is now a good time to do the over-the-phone survey?

___ Yes (proceed to IV.)

___ No What other times would be more convenient for me to call you?

Day: _____ Time: _____

Day: _____ Time: _____

- IV. Great! Let's get started. (proceed to sleep pattern survey)

Child Name: _____

Child's sex: 0. Female 1. Male

DOB: _____

Parents: _____

Calls: (Date & Time) _____

1. Before we begin, we would like to ask if _____ is currently on any medications that may be sleep related or may be affecting his/her sleep.

1. ___ yes 2. ___ no 99. ___ DK

If yes, note _____

2. Also, does your child have any medical condition that you believe currently causes him/her to have sleep problems- such as an ear infections, congestion, pain, or allergies?

1. ___ yes 2. ___ no 99. ___ DK

If yes, note _____

3. Does your child attend daycare?

1. ___ yes 2. ___ no 99. ___ DK

4. Does _____ take naps during the day? (If no- skip to # 9)

1. ___ yes 2. ___ no 99. ___ DK

5. How long do typical naps last _____

6. Does he/she have a scheduled nap time?

1. ___ yes 2. ___ no 99. ___ DK

7. (If yes) what time (s) does ___ usually take a nap during the day _____

8. Where does ___ take naps? (Interviewer: check all that apply)

1. ___ own room 2. ___ with siblings 3. ___ own bed in parents' room

4. ___ parents' bed 5. ___ other

9. Does _____ usually wake on his/her own or does he/she need to be wakened from naps?

1. ___ wake on own 2. ___ needs to be wakened

10. Does he/she have a problem taking naps?

1. ___ yes 2. ___ no 99. ___ DK

If yes, please specify the problem (e.g., excessive crying, refusal to sleep) _____

11. Do you have a scheduled bedtime for ____?
1. ____ yes 2. ____ no 99. ____ DK
12. What time does _____ typically go to bed at night _____?
13. (If yes) Did you determine his/her bedtime or did _____ set (his/her) own schedule?
1. ____ parent set 2. ____ child developed own 99. ____ DK
14. Do you like, dislike, or feel neutral about bedtimes for _____ right now?
1. ____ like 2. ____ dislike 99. ____ DK/neutral
15. Where does ____ sleep at night? (Interviewer: check all that apply)
1. ____ own room 2. ____ with siblings 3. ____ own bed in parents' room
4. ____ parents' bed 5. ____ own bed in siblings' room 6. ____ other
16. Does ____ have a problem settling (going) to sleep at night? (If no, skip to #18)
1. ____ yes 2. ____ no 99. ____ DK/Neutral
17. (If yes) How many times a week do you have problems settling him/her to sleep on average?
0. ____ problems less than once a week 1. ____ problems 1 night a week
2. ____ problems 2 nights a week 3. ____ problems 3 nights a week
4. ____ problems 4 nights a week 5. ____ problems 5 nights a week
6. ____ problems 6 nights a week 7. ____ problems every night of the week
18. (If yes) How long has the settling problem been going on?.....months () not applicable
19. How long does it usually take for your child to settle to sleep (on average)? (Note to interviewer: Offer choices in ten minute intervals)
1. ____ less than ten minutes 2. ____ 10 to 20 minutes 3. ____ 20 to 30 minutes
4. ____ 30 to 40 minutes 5. ____ 40 to 50 minutes 6. ____ 50 to 60 minutes
7. ____ 1 hour or longer
20. So, at what time does _____ actually fall asleep at night after you put him/her in bed? (most typical)
- _____
21. Do you have a bedtime routine?
1. ____yes 2. ____no

22. Which of the following does your routine include? (check all that apply)
- | | | | |
|----------------|-------------------------|----------------------------|----------------|
| 1. ___ bath | 4. ___ favorite tv show | 7. ___ white noise machine | 10. ___ prayer |
| 2. ___ stories | 5. ___ rocking | 8. ___ self-soothe | 11. ___ Other |
| 3. ___ singing | 6. ___ taped music | 9. ___ brush teeth | 12. ___ DK |
| | | | 13. ___ NA |
23. Would you say that ___ has a problem waking during the night?
1. ___ yes 2. ___ no 99. ___ DK/Neutral
24. When is _____ usually awake at night and for how long? _____
- _____
25. How many nights a week does your child wake on average?
0. ___ none of less than once a week 1. ___ 1 night a week 2. ___ 2 nights a week
3. ___ 3 nights a week 4. ___ 4 nights a week 5. ___ 5 nights a week
6. ___ 6 nights a week 7. ___ every night of the week
26. On the nights that he/she wakes, how many times does he/she wake and need resettling on average?
0. ___ does not wake 1. ___ once a night 2. ___ twice a night
3. ___ 3 times a night 4. ___ 4 times a night 5. ___ 5 or more times a night
27. If your child wakes, how long does it take for him/her to go back to sleep on average?
1. ___ less than ten minutes 2. ___ 10 to 20 minutes 3. ___ 20 to 30 minutes
4. ___ 30 to 40 minutes 5. ___ 40 to 50 minutes 6. ___ 50 to 60 minutes
7. ___ 1 hour or longer
28. How long has the night waking been going on? _____years _____ months _____not applicable
29. How many nights a week does your child fall asleep in a place that's not his/her own bed or your bed (e.g., couch, floor, in front of the television)?
0. ___ none of less than once a week 1. ___ 1 night a week 2. ___ 2 nights a week
3. ___ 3 nights a week 4. ___ 4 nights a week 5. ___ 5 nights a week
6. ___ 6 nights a week 7. ___ every night of the week

30. How often do you end up taking your child into your bed because he/she is upset and won't sleep?

0. ___ none of less than once a week 1. ___ 1 night a week 2. ___ 2 nights a week
3. ___ 3 nights a week 4. ___ 4 nights a week 5. ___ 5 nights a week
6. ___ 6 nights a week 7. ___ every night of the week

31. After you have taken _____ into bed and he/she falls back to sleep, do you typically...

1. ___ Return child to his/her own bed and leave the child's room
2. ___ Return child to his/her own bed and stay with child in his/her room.
3. ___ Keep him/her in bed with you the remainder of the night.
4. ___ Other: _____

32. How long have you needed to take your child into bed to help him/her sleep? ___ mos ___ NA

33. What time does _____ usually wake in the morning? _____

34. Does _____ wake on his/her own or does he/she need to be wakened in the morning

1. ___ wake on own 2. ___ needs to be wakened

35. Does _____'s bed and nap schedule changes on the weekends and vacations?

1. ___ yes 2. ___ no 99. ___ DK/Neutral

Notes: _____

36. Does _____'s sleep and nap times change when being cared for by different adults

1. ___ yes 2. ___ no 99. ___ DK/Neutral

37. Do you typically have a scheduled mealtime for _____ or do you feed him/her on demand when he/she gets hungry?

1. ___ scheduled 2. ___ on demand 99. ___ DK or neutral

38. At what times does _____ typically eat throughout the day? _____

Notes:

Ending the call: *This will complete our survey. We would just like to thank you again for taking time out of your busy schedule to answer questions about your child. We may be contacting you again to participate in our treatment study and to earn 100 dollars. We look forward to talking to you again. Thank you and have a nice day (evening)!*

APPENDIX B

SLEEP DIARY

Child: _____ Date: _____

| | |
|--|----------------------------------|
| Waking | |
| Time Awake in the Morning: | |
| Did he/she awake on own in morning? | |
| Any problems on waking? If yes, please describe. | |
| Naps | |
| Length and time of daytime naps: | |
| White noise used? | |
| Graduated extinction used? | |
| Nap Routines (Place a check mark if completed.) | 1. 2. 3. |
| Bedtime | |
| Bedtime Routines (Place a check mark if completed.) | 1. 2. 3. 4. 5. 6. |
| Time put to bed at night: | |
| Time actually fell asleep (indicated by silence): | |
| Please list any problems going to bed/ getting to sleep: | |
| White noise used? | |
| Graduated extinction used? | |
| Night Wakings | |
| Number and length of night wakings: (Please describe why he/she woke and how he/she went back to sleep.) | |
| Graduated extinction used? | |
| Any unusual circumstances (e.g., vacation, illness, etc.): | |
| Meal Times | |
| Breakfast: | |
| Lunch: | |
| Dinner: | |

APPENDIX C

EVALUATION OF TREATMENT PACKAGE (CRM, BEDTIME ROUTINES, WHITE NOISE, & GRADUATED EXTINCTION) RESEARCH

This is a survey giving you the opportunity to evaluate the study. You are not obligated to complete this form; however, your opinions are very valuable and can help other children and help in future research. Thank you for your opinions!

For the following items, please **circle the number**, which indicates your opinion.

I believe that my child falls asleep better now than before this experiment.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I believe that the treatment package reduced his/her trouble falling to sleep.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I believe that the treatment package has decreased my child's night awakenings.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I would recommend the treatment package to others who have a child with sleep problems.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable following scheduled wake times for my child.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable following scheduled nap times for my child (if applicable).

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable following scheduled bedtimes for my child.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable following scheduled meal times for my child.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable using bedtime routines.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable using white noise.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I felt comfortable using graduated extinction (if applicable).

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

Overall, the treatment package helped my child sleep.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

I liked the overall experience of participating in this project.

| | | | | |
|----------------|-------|--------------------------|----------|-------------------|
| 1 | 2 | 3 | 4 | 5 |
| Strongly Agree | Agree | Neutral or No opinion | Disagree | Strongly Disagree |

Average time to fall asleep: _____

Average number of night wakings: _____

COMMENTS?

THANK YOU FOR HELPING US HELP YOUR CHILD SLEEP BETTER!!!

APPENDIX D

PARENT INFORMATION FORM



Does your child have trouble sleeping at night? Let us help your child sleep better!

Introductory Statement

You are invited to participate in a study regarding your child's sleeping habits. All details of the study are provided in a further consent document. Please feel free to address any questions about the study to either Rachel Knight or Dr. Johnson.

Study Title: Using a Behavioral Treatment Package for Sleep Problems in Children with Autism

Research Investigators' Names and Departments: Rachel Knight, School Psychology; Dr. Carl M. Johnson, Psychology

Contact information for researcher:

Rachel Knight can be reached by phone at 586-322-3887 or e-mail at mack1rm@cmich.edu.

Dr. Carl Johnson can be reached by phone at 989-774-6493 or e-mail at johns1cm@cmich.edu.

What is the purpose of this study?

The purpose of this study is to determine the effectiveness of a non-drug treatment package consisting of circadian rhythm management, bedtime routines, white noise, and graduated extinction (Ferber Technique) for sleep problems in children who have been diagnosed with autism.

What are the benefits of participating in the study?

Potential benefits to families in the study include possible improvement in their child's sleep problems. All families will earn \$100 for participation in the entire study. Also, this research will provide more information regarding treatment options for sleep problems in children who have been diagnosed with autism.

If you are interested in participating in this study, please contact Rachel Knight or Dr. Carl Johnson.

We hope to help your child sleep better!

APPENDIX E

ADULT CONSENT FORM



Study Title: Using a Behavioral Treatment Package for Sleep Problems in Children with Autism

Research Investigators' Names and Departments: Rachel Knight, School Psychology; Carl M. Johnson, Ph.D., Psychology

Contact information for researcher:

Rachel Knight can be reached by phone at 586-322-3887 or e-mail at mack1rm@cmich.edu.

Dr. Carl Johnson can be reached by phone at 989-774-6493 or e-mail at johns1cm@cmich.edu.

Introductory Statement

You have been invited to participate in a study regarding your child's sleeping habits. All details of the study are provided in the consent document. Please feel free to address any questions about the study to either Rachel Knight or Dr. Johnson.

What is the purpose of this study?

The purpose of this study is to determine the effectiveness of a treatment package consisting of circadian rhythm management, bedtime routines, white noise, and graduated extinction (i.e., Ferber Technique) for sleep problems in children who have been diagnosed with autism.

What will I do in this study?

Parents will be instructed to follow all components of the treatment package. The researcher and participants will work together to establish sleep and meal schedules for their child that will comfortably fit into the families' schedules. Parents will then be instructed to put their child to bed at the same time every night, wake them up at the same time every morning, and have set times for naps and meals each day. Bedtime routines will consist of 4-6 calm activities that families will be instructed to complete before putting their child to bed. Parents will be instructed to use a white noise generator, provided by the researcher, in the child's room while he or she is sleeping. Also, parents will be instructed to follow graduated extinction procedures for tantrums that may occur when putting the child to bed or during night wakings. In graduated extinction, parents ignore bedtime and night-waking tantrums for progressively longer time intervals. After the designated time interval (5 to 30 minutes), parents may enter the room, briefly soothe their child, and then leave the bedroom before he or she falls back to sleep.

Parents will complete weekly sleep diaries regarding their child's sleeping patterns, which will be used for data collection. Parents will receive sleep diaries on a weekly basis through e-mail or the mail from the psychology department at Central Michigan University, depending on the parents' preferences. The researcher will contact the parents by phone twice per week to answer questions and ensure that the sleep diaries were received. Parents will submit completed sleep diaries to the researcher each week either through e-mail, mail, or by dropping them off in sealed envelopes at the psychology department at Central Michigan University. The treatment phase for each participant will last no less than 1 month.

After 1 month of treatment, the parents will still be encouraged to continue the use of the treatment package. One month after treatment, parents will be asked to fill out a sleep diary for one week. An additional meeting will be scheduled to pick up the sleep diary and to discuss the parents' reactions to the treatment.

How long will it take me to do this?

Parents will record sleep diaries for about 2-3 months, with the treatment package lasting for 1 month of that time.

Are there any risks of participating in the study?

There are no risks to participants involved in this study other than not being able to sleep late on weekends. There is a chance that the techniques learned may not be effective for some individuals. However, past research studies have shown the effectiveness of each component of the treatment package with typically developing children. Additionally, current research indicates that CRM, bedtime routines, and graduated extinction have been effective in treating sleep problems in children with autism when used as part of a treatment package. However, if the techniques learned are not effective, alternative non-drug treatments will be made available to participants at the conclusion of participation, either at the conclusion of the study or upon a participant's decision to discontinue the study.

What are the benefits of participating in the study?

Participants will be paid \$100 for participating in this study. Participants will be paid \$25 after baseline, \$50 upon completion of one month of treatment, and they will be paid an additional \$25 upon completion of the follow-up interview session. Additional benefits include possible improvement in their child's sleeping habits and increased knowledge regarding effective treatment methods for sleep problems in children with autism.

Will anyone know what I do or say in this study (Confidentiality)?

All participant information will be kept confidential. Only Rachel Knight and Dr. Johnson will have access to participant information. In all other instances, any data under the investigator's control will, if disclosed, be presented in a manner that does not reveal the subject's identity, except as may be required by law. Recording using DVD's will only be requested if parents express concerns that their child's night wakings are night terrors. Recording these episodes will provide the researchers with information necessary to determine if the night wakings are indeed night terrors. Parents will conduct the taping in the privacy of their own home.

The researcher will set up a meeting with the parents to pick up the recording. DVD's will be stored in a locked room, 180 Sloan Hall. Only Rachel Knight and Dr. Johnson will have access to the DVD's. DVD's will be used for this research to evaluate if the child is having night terrors. If parents provide permission, DVD's may be used for future presentations regarding childhood sleep problems. If parents do not provide permission to use recordings for future research, all recordings will be destroyed one year following the study.

Will I receive any compensation for participation?

Participants will be paid \$25 after baseline, \$50 upon completion of treatment, and they will be paid an additional \$25 upon completion of the follow-up interview session.

Is there a different way for me to receive this compensation or the benefits of this study?

There is no other method for compensation at this time.

Who can I contact for information about this study?

Rachel Knight can be reached by phone at 586-322-3887 or e-mail at mack1rm@cmich.edu.
Dr. Carl Johnson can be reached by phone at 989-774-6493 or e-mail at johns1cm@cmich.edu.

You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled. Your participation will not affect your relationship with the institution(s) involved in this research project.

If you are not satisfied with the manner in which this study is being conducted, you may report (anonymously if you so choose) any complaints to the Institutional Review Board by calling 989-774-6777, or addressing a letter to the Institutional Review Board, 251 Foust Hall Central Michigan University, Mt. Pleasant, MI 48859.

My signature below indicates that all my questions have been answered. I agree to participate in the project as described above.

Signature of Subject

Date Signed

A copy of this form has been given to me. _____ Subject's Initials

For the Research Investigator—I have discussed with this subject the procedure(s) described above and the risks involved; I believe he/she understands the contents of the consent document and is competent to give legally effective and informed consent.

Signature of Responsible Investigator

Date Signed

APPENDIX F

CHILD ASSENT FORM FOR MINORS AGED UNDER AGE 7



(To be read to the child)

Title of Project: Using a Behavioral Treatment Package for Sleep Problems in Children with Autism

Name of Investigator: Rachel Knight

Phone: 586-322-3887

Name of Investigator: Carl M. Johnson, Ph.D.

Phone: 989-774-6493

Invitation to Participate:

You and your mom/dad have been asked to help us learn about how kids sleep. If you want to do this, you will go to bed at the same time each night. Your mom/dad will wake you up at the same time each morning. We will put a machine in your room while you sleep that sounds like a fan. Your parents said that this is okay for you to do. Do you want to do this?

APPENDIX G

PARENT INFORMATION FORM



MUNROE-MEYER INSTITUTE
Department of Psychology

Does your child have trouble sleeping at night? Let us help your child sleep better!

Introductory Statement

You are invited to participate in a study regarding your child's sleeping habits. All details of the study are provided in a further consent document. Please feel free to address any questions about the study to either Rachel Knight or Dr. Johnson.

Study Title: Using a Behavioral Treatment Package for Sleep Problems in Children with Autism

Research Investigators' Names and Departments:

Rachel Knight, M.A., PLMHP, Department of Psychology, Munroe-Meyer Institute

Carl Merle Johnson, Ph.D., Psychology, Central Michigan University

Contact information for researcher:

Rachel Knight can be reached by phone at 402-559-3731 or e-mail at

rachel.knight@unmc.edu

Dr. Carl Johnson can be reached by phone at 989-774-6493 or e-mail at

johns1cm@cmich.edu.

What is the purpose of this study?

The purpose of this study is to determine the effectiveness of a non-drug treatment package consisting of circadian rhythm management, bedtime routines, white noise, and graduated extinction (Ferber Technique) for sleep problems in children who have been diagnosed with autism.

What are the benefits of participating in the study?

Potential benefits to families in the study include possible improvement in their child's sleep problems. All families will earn \$100 for participation in the entire study. Also, this research will provide more information regarding treatment options for sleep problems in children who have been diagnosed with autism.

If you are interested in participating in this study, please contact Rachel Knight or Dr. Carl Johnson.

We hope to help your child sleep better!

APPENDIX H

ADULT/PARENTAL CONSENT FORM



MUNROE-MEYER INSTITUTE
Department of Psychology

USING A BEHAVIORAL TREATMENT PACKAGE FOR SLEEP PROBLEMS IN CHILDREN WITH AUTISM

Invitation

You and your child are invited to take part in this research study. The information in this form is meant to help you decide whether you and your child should take part. If you have any questions, please ask.

Why is your child being asked to be in this research study?

You are being asked to be in this study because your child has sleep problems and has autism spectrum disorder.

What is the reason for doing this research study?

Children with autism spectrum disorder often have severe sleep problems. Behavioral treatments have been shown to be effective in treating sleep problems in typically developing children. The purpose of this study is to determine the effectiveness of a treatment package consisting of circadian rhythm management, bedtime routines, white noise, and graduated extinction (i.e., Ferber Technique) for sleep problems in children who have been diagnosed with autism.

What will be done during this research study?

Parents will be instructed to follow all components of the treatment package. The researcher and participants will work together to establish sleep and meal schedules for their child that will comfortably fit into the families' schedules. Parents will then be instructed to put their child to bed at the same time every night, wake them up at the same time every morning, and have set times for naps and meals each day.

Bedtime routines will consist of 4-6 calm activities that families will be instructed to complete before putting their child to bed. Parents will be instructed to use a white noise generator, provided by the researcher, in the child's room while he or she is sleeping.

Also, parents will be instructed to follow graduated extinction procedures for tantrums that may occur when putting the child to bed or during night awakenings. In graduated extinction, parents ignore bedtime and night-waking tantrums for progressively longer time intervals. After the designated time interval (5 to 30 minutes), parents may enter the room, briefly soothe their child, and then leave the bedroom before he or she falls back to sleep.

Parents will complete weekly sleep diaries. The researcher will contact the parents by phone twice per week to answer questions and ensure that the sleep diaries were received. Parents will submit completed sleep diaries to the researcher each week either through e-mail, mail, or by dropping them off in sealed envelopes at the psychology department at the Munroe-Meyer Institute. The treatment phase for each participant will last no less than 1 month.

After 1 month of treatment, the parents will still be encouraged to continue the use of the treatment package. One month after treatment, parents will be asked to fill out a sleep diary for one week. An additional meeting will be scheduled to pick up the sleep diary and to discuss the parents' reactions to the treatment.

What are the possible risks of being in this research study?

There are minimal risks to participants involved in this study (i.e., not being able to sleep late on weekends). There is a chance that the techniques learned may not be effective for some individuals. However, past research studies have shown the effectiveness of each component of the treatment package with typically developing children. Additionally, current research indicates that CRM, bedtime routines, and graduated extinction have been effective in treating sleep problems in children with autism when used as part of a treatment package. However, if the techniques learned are not effective, alternative non-drug treatments will be made available to participants at the conclusion of participation, either at the conclusion of the study or upon a participant's decision to discontinue the study.

What are the possible benefits to you and your child?

The possible benefits for you and your child include improvement in his/her sleeping habits.

What are the possible benefits to other people?

This study will lead to increased knowledge regarding effective treatment methods for sleep problems in children with autism.

What are the alternatives to being in this research study?

Instead of being in this research study, you can choose that your child not participate.

What will your child being in this research study cost you?

There is no cost for you or your child to be in this research study.

Will you or your child be paid for being in this research study?

Families will be paid \$100 for participating in this study. Participants will be paid \$25 after baseline, \$50 upon completion of one month of treatment, and they will be paid an additional \$25 upon completion of the follow-up interview session.

Who is paying for this research?

This research is being paid for by grant funds from the College of Graduate Studies at Central Michigan University.

What should you do if you have a problem during this research study?

Your child's welfare is a major concern of every member of the research team. If you or your child has a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about you be protected?

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person or agency required by law. The information from this study may be published in scientific journals or presented at scientific meetings, but your identity will be kept strictly confidential.

What are your child's rights as a research subject and your rights as a parent and research subject?

Your child has rights as a research subject, and you have rights as the parent of a research subject and as an adult participant. These rights have been explained in this consent form and in *The Rights of Research Subjects* that you have been given. If you have any questions concerning your rights or complaints about the research, talk to the investigator or contact the Institutional Review Board (IRB) by:

- Telephone (402) 559-6463
- Email: IRBORA@unmc.edu
- Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830

What will happen if you decide not to allow your child to be in this research study or decide to have your child stop participating once he/she has started?

You can decide not to allow your child to be in this research study, or your child can stop being in this research study ("withdraw") at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship

or your child's relationship with the investigator, or with the University of Nebraska Medical Center. Your child will not lose any benefits to which he/she is entitled. If the research team gets any new information during this research study that may affect whether you would want your child to continue being in the study you will be informed promptly.

Documentation of informed consent

You are freely making a decision whether to allow your child to be in this research study and that you agree to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided that you and your child will be in the research study.

If you have any questions during the study, you should talk to one of the investigators listed below. You will be given a copy of this consent form to keep.

Signature of Parent:

Date:

Time:

For Youth ages 12-18:

You are agreeing to be in this research study. You have had someone explain the study to you, and answer your questions.

Signature of Subject:

Date:

Time:

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject's parent and, as appropriate, the subject. In my judgment, the parent possesses the legal capacity to give informed consent to have the child participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person obtaining consent:

Date:

Authorized Study Personnel

Primary Investigator: Rachel M. Knight, M.A., PLMHP
Office: 402-559-3731
E-mail: rachel.knight@unmc.edu

Secondary Investigator: Carl Merle Johnson, Ph.D.
Office: 989-774-6493
E-mail: johns1cm@cmich.edu

APPENDIX I

CHILD INFORMATION SHEET



MUNROE-MEYER INSTITUTE
Department of Psychology

IRB# 506-11 FB

TITLE: USING A BEHAVIORAL TREATMENT PACKAGE FOR SLEEP PROBLEMS IN CHILDREN WITH AUTISM

We are asking you to be in a research study. You don't have to be in this research study to get treated. If you don't want to be in the study your doctor will still take care of you.

You and your mom/dad have been asked to help us learn about how kids sleep. If you want to do this, you will go to bed at the same time each night. Your mom/dad will wake you up at the same time each morning. We will put a sound machine in your room while you sleep that sounds like a fan.

You do not have to be in this research study. You can say no at any time. No one will be upset with you if you stop.

APPENDIX J

YOUTH INFORMATION SHEET



MUNROE-MEYER INSTITUTE
Department of Psychology

IRB# 506-11 FB

TITLE: USING A BEHAVIORAL TREATMENT PACKAGE FOR SLEEP PROBLEMS IN CHILDREN WITH AUTISM

You are invited to be in this research study. Being in this research study is voluntary – you don't have to be in this research study to get treated. If you decide not to be in the study your doctor will still take care of you.

The goal of this study is to learn how to help children with an autism spectrum disorder sleep better. You can ask a question at any time and you can say no anytime you want to. Your parents or legal guardian said that it is OK for you to be in this study, but we want to let you choose if you want to do this.

In this study, you will have a set bedtime every night of the week, and you will do the same activities right before bed every night, such as brushing your teeth or reading a book. Your parents will wake you up at the same time every morning. You will eat meals at the same time every day. Also, your parents will put a sound machine in your room during the night while you sleep. It sounds like a fan.

You will be asked to follow the same bedtime activities for one month. After that month is over, we will wait a month, and then we will ask you to follow the set bedtime activities for one week.

Nothing bad will happen to you because of the study except that you will not be able to sleep late on weekends. Let your parents know if you feel sick during this study.

This study might help you to sleep better at night. Also, it will provide information to help other children who have trouble sleeping at night.

You may choose not to do this.

Only those people conducting the study will know that you are in it.

You do not have to be in this research study. You can say no at any time. No one will be upset with you if you stop.

APPENDIX K

INTERVENTION PHASE DIRECTIONS

1. Circadian rhythm management

- Put the child to bed at the same time every night.
- Wake the child up at the same time every day.
- Have meals at the same time each day.

2. Bedtime routines

- Follow the same 4-6 activities in the same order each night before bed.
- Refer to the activities on the sleep diary.

3. White noise generator

- Turn on the white noise generator during naps and at bedtime.
- Use the same setting each night.
- Keep track of the distance from the head of the bed. Try to place the device about 12 inches from the head of the bed.

4. Ferber method/graduated extinction (if necessary)

If the child awakens during the night and cries, parents will be requested to use graduated extinction (i.e., the Ferber method) in which they do not respond to the child's cries for increasing intervals of time. After the required waiting interval has lapsed, parents may enter the room, check to make sure the child is not sick or hurt, and then promptly leave the room while the child is still awake. Parents will be requested to follow this procedure for tantrums that may occur immediately after completing routines and putting the child to bed for the night or that occur when the child awakens throughout the night. Please refer to the chart below.

| NUMBER OF MINUTES TO WAIT BEFORE RESPONDING TO YOUR CHILD | | | | |
|--|---|--------------------|-------------------|-------------------------|
| | If Your Child Is Still Crying or Calling | | | |
| Day | At First Wait | Second Wait | Third Wait | Subsequent Waits |
| 1 | 3 | 5 | 10 | 10 |
| 2 | 5 | 10 | 12 | 12 |
| 3 | 10 | 12 | 15 | 15 |
| 4 | 12 | 15 | 17 | 17 |
| 5 | 15 | 17 | 20 | 20 |
| 6 | 17 | 20 | 25 | 25 |
| 7 | 20 | 25 | 30 | 30 |

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