Parental Reports of Symptoms and Treatment of
Sleep Problems In Children With Autism
or Pervasive Developmental Disorder

by

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Abstract

This study examined parental reports of sleep problems in children with autism or Pervasive Developmental Disorder (PDD) first purpose of this investigation was to describe, through parent report, the types of sleep symptoms experienced by children with autism or PDD. Secondly, this study investigated whether specific types of treatments were tried to treat particular sleep symptoms. In addition, through parent report, this study examined whether particular sleep symptoms were successfully treated by specific treatment types.

Parent participants (N=52) who had children aged 3 to 11 with a diagnosis of autism or PDD completed a questionnaire regarding their child’s sleep history, specific sleep symptoms, assessment and treatment history. Information was also gathered on parent reports of treatment effectiveness for specific sleep symptoms.

Of the 52 participants, 40 (76.9%) reported their child had experienced a past or present sleep problem. The six main symptoms for children with a past or present sleep problem were, ‘trouble falling asleep’ (62.5%), ‘waking to engage in disruptive or self-stimulatory behavior (60.0%) ‘sleeps less than other children their age’ (30.0%), ‘gets less than 6 hours of sleep in a 24 hour period’ (20.0%), ‘sleeps in my room now’ (17.5%) and requires medication to sleep (17.5%).

The symptom, ‘waking to engage in disruptive or self-stimulatory behavior’ was revealed from information volunteered by parent participants during data collection. This symptom was not part of the initial assessment tool used in the questionnaire. As participants did not have an opportunity to select this symptom during the assessment of their child’s sleep problem as it was volunteered by some parents, the frequency of this sleep symptom may be underreported.
When treatment effectiveness for specific sleep symptoms was examined, the hormone melatonin was frequently reported by parents as an effective treatment for all of the six main sleep symptoms. The behavioral technique, 'extinction' was also reported by parents as an effective treatment for the symptom, 'waking to engage in disruptive and self-stimulatory behavior'. The behavioral technique, 'bedtime fading' was the next most effective treatment reported by parents for both of the symptoms, 'sleeps less than other children their age', and for, 'gets less than 6 hours sleep in a 24 hour period'. Results are discussed in relation to the literature on treatment effectiveness in conjunction with research areas that require future study.
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Parental Reports of Symptoms and Treatment of Sleep Problems in Children With Autism or Pervasive Developmental Disorder

Chapter 1

Introduction

The purpose of this investigation was to describe sleep problems in children with Autistic Disorder or Pervasive Developmental Disorder (PDD). Although relatively few studies have investigated the prevalence and treatment of sleep problems in children with autism or PDD, the few published reports conclude that sleep problems in this population are both common and problematic (DeMyer, 1979; Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984; Taira, Takase & Sasaki, 1998; Takase, Taira, & Sasaki, 1998; Richdale & Prior, 1995; Schreck, 1997; Stores & Wiggs, 1998). Hoshino, Watanabe, Yashima, Kaneko & Kumashiro (1984) found that 65% of their sample of 75 children with autism showed sleep disturbances and consequently, the authors concluded that "sleep disturbance might be one of the main symptoms and related to the pathophysiology of infantile autism" (p.45). Left untreated, the problems usually do not improve, causing extensive difficulties for both the child and their families (Richdale & Prior, 1995; Stores & Wiggs, 1998).

The primary purpose of this study was to describe, through parent report, the types of sleep symptoms experienced by children with autism or PDD. This study also examined whether specific types of treatments were tried to treat particular sleep
symptoms. Thirdly, through parent report, this investigation examined whether particular sleep symptoms were more successfully treated by specific types of treatments.

Sleep Patterns in Children with Autism and PDD

Reports of sleep problems in children with autism and PDD have consistently described specific behavioral symptoms in this population. For example, Richdale and Prior (1995) report that, "severe and specific sleep problems, including long sleep latencies, long periods of night waking, short night sleep and early morning waking may be a feature of autism, particularly at younger ages" (p. 184). Many other researchers have also described frequent night wakings, (Clements, Wing, & Dunn, 1985; DeMyer, 1979; Howlin, 1984; Jan, Espezel & Appleton, 1994; Piazza, Fisher & Sherer, 1997; Richdale, & Prior, 1992; Taira, Takase, & Sasaki, 1998), sleep initiation difficulties (DeMyer, 1979; Durand, Gernert-Dott & Mapstone, 1996; Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984; Howlin, 1984; Piazza, Fisher & Sherer, 1997; Richdale, & Prior, 1992; Taira, Takase, & Sasaki, 1998), short night sleep (Clements, Wing, & Dunn, 1985; Jan, Espezel & Appleton, 1994; Piazza, Hagopian, Hughes and Fisher, 1998; Richdale, & Prior, 1992), and early wakings (Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984; Piazza, Fisher & Sherer, 1997; Richdale, & Prior, 1992; Taira, Takase, & Sasaki, 1998) in children with autism or PDD. Biological symptoms in sleep patterns of children with autism or PDD have also been described by researchers investigating sleep stages and abnormalities in sleep physiology (Elia, Ferri, Musumeci & Bergonzi, 1991; Nir, Meir, Zilber, Knobler, Hadjez & Lerner, 1995; Segawa, Katoh, Katoh & Normura, 1992; Zappella, 1993).

1 All terms in italics are defined in Appendix A
Incidence and Prognosis of Sleep Problems in Children with Autism and PDD

In reporting the incidence of sleep problems in children with autism, the research is difficult to analyze because many authors have not restricted their samples to children with autism or PDD (Clements, Wing & Dunn, 1985; Piazza, Fisher & Kahng, 1996; Shibagaki, Kiyono & Watanabe, 1980; Quine, 1991; Quine, 1992). Although the description of the samples appear to include children with autism or PDD, when children with different cognitive and physical diagnoses are grouped together in the same incidence report, it is difficult to make generalizations that will relate specifically to children with autism or PDD. For example, even though Quine (1991) found that in her sample of children with severe learning difficulties, “sleep problems were associated with a number of child characteristics: poor communication skills, poor academic skills, poor self-help skills, incontinence, daytime behavior problems and epilepsy,” (p.269) which are all symptoms common to many children with autism, because she did not include the individual diagnoses of the children in the study, it is difficult to make generalizations to other children with autism. Stores (1992) emphasizes that, “investigators have often described heterogeneous groups of patients, failing to make important distinctions regarding severity of mental handicap or its cause, for example. It is essential in the much needed further research in this area to consider subgroups and types individually” (p.1303).

DyMyer (1979) restricted her sample to children with diagnoses of autism and PDD and found that all 32 parents in her study reported that their child with autism had experienced disturbed sleep at some point. Similarly, Hoshino, Watanabe, Yashima, Kaneko & Kumashiro (1984) also studied only children with autism and reported sleep problems in 65% of a sample of 75 children with autism. Richdale and Prior (1995)
examined sleep patterns in children with autism and suggested that, "the majority of children with autism are likely to experience severe and specific sleep disturbances at some stage during childhood, particularly under 8 years of age" (p. 182). Recently, Taira, Takase & Sasaki (1998) found that in a sample of 88 children with autism, 65.1% had experienced a sleep disorder and Schreck (1997) found that children with autism exhibited more dyssomnia and parasomnia-related behaviors than did children with mental retardation, children in special education classrooms, and children classified as typically developing.

Hering, Epstein, Elroy, Iancu & Zelnic (1999) administered questionnaires to parents of children with autism and found that 54% reported that their child had a sleep problem. Yet, when some of the children were given a 72 hour actigraphy, other than consistent and statistically significant early wakings, the sleep patterns of the children with autism looked similar to the sleep patterns of the normal control children. While the authors concluded that parents of children with autism may be overselective to sleep problems, it is unclear if a 72 hour actigraphy is comprehensive enough to provide a representative sample of a child's typical sleep pattern. In addition, the sample of children tested with the 72 hour actigraphy in this study included only the children with autism who would tolerate the testing equipment which eliminated the younger and more intolerant subjects, possibly affecting the results.

Even though the literature reports that the prevalence of sleep problems in children with autism is high, and that long-term sleep disturbance can cause prolonged injury to both the child and their families, the course and prognosis of sleep problems in children with autism is unclear. For example, although some researchers claim that the prognosis of sleep problems in children with developmental disabilities is poor (Durand, Gernert-Dott
& Mapstone, 1996), it is unclear whether this pessimistic prediction is referring to treated or untreated sleep disorders. Similarly, while DeMyer (1979) reported slight improvements over time in sleep problems in her sample of 32 children with autism, it is unclear if she is describing successfully treated problems or neglected problems that simply improved over time.

In describing the course of sleep problems, current research findings suggest that sleep patterns in children with autism or PDD are the most stable during infancy, but that problems rapidly reach their peak when the child is approximately 2-3 years old, coinciding with the initial cognitive diagnosis of autism or PDD (DeMyer, 1979; Clements, Wing & Dunn, 1985; Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984; Taira, Takase & Sasaki, 1998). While many researchers have described similar problematic sleeping patterns in preschool children with autism, there is considerable confusion about the subsequent course of sleep problems during the rest of childhood. Although DyMyer (1979) reports that improvements in sleep can occur over time, 49% of the children with autism in her own study were still experiencing sleep difficulties at 5½ years of age compared with only 3% of children in the control group of typically developing peers. Similarly, Richdale and Prior (1995) concluded that time was the most consistent factor predicting improvement in the sleep problems of children with autism at all IQ levels. However, they still found that older children with autism with IQ's greater than 55 experienced more frequent sleep problems than did same chronological-age control group children (Richdale & Prior, 1995). Taira, Takase & Sasaki (1998) reported that the sleep problems of 88 children with autism decreased over time when the children began school at about 5 years of age.
Clements, Wing and Dunn (1985) found that sleep problems were most common during the pre-school years, but they also recognized that many older children with autism between 5 and 15 years of age also manifested sleep problems, leading the authors to hypothesize that children with autism do not simply grow out of the sleep difficulties. Other investigators have reached similar conclusions (Durand, 1998; Durand, Gernert-Dott & Mapstone, 1996; Lancioni, O’Reilly & Basili, 1999; Quine, 1991). While there are presently no studies that have investigated the prevalence of sleep problems in adults with autism or PDD, Espie and Tweedie (1991) studied 120 adults with mental handicap and found that 15% were experiencing significant sleep problems which is similar to the level found in the general adult population.

Effects of Sleep Problems on Child and Family

Sleep problems are difficult for children with autism or PDD as they need to be alert during the day to benefit from specialized and intensive interventions that treat language and social difficulties (Johnson, 1996). Not surprisingly, disturbances associated with sleep have been reported to negatively affect the daytime behavior of children with autism (Durand, 1998; Stores & Wiggs, 1998). Hoshino, Watanabe, Yashima, Kaneko & Kumashiro (1984) claim that, “sleep disturbance of autistic children is closely related to their developmental level and aggravates other clinical symptoms such as autistic isolation and hyperactivity” (p.50). Researchers who have looked at individuals with various developmental disabilities have found that decreased amounts of REM sleep is associated with learning problems and poor information processing (Espie & Tweedie, 1991), as well as problems with the consolidation of new information (Durand, 1998).
Espie and Tweedie (1991) found that inadequate sleep is associated with irregularities in selective attention, task performance, arousal, and mood, while Quine (1991), Wiggs & Stores (1996), and Durand (1998) all report that children who suffer from sleep problems appear to have more behavior problems than non-sleep disordered peers. In a sample of 155 children with disabilities, 16 of whom had a diagnosis of autism, Clements, Wing and Dunn (1985) found that night wakings were strongly associated with self-injurious behaviors, and limited hours of sleep was associated with attachment to routine.

When a child with autism suffers from a sleep problem, an atmosphere is created where the entire household is routinely disrupted during the night, often resulting in sleep deprivation for parents and siblings. There is considerable research describing high levels of parental anxiety and stress resulting from coping with a developmentally disabled child who also suffers from a sleep problem (Clements, Wing & Dunn, 1985; Durand, 1998; DyMyer, 1979; Hewitt, 1985; Howlin, 1984; Jan, Espezel & Appleton, 1994; Lancioni, O’Reilly, 1995; Norton & Drew, 1994; Stores & Wiggs, 1998; Quine, 1991; Quine, 1992; Wiggs & Stores, 1996; Whyte & Schaefer, 1995). For example, Quine (1992) reports that sleep problem severity in children with intellectual difficulties is related to maternal responsiveness, satisfaction, stress, impact of the child on the family, maternal behavior, and attitude towards the child.

Jan, Espezel and Appleton (1994) report that when children with multiple disabilities have recurrent sleep problems, “they tend to fuss, cry, play and demand attention from their exhausted parents, to the point where the sleep disturbance itself can become the major reason for parental exhaustion and the introduction of foster care”
Similarly, Didden, Curfs, Sikkema and Moor (1998) stress that, “sleeping problems may have adverse consequences for both the child and the parents, in that these may result in parental chronic fatigue, stress, curtailment of social life, and even child abuse” (p.86).

Many family members may begin to experience irritability, depression and marital problems, as well as problems with motivation and concentration (Durand, 1998). Sleep problems in children can lead to, “inadequate sleep for the parents, family arguments regarding the proper solution, and an overall decrease in family satisfaction” (Mindell & Durand, 1993, p.732). DeMyer (1979) also described decreased marital satisfaction as well as maternal irritability and exhaustion due to dealing with the constant sleep interruption and subsequent behavior problems without respite.

Treatment for Sleep Disorders in Children with Autism and PDD

Although the pediatric treatment literature is filled with descriptions of behavioral, pharmacological, and natural interventions to treat various types of sleep difficulties, studies that have implemented these procedures have rarely focused on children with autism or PDD and therefore, the results can not be easily generalized to this population (Durand, 1998; Durand, Gernert-Dott & Mapstone, 1996; Stores & Wiggs, 1998). When examining the literature on treatment for sleep problems in children with autism or PDD, the inclusion and exclusion criteria for participants included in each study is important. If children with different neurological difficulties are treated as a homogenous group, information on individual differences in treatment efficacy are lost (Johnson, 1996). For instance, if children with different neurological conditions and clinical diagnoses are differentially affected by specific treatments, but they are directly compared using a single
treatment that disregards these differences, the resulting generalizations about the
prognoses of sleep problems in specific populations may be erroneously pessimistic. A
researcher who only studies children with autism may report very different patterns of
sleep behavior than another investigator who includes children with many different
diagnoses under the heading of, ‘severe intellectual disability’, ‘developmental delay’, or
‘severe mental retardation’. While these labels may be helpful in gathering participants for
a study, grouping children with sleep problems who have different clinical diagnoses may
be problematic if the qualitative nature of their neurological condition affects their
response to similar treatments. These differential responses to various treatments will
affect the generalizability and representativeness of the results.

Many behavioral interventions have been used in the treatment of children
classified as having developmental delay, severe learning disabilities, mental retardation,
behavior disorders, as well as specific cognitive diagnoses, but there are few treatment
studies specifically limited to children with autism with the exception of three case studies
Behavioral interventions such as **extinction**, (Bramble, 1996; Bramble, 1997; Didden,
Curfs, Sikkema & Moor, 1998) **gradual extinction** (Durand, Gernert-Dott & Mapstone,
1996) and **delayed bedtime** or **bedtime fading** (Milan, Mitchell, Berger & Pierson,1981)
have been used to treat children with various developmental disabilities. **Delayed bedtime
procedures with response cost components** (Piazza, & Fisher, 1991), **graded change
approaches** (Hewitt, 1985; Howlin, 1984; Piazza, Fisher, & Sherer, 1997) and **stimulus
control** (Bramble, 1996; Bramble, 1997; Didden, Curfs, Sikkema & Moor, 1998) have

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2 All terms in italics are defined in Appendix A
also been used in treating sleep problems in children with different developmental
disabilities. Improving *bedtime routine* (Durand, Gernert-Dott and Mapstone, 1996;
Hewitt, 1985; Milan, Mitchell, Berger & Pierson, 1981), *bedtime scheduling* with the
elimination of daytime sleep (Piazza, Fisher, & Sherer, 1997), *chronotherapy* (Piazza,
Hagopian, Hughes & Fisher, 1998), and *relaxation techniques* (Hewitt, 1985) are
additional behavioral techniques that were used to treat sleep problems in children with
various developmental disabilities.

Pharmacological interventions have also been used to treat children and adults
with sleep problems according to descriptions of clinical practice (Bramble, 1997; Hewitt,
1985; France & Hudson, 1993; Kales, Bixler, Tan, Scharf, and Kales, 1974; Richman,
1985; Stores & Wiggs, 1998; Wiggs & Stores, 1996), but there is a lack of controlled
studies that have tested the long-term success and side effects of sleep medications with
children with autism or PDD. Some studies that have tested sleep medications with
typically developing children and adults have found that the pharmacological treatments
have not been successful over the long-term in improving sleep problems (Kales, Bixler,
Tan, Scharf, & Kales, 1974; Richman, 1985). Other investigators have found that
prescriptive medications have provided some short-term benefits for the sleep problems of
some children (Simonoff & Stores, 1987), but they do not advise them for extended use
because long-term effectiveness and potential side effects resulting from prolonged usage
with children have not yet been investigated (Simonoff & Stores, 1987). Wiggs & Stores
(1999) claim that medication most frequently used with children are not only ineffective
for long periods but may actually cause negative effects such as daytime sleepiness,
rebound sleepiness upon withdrawal and even increased excitation. Since people with
autism are often a highly medicated population (Aman, Van Bourgondien, Wolford, & Sarphare, 1995), and the literature is inconclusive about the success of pharmaceutical treatments for sleep difficulties for this population, there remains a critical need for further research.

The hormone melatonin has been identified as a possible treatment for children with autism who are suffering from sleep problems (Jan & Espezel, 1995; Jan, Espezel & Appleton, 1994; Jan, Freedman & Fast, 1999) and Horrigan and Barnhill (1997) reported success in improving the sleep of an adolescent with Asperger’s Syndrome using melatonin. Research has not yet identified specific child characteristics that may reliably predict success from melatonin treatment, and there is presently limited research available describing dosages, side effects, fading, or the long term effects of continued use of melatonin for children with autism or PDD.

Additional problems in determining the most beneficial method to treat children with autism include; inconsistent outcome measures used to assess treatment efficacy across intervention studies, varied treatment lengths, small sample sizes, and samples that include children with different cognitive and physical diagnoses. In addition, researchers often group children of different ages together despite findings that report developmental differences in sleep patterns (Wolfson, 1996). Finally, sleep symptoms are typically not categorized into specific sleep disorders in the assessment procedures that are eventually used in designing treatments which makes comparisons across different treatment procedures difficult. When sleep symptoms are listed individually for each child and are not organized into larger factors or categories, it is difficult to compare the treatment results of many individual children. When symptoms are organized into factors or are
classified into specific sleep disorders, comparisons of treatment effectiveness for different children can be made.

In sum, there are numerous critical questions about the prevalence and treatment of sleep problems in children with autism and PDD that remain unanswered at this time, even though research repeatedly describes the debilitating effects that recurrent sleep disturbance can have on children with autism and their families. Three research questions were investigated in this study. The first question examined the types of sleep symptoms experienced by children with autism or PDD. The second research question looked at whether specific treatment types were chosen to treat particular sleep symptoms. The third research question investigated the effectiveness of different treatment types for specific sleep symptoms.
Chapter 2
Sleep Patterns, Disorders and Treatments

The purpose of this chapter is to examine research evidence related to the sleep patterns in typically developing children, the different types of childhood sleep disorders and the different ways they are assessed. The second purpose of this chapter is to review studies that have looked at sleep patterns in children with autism or PDD which have identified behavioral symptoms of sleep problems, irregularities of the sleep-wake cycle and biological abnormalities in sleep patterns. The final goal is to review the literature on the treatment of sleep problems in children with autism or PDD and to discuss how treatment has been implemented using either an individualized approach, a grouped approach or a modified grouped design.

Sleep Patterns in Typically Developing Children

From infancy to young adulthood, sleep patterns of children who are typically developing progress through specific stages. The sleep patterns of an infant begin to develop in utero and soon after they are born, their sleep patterns can be organized into three distinct stages (Wolfson, 1996). Although the stages of infant sleep are not as clearly differentiated as adult sleep patterns, active sleep (REM sleep), quiet sleep (NREM sleep), and indeterminate sleep can be identified (Sheldon, Spire & Levy, 1992; Wolfson, 1996). Unlike adults, the sleep cycle of an infant initially moves straight from wakefulness to active sleep (REM), but over the first year of life, active sleep (REM) begins to occur more towards the end of the night, while quiet sleep (NREM) begins to occur in the beginning of the night (Ferber & Kryger, 1995; Sheldon, Spire & Levy, 1992;
Wolfson, 1996). Although an infant spends more time in REM sleep than does an adult, during the first year, the amount of REM sleep in the infant’s sleep patterns begins to decrease (Sheldon, Spire & Levy, 1992; Wolfson, 1996). As the infant develops, sleep spindles and slow wave delta activity appears and infants begin to sleep for longer durations, while beginning to establish relatively consistent sleep patterns for naps and night sleeping (Sheldon, Spire & Levy, 1992; Wolfson, 1996).

While an infant typically sleeps 16-17 hours per day, from approximately age 2 to 5, the amount of time that a preschooler sleeps decreases from 13.5 hours at about 18 months, to about 11 hours of sleep at age 5 (Hopkins, Isaacs & Pitterle, 1995; Wolfson, 1996). In addition, the amount of daytime naps decreases during this time, and the length of the REM-NREM sleep cycle begins to increase until 5 years of age when it reaches adult levels (Hopkins, Isaacs & Pitterle, 1995; Wolfson, 1996). The amount of REM sleep also decreases from approximately 30-50% of total sleep, to about 20-25% of total sleep time during the first 2 to 5 years of life (Sheldon, Spire & Levy, 1992; Wolfson, 1996). Night wakings are common in most infants, (Sheldon, Spire & Levy, 1992; Wolfson, 1996) and Wolfson (1996) also reports that in preschoolers, “night time awakenings continue to be a common behavior for children in this age group. Although brief awakenings are normal, regular night wakings appear to be a problem for approximately 20% to 30% of 1- to 2 year olds, 14% of 3 year olds, and 5% of 8 year olds” (p.558).

During middle childhood, from about 6 to 11 years of age, the total amount of time that a child sleeps decreases to about 8-9 hours by early adolescence (Wolfson, 1996), and daytime sleep is rare (Sheldon, Spire & Levy, 1992). During the middle
childhood years, sleep patterns continue to change and begin to resemble the sleep stages and patterns of adolescence and adulthood (Sheldon, Spire & Levy, 1992).

**Childhood Sleep Disorders**

Sleep disorders in childhood are not uncommon, even for children who are characterized as typically developing (Dahl, 1995; Whyte & Schaefer, 1995). Dahl (1995) reports prevalence rates of 27% of children between the ages of 2 to 15 years of age who sought professional assistance for problems relating to falling asleep and night waking. Whyte & Schaefer (1995) describe studies that have found that 34% of young children aged 4-5 years old were still waking at night. Typically developing children often suffer from symptoms such as problems falling asleep, persistent night wakings, problematic behaviors occurring during sleep and excessive daytime sleepiness (Dahl, 1995).

In the past 10 years, different systems of classifying sleep disorders have evolved, each altering the overall organization to incorporate new research findings. Consequently, the systems have slight variations in their classification systems of parasomnias and dyssomnias. Three of the more popular manuals are the Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition (DSM-IV; American Psychiatric Association, 1994), the International Classification of Sleep Disorders Diagnostic and Coding Manual, the original version, (ICSD: American Sleep Disorders Association, 1990), and the revised version. (ICSD-R: American Sleep Disorders Association, 1997). While the three manuals do have minor inconsistencies concerning the exact criteria of which disorders constitute a dyssomnia and which fall under the heading of a parasomnia, the discrepancies are minor.
The most common sleep problems in childhood are typically bedtime difficulties and night wakings (Dahl, 1995; Ferber, 1996; Whyte & Schaefer, 1995), which would be classified as Primary Sleep Disorders according to the DSM-IV coding manual (American Psychiatric Association, 1994). The DSM-IV further subdivides the Primary Sleep Disorders into sleep symptoms. According to the DSM-IV, dyssomnias involve difficulties in the amount, quality or timing of sleep and include, Primary Insomnia, Primary Hypersomnia, Narcolepsy, Breathing-Related Sleep Disorder, Circadian Rhythm Sleep Disorder, and Dyssomnia Not Otherwise Specified (American Psychiatric Association, 1994). In addition, dyssomnias are the disorders that result in complaints of either insomnia or sleepiness.

Parasomnias are described in the DSM-IV as disorders that involve abnormal behavioral or physiological events during sleep that occur at specific sleep stages or at the sleep-wake transition (American Psychiatric Association, 1994). Parasomnias typically result in complaints of unusual behavior during sleep, as opposed to complaints of insomnia or sleepiness. According to the DSM-IV, parasomnias include Nightmare Disorder, Sleep Terror Disorder, Sleep Walking Disorder, and Parasomnia Not Otherwise Specified.

The first edition of the International Classification of Sleep Disorders (ICSD) (American Sleep Disorders Association, 1990) differs slightly from the DSM-IV (American Psychiatric Association, 1994) in the organization of sleep disorders into sleep symptoms. For example, a few of the disorders, such as Narcolepsy and Breathing-Related Sleep Disorder, appear under the heading of dyssomnia in the DSM-IV, but are listed as parasomnias in the first edition of the ICSD. In the ICSD (American Sleep Disorders
Association, 1990), Confusional Arousals, Narcolepsy, Night Terrors, Nightmares, Sleep Walking, Enuresis, Sleep Apnea, Rhythmic Movement Disorder, REM Behavior Sleep Disorder, Sleep Starts and Sleep Paralysis are listed as parasomnias. The dyssomnias in the first edition of the ICSD are Inadequate Sleep Hygiene, Nocturnal Eating and Drinking, Limit-Setting Sleep Disorder, Insufficient Sleep, Environmental Sleep Disorder, Sleep-Onset Association, Adjustment Sleep Disorder, Food Allergies, and Hypnotic & Stimulant Dependent Sleep Disorder (American Sleep Disorders Association, 1990).

In the International Classification of Sleep Disorders Coding Manual Revised (ICSD-R) (American Sleep Disorders Association, 1997), there are also minor changes in the organization of sleep symptoms. For example, Narcolepsy and Sleep Apnea are re-assigned to the category of dyssomnias, which is now consistent with the DSM-IV categorization (American Psychiatric Association, 1994). The ICSD-R characterizes dyssomnias as “disorders that produce either excessive sleepiness or difficulty in initiating or maintaining sleep” (p. 25), while the parasomnias are described as, “disorders of arousal, partial arousal and sleep-stage transition” (p.141), that do not typically result in complaints of insomnia or excessive sleepiness (American Sleep Disorders Association, 1997).

Assessment of Sleep Disorders

In the assessment of a child’s sleep problem, a detailed sleep history should be completed by a parent through an interview, a sleep questionnaire, or by the completion of a sleep diary over the course of a few nights (Johnson, 1996; Stores, 1996; Stores and Wiggs, 1998). If the child is verbal and able to contribute information to this interview, their perspective on the problematic sleeping situation is valuable (Stores, 1994; Stores,
Unfortunately, children with autism who have sleeping problems are often nonverbal or unable to articulate their perspective on the situation which puts them at a disadvantage during the assessment procedure.

The sleep history should consist of a detailed description of the child's sleeping patterns throughout a 24 hour period, all medications, the sleeping environment, the child's bedtime routine and level of physical activity, as well as a description of general family functioning (Stores & Wiggs, 1998). In addition, the parental reaction and response to the child's problematic sleeping behaviors during the night should also be included in the sleep history and can contribute to a functional analysis (Johnson, 1996; Minde, Popiel, Leos, Falkner, Parker & Handley-Derry, 1993; Stores and Wiggs, 1998). Medical, treatment and developmental histories, as well as descriptions of daytime behavior and general functioning are also necessary components of a thorough sleep assessment.

Behavioral observations using overnight video recording or live recording by a researcher or parent can be done at home or in a sleep lab, but these methods take considerable time and planning and may only be attempted if the child's sleep difficulties are critical. While behavioral observations with live recorders can be expensive and high maintenance procedures, all-night video recording can provide similar information and good agreement rates have been reported between video recordings of the child's sleep, and results of parental sleep diaries (Stores and Wiggs, 1998).

Polysomnography is used in the assessment of sleep problems in children when a physical problem is suspected and when other potential causes of the problems have been ruled out. The main types of polysomnography recordings are the electroencephalogram
(EEG), the electrooculogram (EOG), electromyographic activity (EMG),
electrocardiographic activity (ECG) and recordings of respiratory activity (Sheldon, Spire & Levy, 1992).

The electroencephalogram (EEG) is used to monitor the activity of the central nervous system during sleep, and can also provide information that differentiates the non-rapid eye movement (NREM) portions of sleep into specific sleep stages (Sheldon, Spire & Levy, 1992). The EEG requires that electrodes are attached to the scalp of the child for the entire duration of the recording period to record the changes in the electrical potentials of cortical neurons (Sheldon, Spire & Levy, 1992).

The electrooculogram (EOG) records eye movements during sleep and identifies when the child is in sleep stages associated with slow eye movement and when they have moved into the rapid eye movement stage (Sheldon, Spire & Levy, 1992). The EOG recording involves attaching electrodes to the skin surface on the outer canthi of the eyes, and records the electrical potential difference between the cornea and the retina of the eye (Sheldon, Spire & Levy, 1992).

Electromyographic recordings (EMG) are used to monitor the child’s muscle tone during sleep, and usually involves attaching electrodes to the skin on the child’s chin (Sheldon, Spire & Levy, 1992). The information from this device can be helpful in assessing atypical muscle activity and identifying sleep disorders such as bruxism and REM sleep behavior disorder (Sheldon, Spire & Levy, 1992). Leg movements are measured using leg muscle EMGs (Sheldon, Spire & Levy, 1992). Electrocardiogram recordings (ECG) are used to monitor the child’s cardiac rate and rhythm during sleep and
respiratory information is gathered from monitoring nasal-oral airflow, respiratory effort and oxygen saturation (Sheldon, Spire & Levy, 1992).

Many children with autism may not cooperate with the procedures involved in conventional polysomnography measurements, such as the attachment of electrodes and sleeping in a strange environment. Ambulatory monitoring systems have been developed that allow the child to sleep in their own beds at home during the recording period (Stores, 1994). Video recording or the use of actometers may be necessary replacements for some children who cannot tolerate the electrodes involved in conventional polysomnography recordings (Stores & Wiggs, 1998). Actometers are small movement sensors that can be worn on the child’s wrist or ankle and can detect whether the child is awake or asleep (Stores and Wiggs, 1998).

While an ideal assessment may be made up of a combination of all of the above assessment methods, including personal histories, sleep diaries, behavioral observations and polysomnography measurements, in reality, expense, access to services and acceptability to the parents and the child are all factors that restrict the comprehensiveness of the assessment procedure (Stores, 1994; Stores & Wiggs, 1998). The use of complicated behavioral observations and polysomnography techniques may be rarely used with children with autism because the child may have other language, social and behavioral challenges that parents may deem as more deserving of intensive intervention (Stores, 1996). While there are many useful assessment procedures available for use in the investigation of sleep disorders in children with autism, it is unclear if the procedures are actually being used in clinical practice. Furthermore, it is difficult to identify which of the assessment procedures are the most beneficial in isolating the causes of sleep problems for
children in this population, because assessment procedures are rarely consistent from one study to the next. Anders and Eiben emphasize that in sleep studies, “procedures for assessing and collecting data, especially with pediatric populations need to be more structured and standardized in order to compare results from one study and one laboratory to another” (Anders & Eiben, 1997, p.18).

While a few different questionnaires for assessing sleep do exist, they do not classify behaviors into specific sleep disorders, they are either limited to literate or vocal children, or they fail to target childhood sleep problems completely (Schreck, 1997). A consistent problem in the use of sleep assessment instruments with children with autism or PDD is that the questionnaires do not organize descriptions of sleep symptoms into universally recognized medical or psychological diagnoses of specific sleep disorders. Sleep difficulties are often described in a general and conversational manner and specific sleep symptoms for individual children are not consistently classified into diagnoses of sleep disorders. General descriptions of symptoms may accidentally group children together who all have autism or PDD and who also appear to display similar sleep behaviors, but who may actually have different underlying etiologies for their symptoms. As a result, these children may be erroneously prescribed identical treatments which may not be ideal matches for the actual sleep symptoms they are experiencing. It is likely that children with autism and PDD may be homogeneously prescribed similar treatments for sleep disorders because the assessment techniques focus on their cognitive diagnosis rather than organizing their individual sleep symptoms into clinical diagnoses of parasomnias and dyssomnias that may be treated very differently.
When sleep assessment instruments fail to produce reliable and consistent diagnoses of parasomnias and dyssomnias, quantitative comparisons of treatment success across many different intervention studies is difficult. In the present investigation the Behavioral Evaluation of Disorders of Sleep (BEDS) an assessment instrument that clearly differentiates between the specific symptoms of individual children was used (Schreck, 1997). The Behavioral Evaluation of Disorders of Sleep (BEDS) can be used with non-verbal children to assess their sleep problems by categorizing their sleep symptoms into specific factors using parent report. In developing this instrument, childhood sleep disorders were chosen from the International Classification of Sleep Disorders Diagnostic and Coding Manual (American Sleep Disorders Association, 1990) and the diagnostic criteria for those disorders were used in the formulation of 107 test items. Schreck (1997) then reduced the number of items to 31 and conducted a factor analysis of the final 31 items which revealed five main factors including Nightmares/Terrors; Environment; Medication/Anxiety; Confusional Arousal; and Apnea/Bruxism. Children with autism and PDD often have limited communication skills, and this questionnaire can be completed by a parent.

Sleep Patterns in Children with Autism and PDD

In investigating the sleep patterns of children with autism and PDD, some researchers have focused on the behavioral symptoms that are reported by families and attempt to identify problematic behavioral contingencies in the child’s environment that may be maintaining the sleep problem. Other researchers have studied the children’s overall sleep-wake cycle and looked at their circadian rhythms as potentially problematic.
A third group of researchers have used various polysomnography techniques and have looked for specific biological etiologies for the sleep disturbances.

**Behavioral Symptoms Associated with Sleep Disorders**

The investigators who have focused on the behavioral symptoms of sleep problems in children with autism or PDD have consistently found frequent night wakings, sleep initiation problems, short night sleep and early wakings. For example, Richdale and Prior (1995) compared children with autism to typically developing children and found that the children with autism were more likely to demonstrate one or more symptoms of "extreme sleep latency, extended night wakings, short night sleep and early morning waking. The authors concluded that, "differences in sleep behavior between children with autism and control children in these studies reflect differences specific to autism" (Richdale & Prior, 1995, p. 182). DyMyer (1979) examined the sleep difficulties of 32 children with autism and also found severe resistance in going to sleep and frequent night wakings. While DeMyer reported similar problems in typically developing children of the same age, the behavior of the children with autism was more frequent, severe, and problematic (DeMyer, 1979). In addition, DeMyer also points out that the typically developing children often woke up for a reason that could be quickly remedied such as to use the bathroom or to get a drink, but the children with autism often woke up only to engage in loud, inconsolable and problematic behaviors such as crying, screaming, hysterical laughter, roaming around the house, or violent rocking which often lasted for hours (DeMyer, 1979).

Taira, Takase and Sasaki (1998) studied 88 children with autism and found that 65% had experienced a sleep problem, and the majority of the children had experienced the problem prior to 3 years of age. The authors found that common problems were long
sleep latency, frequent night wakings, early morning wakings, and various bad habits regarding sleep (Taira, Takase & Sasaki, 1998). Similarly, Hoshino, Watanabe, Yashima, Kaneko & Kumashiro (1984) studied 75 children with autism and also found the same incidence rate of 65.1% of children with autism suffering from a sleep problem. These authors found a negative correlation between the child’s developmental level, and the length of time they had experienced the problematic symptoms (Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984).

Hering, Epstein, Elroy, Iancu & Zelnic (1999) gave questionnaires to parents of children with autism and found that 54% reported that their child experienced a sleep problem. Contradictory to these parental reports however, the authors also tested the same children with a 72 hour actigraphy which is an ambulatory device that detects whether the child is awake or asleep and found different results. While they reported a statistically significant difference in the early waking times of the children with autism, the authors reported that the “sleep problems of children with autism were similar to that of normal children” (Hering, Epstein, Elroy, Iancu & Zelnic, 1999, p.143). To explain the inflated incidence rate of sleep problems reported in the parent questionnaires, the authors suggested that, “parental overselectivity to sleep disturbances of the autistic children may explain this phenomenon” (Hering, Epstein, Elroy, Iancu & Zelnic, 1999, p.143). Because the statistics from an actigraphy only record when a child is awake or asleep, these results fail to describe the extent of the child’s problematic behaviors when they wake in the night. Children with autism often wake up to loudly cry, scream, sing, laugh hysterically, chant repetitive verbal phrases, engage in self-injurious behaviors, smear feces, rock and bang objects in their room, destroy property and roam around the house. Consequently,
the authors do note that the inconsistency in their findings between their parent
questionnaires and their actigraphy results may be due to the fact that, "the restless and
atypical behavior of these children may disturb the parents or other persons living with
them even if their night wakings are not longer or more numerous than normal children
who do not disturb the family even when they wake at night" (Hering, Epstein, Elroy,
Iancu & Zelnic, 1999, p.146). Another explanation for their inconsistent results may be
that the actigraphy recording interval was unrealistically short. Because behavior is often
inconsistent and unpredictable, perhaps the 72 hour 'snapshot' actigraphy was unable to
provide a representative sample of a child with autism’s typical sleep behavior, while the
parent questionnaires were able to capitalize on, and to incorporate hundreds of sleepless
nights as examples of the child’s sleep problems. In addition, the subjects that were tested
with the actigraphy were the older subjects (ages 8.0 ±3.0 years) that would tolerate the
testing equipment, which excluded four of the younger children in the sample (ages 4.3
±1.6 years). If the researchers had not limited the actigraphy to the older and more
cooperative children, they may have found results that more closely paralleled the parent
reports.

Some researchers hypothesize that sleep disturbance may develop in children with
developmental disabilities from a lack of parental consistency in response to the child’s
problematic behavior during the night (Durand, 1998). This hypothesis describes the
problems as resulting from an environment where the child’s disturbing behaviors during
the night are being positively or negatively reinforced by the reactions and responses from
their caregivers. Quine (1992) found that, “parents of children with sleep problems seem
to be more responsive to the child, being prepared to attend more quickly when the child
wakes, stay with the child until they fall back asleep, or allow them to share the marital bed. This may have the effect of rewarding the child for inappropriate behavior, and it fails to encourage appropriate behavior” (p.256). Mindell and Durand (1993) also believe that the parents play an integral role in the persistence of sleep problems as, “the child’s sleep problems are maintained by a situation in which the child does not know how to return to sleep upon waking, and by continued attention and reinforcement by the parents” (p.733). Durand, Gernert-Dott and Mapstone (1996) conducted a study with children diagnosed with developmental disabilities and emphasize the critical effect of the parent’s behavior on the child. Similarly, Ferber stresses that, “just because the child wakes at night, even if the child has a chronic illness or is neurologically abnormal, does not mean that the wakings are pathologic. These youngsters are just as subject to behavioral and schedule-related problems as are other children, perhaps more so” (Ferber, 1996, p.504).

Irregularities of the Sleep-Wake Cycle Associated with Sleep Disorders

A second group of studies have targeted the sleep-wake cycle as a possible contributor to sleep problems in children with autism. The sleep-wake cycle is the organization of sleep and wakefulness into day and night intervals that coordinate with the 24 hour environmental cycle which is regulated by environmental stimuli such as light and dark (Segawa, Katoh, Katoh & Normura, 1992). While circadian rhythms are typically organized into a consistent sleep-wake cycle by the light and dark cycle outside, social factors are also hypothesized to play a role (Richdale & Prior, 1992). Although the sleep-wake cycle and the child’s circadian rhythms usually becomes synchronized with the 24 hour day-night cycle in the early post-natal period of development in most typically developing children, some researchers have hypothesized that this may not happen in
children with autism (Segawa, Katoh, Katoh & Normura, 1992). Segawa (1984) reported that children with early infantile autism demonstrated abnormal circadian oscillations because the children in his study woke up later in the morning, went to sleep later in the evening, and they had longer day sleep and shorter night sleep than did their typically developing siblings. Segawa hypothesizes that the abnormalities observed in the circadian rhythm and sleep-wake cycle of the children with autism in his sample represents, "a cardinal or basic pathophysiology of the behavioral disorder" (Segawa, 1984, p.152), and in a later study suggests that the problematic sleep-wake cycle which occurs around the critical age of development of the child’s circadian rhythm may cause behavioral disturbances in the child’s future (Segawa, Katoh, Katoh & Normura, 1992).

While Segawa reports claims of a problematic circadian rhythm and sleep-wake cycle in children with autism, (Segawa, 1984; Segawa, Katoh, Katoh & Normura, 1992), results from other researchers call into question these assumptions. Takase, Taira & Sasaki (1998) investigated the 24 hour sleep-wake rhythm of 89 children with autism and found that only one child demonstrated a non-24 hour sleep-wake pattern. Contrary to Segawa’s (1984) reports of later waking time in the morning, Takase, Taira & Sasaki (1998) found that the majority of the children in their sample demonstrated early rising from bed in the morning.

Melatonin has also been an area of interest to researchers as it is integral in regulating the sleep-wake cycle. Melatonin is produced in the pineal gland when the body receives signals that it is dark outside and the continued secretion of melatonin throughout the night helps to regulate the child’s sleep-wake cycle (Stores & Wiggs, 1998). In the morning when it is light outside, the production of melatonin is suppressed and remains at
very low amounts throughout the day (Stores & Wiggs, 1998). Some researchers hypothesize that children who experience multiple disabilities may not be able to generate appropriate cerebral signals in response to environmental cues that trigger melatonin release (Jan, Espezel & Appleton, 1994; Stores & Wiggs, 1998). This hypothesis assumes that the children are not naturally releasing adequate amounts of melatonin when it gets dark outside, and therefore, they are not feeling tired at natural bedtimes. Nir, Meir, Zilber, Knobler, Hadjez & Lerner (1995) studied the melatonin levels in young adults with autism and did find an irregular circadian pattern of melatonin. They found that the individuals with autism had, “disturbances in the functional rhythm of melatonin, indicating involvement of the coordinating system” (Nir, Meir, Zilber, Knobler, Hadjez & Lerner, 1995, p.650).

Biological Abnormalities Associated with Sleep Disorders

A third group of researchers have examined possible biological markers of sleep disturbance in children with autism. For example, Elia, Ferri, Musumeci & Bergonzi (1991) have compared the sleep stages of individuals with autism to matched controls and claim that the individuals with autism displayed higher rapid eye movement (REM) density and R-index (Elia, Ferri, Musumeci & Bergonzi, 1991). In addition, they also found that the REMs were less likely to cluster together in bursts in the individuals with autism compared to the matched controls (Elia, Ferri, Musumeci & Bergonzi, 1991). Other researchers have examined both irregular EEG patterns and spindle fiber frequencies during specific sleep stages (Espie & Tweedie, 1991; Shibagaki, Kiyono & Watanabe, 1980). Investigators have also considered such factors as the length of delivery during
birth of the child, perinatal factors, and sensory threshold as potential contributors to later sleep disturbances in childhood (Durand, Gernert-Dott & Mapstone, 1996).

Quine (1992) questioned parents of children with severe learning difficulties and asked them what they thought was the cause of the child's sleep disorder and found that, "86% of parents mentioned brain damage, intellectual impairment, mental handicap, or particular diagnoses associated with learning difficulties. Parent comments suggested that they believed that sleep disturbance was an inherent feature of brain damage or intellectual impairment and something they had to tolerate as best they could" (Quine, 1992, p.257).

Treatment Studies

The following studies have developed interventions to treat sleep problems in children with autism, PDD and other developmental disabilities. Although some researchers have limited their samples to only include children with autism or PDD (Howlin, 1984; Piazza, Hagopian, Hughes and Fisher, 1998; Wolf & Risley, 1963), others have grouped children with autism or PDD with children who have other developmental and learning disabilities.

Children with various developmental disabilities and cognitive impairments are often categorized homogeneously in the literature on treatment of sleep problems, regardless of their different diagnoses, physical impairments and home environments. Since it has been discovered that children with Downs Syndrome have sleep problems for reasons that appear specific to their diagnoses, (Stores, Stores & Buckley, 1996), perhaps children with autism or PDD also have recurrent sleep problems for reasons that are specific to the diagnosis of autism or PDD.
Although a few investigators appear to conduct intricate assessments and to base treatment plans directly on the results of these assessments, other researchers appear to prescribe pre-established treatment protocols for groups of children without differentially acknowledging individual information identified through assessment procedures such as age, diagnosis, or the child’s individual sleep symptoms (Stores & Wiggs, 1998). By broadly prescribing treatments without acknowledging these important factors, researchers and clinicians may not be making the most idealistic match between the child and the chosen treatment.

The following treatment studies are grouped according to the researcher’s use of individualized assessment information in the planning of treatment protocols. In addition, the studies are also organized according to whether the researchers acknowledge each child’s cognitive diagnosis and specific sleep symptoms in their final analysis of treatment efficacy.

Extensive Use of Assessment Information in Developing Treatment Design

In the first group of treatment studies for sleep problems in children with autism or PDD, researchers used detailed assessment instruments that included intricate descriptions of individual behaviors and specific sleep symptoms. Although the studies did not classify the symptoms into specific parasomnias or dyssomnias, the assessments required precise accounts of a child’s typical night which clearly illustrated bedtime routines, disruptive behaviors, disturbed sleep patterns, as well as the parent’s response to the child’s behaviors. In addition, these studies also clearly differentiated between children with different cognitive diagnoses. While the results of children with different neurological difficulties were occasionally reported in the same study, the sleep patterns
of individual children were compared only to their own previous patterns of behavior, and not to the behavior of other children reported in the study.

Wiggs & Stores (1999) conducted functional analyses to design individualized treatment plans for 16 children with sleep problems and severe learning disabilities, four of whom had a diagnosis of autism. Because the participants all had different cognitive diagnoses, and because the functional analyses revealed that they were displaying similar sleep symptoms for very different reasons, the authors designed individual treatment plans that were specific to each child. Various combinations of different treatments were used for each child such as extinction, graded extinction, stimulus control procedures, and positive reinforcement. The authors found that all treatments resulted in substantial reduction of sleep problems in all children, and that the results were maintained at follow-up. The parents of the control group children in this study who did not receive treatment did not report any improvement in their child’s sleep patterns at any of the follow up points. Although the parents of the children in the control group did not report any improvements in sleep, objective improvements in sleep such as increased sleep duration, reduced movement during sleep and less fragmentation of sleep by movement was seen for both the treatment and the control group children (Wiggs & Stores, 1999).

Similarly, Durand, Gernert-Dott and Mapstone (1996) used assessment instruments that differentiated between different sleep symptoms to treat the disturbed sleep patterns of four children with developmental delay, two of whom had a diagnoses of autism or PDD. The authors devised individual treatment plans for each child by establishing bedtime routines and consistent responding by parents to disruptive behavior using gradual extinction. The authors found that the individual treatments successfully
decreased the targeted night wakings for two participants and successfully decreased the targeted bedtime disturbances for the other two children (Durand, Gernert-Dott and Mapstone, 1996).

Piazza, Hagopian, Hughes and Fisher (1998) used an individualized treatment protocol in a case study involving an 8 year old girl diagnosed with autism, severe mental retardation, congenital omphalocele, a sleep disorder, and food refusal. The authors used a chronotherapy treatment which involved “systematically delaying the child’s bedtime each night while maintaining a regular schedule during waking hours until an age appropriate bedtime was observed (Piazza, Hagopian, Hughes & Fisher, 1998, p.358). Following 11 nights of treatment, the child experienced fewer night wakings, her sleep onset time decreased, and she began to sleep on a desired sleep-wake schedule (Piazza, Hagopian, Hughes and Fisher, 1998). Wolf and Risley (1964), and Howlin (1984) also conducted successful case study interventions to improve the sleep behaviors of children with autism. Wolf and Risley (1964) used an extinction and mild punishment intervention (time out from positive reinforcement) to successfully decrease the nighttime tantrums of a 3 year old boy with autism while Howlin (1984) used a graded-change technique to decrease the tantrums and night wakings in a 5 year old boy with autism.

In addition to using intricate assessment instruments and limiting comparisons of results to each child’s own previous patterns of behavior, the above five studies all have relatively small sample sizes. It appears that the researchers in all of the first five studies were open to different possible treatments at the beginning of the study, and then based their final choice of treatment protocols on the results from the individual assessments. Unlike methodologies which have a pre-determined treatment design before assessment
even takes place, this first group of studies appear to demonstrate flexibility in their desire to design a compatible treatment before they prescribe a particular treatment. Because the studies have small sample sizes, the results have limited generalizability to other children who may have similar problems. Because the treatment protocols were designed for children with very specific symptoms which were not diagnosed as specific disorders such as parasomnias or dyssomnias, it is difficult to predict who else might benefit from the same treatments.

**Moderate Use of Assessment Information in Developing Treatment Design**

In the second group of studies, the researchers used detailed assessment instruments that included explicit descriptions of specific sleep symptoms, but they did not appear to differentially utilize information in planning treatment protocol. The researchers in the second group of studies appeared to have a particular treatment chosen before the assessments of the individual children were conducted. The main purpose of the assessments were more to provide baseline information, than to identify a starting point at which to select a treatment design. Yet, although these researchers tried the same treatments for all of their participants, they did modify treatment protocols slightly to personalize treatments for individual children.

Piazza and Fisher (1991) used a faded bedtime with a response-cost procedure to treat sleep problems in 4 developmentally delayed children who were nonverbal, profoundly mentally retarded, self-injurious and were suffering from insomnia. It is unclear if any of the children classified as developmentally delayed had a specific diagnosis of autism or PDD. In this study, extensive data was gathered during an initial assessment through parent reports of each child’s sleep symptoms, however it appears that the
researchers had previously decided on the type of treatment each child would receive before the initial assessments were conducted. Although all of the participants in each study received the same treatment, the treatments were all slightly altered to match each child’s specific situation as individual behavior problems and other medical procedures were incorporated into treatment plans. After treatment, Piazza and Fisher found that all four of their participants had increased amounts of nighttime sleep as well as decreased amounts of daytime sleep and fewer night wakings. Because the researchers did not classify the individual sleep problems into sleep disorders, it is difficult to predict who else would benefit from this treatment.

Jan, Espezel and Appleton (1994) studied the effect of 2.5-5.0 mg of oral melatonin supplements on sleep problems of multiply disabled children and discussed each child’s sleep pattern and treatment success individually which made it possible to examine the one child with autism who was successfully treated in this study. Although they did discuss each child individually, the researchers grouped the children together under a general descriptor of ‘multiply disabled’ when they reported that for all 15 participants, oral melatonin administered at bedtime was successful in improving sleep patterns with no adverse side effects. The authors also reported that additional health, behavioral, and social benefits were significant. The researchers conducted detailed assessments that differentiated between specific symptoms, but each child received the same treatment of oral melatonin at bedtime. Although it appeared that the researchers had pre-determined the type of treatment each child would receive, the dosage of melatonin was tried to match each child’s need.
Camfield, Gordon, Dooley and Camfield, (1995) also conducted an intervention using oral melatonin to improve the fragmented sleep patterns of children with mental handicap. One child with PDD was included. The researchers obtained individualized assessment information, but all of the children received the same intervention which was 0.5-1.0 mg of oral melatonin each evening at 6:00pm. The authors found that none of the children showed a marked improvement in sleep pattern (Camfield, Gordon, Dooley & Camfield, 1995). While these results initially appear to contradict the more successful treatment findings of Jan, Espezel and Appleton (1994), Jan, Espezel, Freeman & Fast (1998) identified many methodological, dosage and timing errors in the study by Camfield, Gordon, Dooley & Camfield, (1995) which may have contributed to unsuccessful results. For example, children in the study by Camfield, Gordon, Dooley & Camfield, (1995) received a very small dose of melatonin (0.5-1.0mg) while children in the study by Jan, Espezel and Appleton (1994), received 2.5 to 5.0 mg (Jan, Espezel, Freeman & Fast 1998). In addition, the subjects in the study by Camfield were administered the melatonin at dinner time, instead of 30 minutes before bed as was directed by Jan, Espezel and Appleton (1994). By giving the dosage at dinner time, the melatonin would have been ineffective at bedtime as the effects would have worn off by this time (Jan, Espezel, Freeman & Fast, 1998).

When the results of assessment are not directly used in the differential planning of treatment protocol, the researchers risk the possibility of selecting a treatment that may not be the most compatible treatment for the specific characteristics of the child. When a researcher tries to fit individual children into pre-determined profiles, they may not adequately acknowledge each child's individual diagnosis, sleep symptoms or their unique
set of behavioral circumstances, they may not choose the most compatible treatments for each child.

**Limited Use of Assessment Information in Developing Treatment Design**

The third and final group of studies in this literature review all have relatively large sample sizes, and the researchers fail to mention the specific sleep symptoms of individual children in the assessments of the sleep problems. Although the main sleep problems were generally reported for all of the children as a group, the diagnoses of specific sleep disorders for each child were not mentioned. Because the researchers did not base the planning of treatment protocol on the results from intricate sleep assessments, they do not seem to have differentially planned personalized treatments for any of the participants. As a result, all of the children in the last group of studies received the same treatment as the other participants in the same study. Furthermore, the researchers did not take the different cognitive diagnoses of the participants into account, so in the analysis of treatment effectiveness, there are direct comparisons between children who have different cognitive diagnoses.

Bramble (1996, 1997) conducted two different studies that both investigated sleep problems in children with "severe learning disabilities." In both investigations he compared the sleep habits of participants who had different cognitive diagnoses. Because he does not specify the diagnoses of each child in his sample, it is unclear how many of the children had a diagnosis of autism or PDD. Bramble (1997) found that with a combination of behavioral techniques such as rapid-extinction, cueing and stimulus control, all of the children showed improvements in night settling and night-waking patterns. He also found improvements in daytime behavior and in the mother's stress levels. Bramble (1996)
reports that the changes occurred quickly, and that they were maintained throughout the follow-up periods of 14 and 18 months after the treatment phase. Parents found the treatment to be safe, helpful and acceptable. Although each of the participants did show ‘improvements’ after receiving treatment, it is unclear if the children could have improved more if their treatments had been individually designed, based on intricate analyses of their personal symptoms.

In a study by Piazza, Fisher and Sherer (1997), 4 of the 14 children had a diagnosis of autism or PDD, but the researchers did not provide descriptions of each child’s sleep patterns and consequently, they did not base the treatment designs of different children on their individual characteristics. Researchers randomly assigned 14 children with various developmental disabilities to one of two treatments, regardless of their specific symptom profiles. Half of the children were assigned a treatment that used a faded bedtime procedure with response cost, and the remaining participants were assigned bedtime scheduling. While amounts of disturbed sleep decreased for all participants, the children who received faded bedtime with response cost had larger reductions in disturbed sleep than did the children who received bedtime scheduling. No follow-up data was mentioned. It is unclear if the children could have improved more if they had been assigned to each of the treatment groups based on detailed analyses of their individual sleep symptoms. These researchers directly compared children who had different diagnoses and reported that, “because of the heterogeneity of the sample, it is difficult to draw conclusions about the effects of treatment relative to particular diagnostic categories” (Piazza, Fisher & Sherer, 1997, p.417).
Statement of Problem and Significance of the Study

While researchers have previously reported a high prevalence of sleep problems in children with autism or PDD (DeMyer, 1979; Hoshino, Watanabe, Yashima, Kaneko & Kumashiro, 1984; Takase, Taira, & Sasaki, 1998; Taira, Takase & Sasaki, 1998; Richdale & Prior, 1995; Stores & Wiggs, 1998), they often use assessment instruments that do not describe the specific, individualized symptoms that are being treated. Therefore, to investigate the differential effectiveness of various treatments for specific sleep symptoms in children with autism or PDD, it is first necessary to identify which of the many sleep symptoms are the most prevalent in this population and require treatment. The first purpose of this investigation is to describe, through parent report, the types of sleep symptoms experienced by children with autism or PDD.

In addition, since intricate descriptions of specific symptoms are rarely utilized in diagnosing sleep problems in children with autism or PDD, it is unknown if treatments are selected to treat specific sleep symptoms. The second purpose of this study is to investigate through parent report whether specific treatments are tried to treat particular sleep symptoms in children with autism or PDD.

Finally, although some treatments may be more effective than others for the treatment of particular sleep symptoms, these conclusions are difficult to establish because researchers do not typically compare two or more different treatments in a single study and consistent outcome measures are rarely used across different studies which makes comparisons complicated. Most researchers test single treatment protocols, and then proceed to measure the effectiveness of these treatments with terms such as ‘improvement’, ‘sleeping better’ or ‘less disruptive’. It is extremely difficult to determine
which of the treatments are the most effective for children with specific sleep symptoms. The third goal of this study is to investigate the effectiveness of different treatments for specific sleep symptoms in children with autism or PDD through parent report, and to examine whether particular sleep symptoms are more successfully treated by specific types of treatments.
Chapter 3

Methodology

Participants

Parents or caregivers (N=150) who have children with a clinical diagnosis of Autistic Disorder or Pervasive Developmental Disorder (NOS) aged three to twelve years old were recruited to participate in this study. Participants could have been mothers, fathers, stepparents, grandparents, or any other legal caregiver of the child with autism or PDD. It was recommended that the individual who typically responds to the child during the night be the respondent in this study. Parents or caregivers must have been living in the province of British Columbia to be eligible for this study. If a parent had more than one child with a diagnosis of autism or PDD, a package was completed for each child (N=1).

The child’s diagnosis of autism or PDD was based on a professional diagnosis using the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) criteria. It was not necessary for the child to have a sleep problem for the parent to participate in this study.

Parents were recruited from the Autism Society of British Columbia (A.S.B.C) and Families for Early Autism Treatment of British Columbia (FEAT of B.C.) through parent meetings, workshops, fund-raisers, conferences and through paper and web-page postings sponsored by the two agencies. The researcher also recruited participants through discrete trial training workshops run by the researcher. Participation in this study was entirely voluntary.
Instruments

The first part of the questionnaire contained a section on child history which was given to the parent to gather general information about each child. The Behavioral Evaluation of Disorders of Sleep (BEDS) (Schreck, 1997), was revised and used in the second section of the questionnaire to investigate parent reports of specific types of sleep symptoms that children with autism or PDD were experiencing. The third section of the questionnaire investigated the treatment of the child’s sleep problems to determine the types and effectiveness of any past or current treatments the child may have experienced (see Appendix B).

Child history. Part one of the questionnaire was administered to each parent participant to collect information on their child’s age, gender, diagnoses and all current medications. Information was also gathered on, how many hours the child actually sleeps per night and how long the parent would like the child to sleep, as well as the child’s typical bed time and rising time. Finally, information on the family was collected to determine who was completing the questionnaire and who typically responded to the child in the night. The purpose of this information was to insure that the child of each participant met the eligibility requirements, as well as to record other factors that may have affected sleep patterns in each household.

The Behavioral Evaluation of Disorders of Sleep (BEDS). The Behavioral Evaluation of Disorders of Sleep (BEDS) (Schreck, 1997) was revised for use in the second section of the questionnaire to gather information on the child’s specific sleep symptoms. In the construction of the BEDS, Schreck (1997) chose sleep disorders, both dyssomnias and parasomnias, from the International Classification of Sleep Disorders
Coding Manual (American Sleep Disorders Association, 1990) that were associated with childhood. Schreck chose the following sleep disorders from the ICSD (American Sleep Disorders Association, 1990) classified as dyssomnias; Inadequate Sleep Hygiene; Environmental Sleep Disorder; Adjustment Sleep Disorder; Insufficient Sleep Syndrome; Limit-Setting Disorder; Sleep-Onset Association Disorder; Food-Allergy Insomnia; Nocturnal Eating (Drinking); Hypnotic-Dependent Sleep Disorder and Stimulant-Dependent Sleep Disorder. The following sleep disorders classified as parasomnias were also used; Confusional Arousals; Sleep Walking; Sleep Terrors; Rhythmic Movement Disorders; Sleep Starts; Sleep Talking; Nightmares; Sleep Paralysis; REM Sleep Behavior Disorder; Sleep Bruxism; Sleep Enuresis; Primary Snoring and Infantile Sleep Apnea. She then took the diagnostic criteria from all of the chosen disorders from the manual and generated 107 statements that could be answered using a Likert scale (0=never, 1=rarely, 2=sometimes, 3=frequently, 4=always, and if statement does not apply=0). She also added four general questions at the end regarding how long the child slept at night, how long they napped during the day, as well as the parent's description of their child's sleep difficulties. Schreck (1997) then analyzed the 107 statements for discriminative validity and test-retest validity, discarding statements that did not meet criteria until a total of 31 items were left. A factor analysis was then conducted and the final 31 items were organized into five main factors which included Nightmares/Terrors: Environment; Medication/Anxiety; Confusional Arousal; Apnea/Bruxism.

Schreck (1997) conducted reliability and validity analyses of the five remaining factors. Discriminative validity of the five factors and the total score was computed using a Mann-Whitney U test and she found that all individual factor scores as well as the total
score discriminated between children with sleep problems and those without sleep
difficulties (Schreck, 1997). Because of the instability of sleep patterns in typically
developing preschool aged children, Schreck limited her sample to children aged 5-12
years in the test construction of the BEDS.

The BEDS was revised for the purpose of this study in two ways. First, the four
general questions appearing at the end of the BEDS were eliminated because the same
questions were already asked in the treatment questionnaire. The BEDS was also revised
with the addition of a section on the child’s main five symptoms. In this section, parents
were asked to use the 107 items from the BEDS to identify their child’s main five sleep
symptoms. This revised section of the BEDS is discussed further in the Procedure section
of this paper.

**Treatment Questionnaire.** The last section of the questionnaire focused on the
treatment of the sleep symptoms reported in the previous section using the revised
Behavioral Evaluation of Sleep questionnaire. The first part of the treatment
questionnaire gathered parental reports of information related to the history of the sleep
problem, such as how long the child has had the problem, how challenging the problem
was for the child and for other family members, and if and how the problems were
resolved. The next section assessed parental reports on whether they had ever sought
professional treatment for their child’s sleep problems and from whom. This section also
identified whether their child had a specific diagnosis for their sleep problems (distinctive
from their cognitive diagnosis), what that diagnosis was, and what assessment procedures
were used. The last section required the parent to mark all of the possible behavioral,
natural and pharmaceutical treatment techniques that they have tried in the past to treat
their child’s sleep problems. In addition, the participant was asked to rate each treatment’s effectiveness for each of the 5 main sleep symptoms that were previously identified by the parent on the revised section of the BEDS.

**Procedure**

Participant recruitment letters were given to both the Autism Society of British Columbia and Families for Early Autism Treatment of British Columbia for both their web sites and their bulletin boards (see Appendix C and D). Interested participants contacted the researcher and left their name and home address. A copy of the questionnaire and a cover page (see Appendix E), was then placed in each package with a pre-addressed and postage paid envelope and distributed to each interested participant. The packages were also distributed by the researcher at parent meetings, workshops and conferences sponsored by the two agencies. In addition, the researcher also recruited participants through discrete trial training workshops run by the researcher. Parents were instructed to complete all three sections of the questionnaire and to return it through the post in the postage paid envelope. Each questionnaire was assigned a number that was recorded when the completed information was received back through the mail from the respondent. After all the completed forms were received by the researcher, there was a draw of two $25.00 gift certificates for two participants who completed and returned the forms. At this time, all identifying information was removed from the data needed for the study to protect the confidentiality of the respondents.
CHAPTER 4

Results

Three research questions are addressed in this chapter. The purpose of the first research question was to describe through parent report, the types of sleep symptoms experienced by children with autism or PDD. The purpose of the second research question was to examine whether specific types of treatments were tried to treat particular sleep symptoms according to parent report. The third research question examined whether particular sleep symptoms were more successfully treated by specific treatment types according to parent report.

A total of 57 questionnaires were received after two months of data collection. Five questionnaires were excluded from the final data analysis due to a failure to meet pre-specified inclusion criteria. Two participants were excluded because their children did not have a diagnosis of autism or PDD, and three were excluded because the children were older than 11 years old and the criteria for inclusion was limited to children aged 3 to 11 years old. The participants who filled out the survey were typically the mothers of the children with autism or PDD (96.2%) and were usually the parent who responded to the child in the night when the child woke up (63.5%). In some families, the father would also accompany the mother when the child had a night waking, or would take turns with the mother in dealing with the child at night (25.0%).

Demographic Information

The children of the final 52 participants that were included in the study ranged in age from 3 to 11 years (M = 6.82; SD = 2.34). Of the 52 participants, 43 were male and 9
were female. Although the majority of the children (94.2%) had a diagnosis of autism, 5.8% of children had a diagnosis of PDD. Children with autism and PDD were grouped together in this study as previous research has shown that children with these two diagnoses have similar sleep patterns (Schreck, 1997). Although 76.9% of the children did not have a medical diagnosis other than their diagnosis of autism or PDD, 23.0% of the children did have an additional diagnosis such as, Attention Deficit and Hyperactivity Disorder (N=1), Fragile X Disorder (N=2), Seizure Disorder (N=2), Tourettes Disorder (N=2), Allergies (N=2), Asthma (N=1), or another disorder categorized as ‘other’, (N=2).

Although 59.6% of the children were not on any medication during the study, 40.4% of the children were on various types of medications which included antidepressants (N=2), stimulants (N=3), antihistamines (N=1), sedatives (N=1), DMG (N=2), antipsychotic medications (N=2), secretin (N=1), or additional medications coded as, ‘other’ (N=9).

Sleep History

Of the 52 participants, 76.9% had a child who had experienced a past or current sleep problem. Specifically, 50% of the participants reported that their child had experienced a previous sleep problem, 26.9% of participants reported a current sleep problem and 23.1% of participants reported their children had never experienced a sleep problem.

Most participants reported that their children went to sleep between 8 and 9 pm at night (63.5%). Fourteen percent of children went to bed between 9 and 10 pm, 11.5% went to bed between 10 and 11 pm, 9.6% went to bed between 7 and 8 pm and 1.9%
went to bed between 6 and 7 pm. Most participants reported that their children woke up between 6 and 8 am in the morning (75.0%). Fourteen percent of children woke up between 8 and 10 am, 5.8% woke up between 4 and 6 am, 3.8% woke up before 4 am and 1.9% of participants reported that their child had no steady wake-up time. Each child’s total number of hours in bed was calculated from the data on their bedtimes and wake-up times. Total number of hours in bed was strictly the number of hours between the child’s bedtime and wake-up time, regardless of whether the child was awake or asleep during these hours. Because the data from the child’s bedtime and wake-up time was gathered in discrete intervals (e.g. between 6 and 8am), to calculate each child’s total number of hours in bed, the median time of each reported bedtime and wake-up time was calculated and used in this analysis. Of the 52 total participants, 3.9% of parents reported that their children spent 5-6 hours in bed each night; 7.8% spent 7-8 hours in bed; 9.8% spent 9-10 hours in bed and 78.4% spent more than 10 hours in bed each night.

Although the total hours in bed would presuppose that these children would be getting approximately more than 10 hours of sleep, only 11.5% of the participants actually reported that their children were getting more than 10 hours of sleep per night. In fact, most children were getting either 7-8 hours (34.6%) or 9-10 hours (38.5%) while 15.4% of children were getting only 5-6 hours of sleep each night. This discrepancy between bedtimes, wake up times and hours of sleep may be due to delayed sleep latency, early wakings, or sleep lost during night wakings when the child is still physically in bed, but is not actually asleep.

Many parents (53.8%) indicated that they felt their child needed more sleep than they were actually getting each night. Of the 53.8%, 13.5% of parents felt their child
needed 4 more hours sleep, 5.8% needed 3 more hours, 25.0% needed 2 more hours and 9.6% of parents thought their child needed 1 more hour of sleep per night.

The most common age at which the sleep problems first developed for the 40 children with a past or present sleep problem was before 2 years of age (67.5%). Twenty percent of children developed problems between 2 and 3 years of age, 7.5% between 4 and 5 years of age, 2.5% between 6 and 7 and 2.5% between 8 and 9. The participants were then asked how problematic the sleep problem was for the child and for the family compared to the other difficulties the child may have had at the time. Sixty-eight percent of participants thought that the sleep problem was either 'problematic', or 'very problematic for the child', and 80% responded that the child's sleep problem was either 'problematic', or 'very problematic for the family at the time.

When participants were asked if their child's sleep problems had been successfully treated by a specific treatment protocol, 40% responded that their child's sleep problems had improved because of a particular treatment, 30% reported that their child had simply grown out of the sleep problems and 30% found that their child's problems were not improving at all. Most participants reported going to see a pediatrician (47.5%), a behavioral consultant (42.5%) or a family doctor (37.5%) about their child's sleep problem. Psychologists (17.5%), Psychiatrists (17.5%) and treatment sources coded as, 'other' such as; 'behavioral therapist', 'reference books on sleep', 'neurologist' and 'gastroenterologist' (17.5%) were sometimes consulted. During the assessment of their child's problem, most participants reported that the professional used a parent interview (72.5%), an EEG (27.5%), a sleep diary (15%), or a parent report questionnaire (12.5%). Rarely, participants reported the use of a child interview (7.5%), an ECG (5.0%), or an
EOG (2.5%) Use of other assessment techniques such as behavioral observations in a clinic, by video, a child completed questionnaire, the use of an EMG, or respiratory measures were not reported by any participants.

Of the 40 children with a past or present sleep problem, 5% had received a specific sleep diagnosis from a professional that was separate from their diagnosis of autism or PDD. Of the 2 children who had received specific sleep diagnoses from a professional, one child had a diagnosis of Sleep-Onset Association Disorder and the other had diagnoses of both Night Terrors and Sleep Enuresis.

Types of Sleep Symptoms Experienced by Children with Autism or PDD

Behavioral Evaluation of Sleep (BEDS). Each of the 52 participants completed the Behavioral Evaluation of Sleep (BEDS) questionnaire which consisted of 107 statements that could be answered using a Likert scale (0=never, 1=rarely, 2=sometimes, 3=frequently, 4=always, and if statement does not apply=0). The parent was then instructed to look back at the 107 statements (symptoms) and choose the five that best described their child’s main symptoms. A main symptom was described as a statement that the parent had answered as a 3 (frequently), or a 4 (always) or a symptom that was the most problematic for their child.

Symptoms Coded as ‘Other’. Although most parents did select their child’s 5 main symptoms from the 107 statements as instructed, some participants substituted additional symptoms in this section that were not included in the original list of 107 symptoms from the Behavioral Evaluation of Sleep questionnaire. Participants sometimes described these new symptoms intricately, and reported that these particular symptoms were actually more frequent and problematic than any of the symptoms described in the
Behavioral Evaluation of Sleep questionnaire. When a participant reported a main symptom that was not listed in the Behavioral Evaluation of Sleep questionnaire, the item was preliminarily coded as 'other'.

During data analysis, the resulting 27 main symptoms that were initially coded as 'other' were examined and it was discovered that all of these symptoms could be described using a common heading of, 'waking to engage in disruptive or self-stimulatory behavior'. These disruptive and self-stimulatory behaviors appeared to be qualitatively different from the waking behaviors described in the BEDS questionnaire. For example, examples of night waking behaviors that could be coded by the BEDS questionnaire included the child crying, screaming, or seeking the comfort or attention of caregivers. On the contrary, the behaviors described as, 'other' by participants in the present investigation could not be accurately coded by the BEDS because parents reported their children were often not crying or screaming and did not attempt to seek the comfort or attention of others. Instead, participants described their children as laughing, singing, chanting, jumping and actively playing in a loud and disruptive manner during the night so that the volume of their behavior disrupted other family members who consequently became aware that the child was awake. Items that were originally coded as 'other' were then re-coded as 'waking to engage in disruptive or self-stimulatory behavior' and are listed in Table 1.
Table 1

Description of Main Symptoms Not Included in the BEDS and Coded as ‘Other’

<table>
<thead>
<tr>
<th>Main Sleep Symptom Coded as ‘Other’</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many night wakings and does not go back to sleep (child not crying or screaming)</td>
<td>13</td>
</tr>
<tr>
<td>Wakes to self-talk, sing, giggle or babble in the night</td>
<td>4</td>
</tr>
<tr>
<td>Wakes up to be active (thrashing limbs, jumping and kicking the wall)</td>
<td>2</td>
</tr>
<tr>
<td>Wakes up to eat in the night</td>
<td>1</td>
</tr>
<tr>
<td>Night or early waking to play</td>
<td>3</td>
</tr>
<tr>
<td>Will be awake all night every few months or so</td>
<td>1</td>
</tr>
<tr>
<td>Wanders around the house, often disrupts parents or siblings</td>
<td>3</td>
</tr>
</tbody>
</table>

While there were a total of 27 symptoms that were reported by parents and coded as ‘waking to engage in disruptive or self-stimulatory behavior’, the 27 symptoms were not reported by 27 different participants. Instead, five participants reported more than one symptom coded as, waking to engage in disruptive or self-stimulatory behavior’. Because the five participants who reported more than one symptom coded as, ‘waking to engage in disruptive or self-stimulatory behavior’ described very different behaviors in each of their main symptoms, it was decided that each main symptom should still be recorded separately so as to not lose valuable information about the description of that participant’s main
symptoms. The 27 main symptoms coded as, ‘waking to engage in disruptive or self-stimulatory behavior’ were reported by 18 different participants.

Because the symptom, ‘waking to engage in disruptive or self-stimulatory behavior’ was not part of the original Behavioral Evaluation of Sleep questionnaire, all participants did not have an opportunity to select this symptom as one of their child’s five main symptoms, so the frequency of this category may be underrepresented in this analysis. Nevertheless, because the participants described similar data with such a high frequency, it was decided that this volunteered information was too valuable to discard.

Main Sleep Symptoms. The treatment questionnaire asked only the participants who had children with a past or present sleep problem about their experiences with assessment, diagnoses and treatment (N=40). Therefore, the data from the participants who had children without sleep problems (N=12) was not used in any of the subsequent analyses on the relationships between sleep symptoms and treatment. For children with a past or present sleep problem, the six main symptoms were, ‘trouble falling asleep’ (62.5%), ‘waking to engage in disruptive or self-stimulatory behavior (60.0%) ‘sleeps less than other children their age’ (30.0%), ‘gets less than 6 hours of sleep in a 24 hour period’ (20.0%), ‘sleeps in my room now’ (17.5%) and requires medication to sleep (17.5%). The frequencies of the most common main sleep symptoms for children with past or present sleep problems can be viewed in Table 2.
<table>
<thead>
<tr>
<th>Main Symptom</th>
<th>Frequency of Main Symptoms For Children With A Past or Present Sleep Problem (N=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trouble Falling Asleep</td>
<td>25 (62.5%)</td>
</tr>
<tr>
<td>Waking to Engage In Disruptive Or Self-Stimulatory Behavior</td>
<td>24 (60.0%)</td>
</tr>
<tr>
<td>Sleeps Less Than Other Children Their Age</td>
<td>12 (30.0%)</td>
</tr>
<tr>
<td>Less Than 6 Hours Sleep</td>
<td>8 (20.0%)</td>
</tr>
<tr>
<td>Sleeps In My Room</td>
<td>7 (17.5%)</td>
</tr>
<tr>
<td>Requires Medication To Sleep</td>
<td>7 (17.5%)</td>
</tr>
<tr>
<td>Grinds Teeth</td>
<td>6 (15.0%)</td>
</tr>
<tr>
<td>Wakes Screaming More Than 1 Min.</td>
<td>6 (15.0%)</td>
</tr>
<tr>
<td>Goes To Bed At Different Times</td>
<td>6 (15.0%)</td>
</tr>
<tr>
<td>Wets Bed</td>
<td>4 (10.0%)</td>
</tr>
<tr>
<td>Actively Plays Before Bed</td>
<td>4 (10.0%)</td>
</tr>
<tr>
<td>Needs A Blanket</td>
<td>3 (7.5%)</td>
</tr>
</tbody>
</table>
Types of Treatments Tried For Specific Symptoms

When the 40 parents of children with a current or past sleep problem were asked about all the different treatments they had attempted disregarding specific symptoms, parents reported; Bedtime Routine (70%), Extinction (60%), Graduated Extinction (42.5%), Melatonin (37.5%), and Bedtime Fading (35%). Treatments such as Relaxation (17.5%), Sleep Inducing Medications (12.4%), Benzodiazepines (7.5%), Bedtime Fading with Response-Cost (5%), Sleep Related Medications (2.5%), Scheduled Awakenings (0%), Barbiturates (0%) as well as various additional treatments grouped together as, 'Other' (30%), were not as commonly tried by parents.

To explore the relationship between each child’s particular main symptoms and the type of treatment chosen to treat those symptoms, a frequency table was developed and can be viewed in Table 3. If the parents reported that their child had the symptom, 'trouble falling asleep', most participants tried extinction (52.0%) and bedtime routine (76.0%). For the symptom, 'waking to engage in disruptive and self-stimulatory behavior', most parents reported trying extinction (62.5%) and bedtime routine (66.7%). If the child showed the symptom, 'sleeps less than other children their age', treatments such as, bedtime routine (66.7%), extinction (66.7%) and graduated extinction (66.7%) were all attempted most frequently.

3 Treatments coded as 'other' were; Risperdol (Antipsychotic medication); Nozinan (Neuroleptic medication); Change of Child's Sleep Environment; Secretin; Acupuncture; Dimetapp; Weighted Quilt; Asthma Inhaler; Decreasing Naps from 2 hours to 1 hour; Novo-Ridazine (Histamine Antagonist) Mellaril (Tranquilizer, Antipsychotic); Slept on the Couch with my Child; Nytol (Diphenhydramine Hydrochloride)
Table 3
Treatments Tried to Treat Each Main Symptom

<table>
<thead>
<tr>
<th>Main Symptom</th>
<th>Routine</th>
<th>Extinction</th>
<th>Graduated Extinction</th>
<th>Melatonin</th>
<th>Bedtime Fading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trouble Falling Asleep (N=25)</td>
<td>19</td>
<td>13</td>
<td>11</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>(76.0%)</td>
<td>(52.0%)</td>
<td>(44.0%)</td>
<td>(44.0%)</td>
<td>(36.0%)</td>
</tr>
<tr>
<td>Waking To Engage In Disruptive Or Self-Stimulatory Behavior (N=24)</td>
<td>16</td>
<td>15</td>
<td>5</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(66.7%)</td>
<td>(62.5%)</td>
<td>(20.8%)</td>
<td>(16.7%)</td>
<td>(4.2%)</td>
</tr>
<tr>
<td>Sleeps Less Than Other Children Their Age (N=12)</td>
<td>8</td>
<td>8</td>
<td>8</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>(66.7%)</td>
<td>(66.7%)</td>
<td>(66.7%)</td>
<td>(33.3%)</td>
<td>(58.3%)</td>
</tr>
<tr>
<td>Gets Less Than 6 Hours In A 24 Hour Period (N=8)</td>
<td>6</td>
<td>8</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>(75.0%)</td>
<td>(100.0%)</td>
<td>(50.0%)</td>
<td>(25.0%)</td>
<td>(37.5%)</td>
</tr>
<tr>
<td>Sleeps In My Room (N=7)</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(71.4%)</td>
<td>(14.3%)</td>
<td>(14.3%)</td>
<td>(57.1%)</td>
<td>(14.3%)</td>
</tr>
<tr>
<td>Requires Medicine To Sleep (N=7)</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>(85.7%)</td>
<td>(57.1%)</td>
<td>(57.1%)</td>
<td>(100.0%)</td>
<td>(42.9%)</td>
</tr>
</tbody>
</table>
If one of the child's main sleep problems were, 'gets less than 6 hours in a 24 hour period' participants attempted bedtime routine (75.0%) and extinction (100.0%), and if one of the main problems was, 'sleeps in my room now', parents were most likely to try bedtime routine (71.4%) and melatonin (57.1%). Finally, for the symptom, 'requires medicine to sleep', parents were most likely to attempt bedtime routine (85.7%) and melatonin (100.0%).

**Treatment Effectiveness For Sleep Symptoms**

To examine parent reported treatment effectiveness without yet looking at specific symptoms, the number of participants who reported trying each treatment and the treatment's effectiveness was calculated, disregarding the child's main symptoms. For each treatment, the number of participants who described each treatment as effective was calculated and can be seen in Table 4. In Table 4, both melatonin (66.7%) and bedtime routine (50.0%) were reported to be effective by a greater number of participants.

Although the parent may have described the treatment as generally effective, each treatment may have been effective for some of the child's main symptoms, but not for others. The parent reported effectiveness of each treatment for individual symptoms was then examined and can be seen in Table 5. Melatonin was reported to be effective by a greater number of participants in treating the symptom, 'has trouble falling asleep' (72.7%). Both Extinction (66.7%) and Melatonin (50.0 %) are reported to be effective in treating the symptom, 'wakes to engage in disruptive or self-stimulatory behavior'. To treat the symptom, 'sleeps less than other children their age', both melatonin (50%) and bedtime fading (42.9%) were reported to be effective by a greater number of participants.
In addition, melatonin (50.0%) and bedtime fading (66.7%) were reported to be effective by a greater number of participants in treating the symptom, ‘sleeps less than 6 hours in a 24 hour period’. The symptom, ‘sleeps in my room now’ did not improve despite most treatment attempts, though one parent had success with melatonin (25.0%) where the child was able to then sleep alone in their own bed. Melatonin (57.1%) was reported to be effective by a greater number of participants for treating the symptom, ‘requires medication to sleep’ where the child was able to sleep with melatonin only, without any other additional sleeping medications.

Table 4

<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Number Of Participants Who Tried The Treatment</th>
<th>Number Of Participants Who Reported The Treatment To Be Effective</th>
<th>Percentage Participants Who Reported The Treatment To Be Effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routine</td>
<td>28</td>
<td>14</td>
<td>50.0%</td>
</tr>
<tr>
<td>Extinction</td>
<td>23</td>
<td>10</td>
<td>43.5%</td>
</tr>
<tr>
<td>Graduated Extinction</td>
<td>17</td>
<td>4</td>
<td>23.5%</td>
</tr>
<tr>
<td>Melatonin</td>
<td>15</td>
<td>10</td>
<td>66.7%</td>
</tr>
<tr>
<td>Bedtime Fading (No Reponse-Cost)</td>
<td>13</td>
<td>5</td>
<td>38.5%</td>
</tr>
<tr>
<td>Main Symptom</td>
<td>Routine</td>
<td>Extinction</td>
<td>Graduated Extinction</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---------</td>
<td>------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Trouble Falling Asleep</td>
<td>31.6%</td>
<td>15.4%</td>
<td>9.0%</td>
</tr>
<tr>
<td></td>
<td>(6/19)</td>
<td>(2/13)</td>
<td>(1/11)</td>
</tr>
<tr>
<td>Waking To Engage In Disruptive And Self-Stimulatory Behavior</td>
<td>25.0%</td>
<td>66.7%</td>
<td>20.0%</td>
</tr>
<tr>
<td></td>
<td>(4/16)</td>
<td>(10/15)</td>
<td>(1/5)</td>
</tr>
<tr>
<td>Sleeps Less Than Other Children Their Age</td>
<td>25.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td></td>
<td>(2/8)</td>
<td>(0/8)</td>
<td>(0/8)</td>
</tr>
<tr>
<td>Gets Less Than 6 Hours Sleep In A 24 Hour Period</td>
<td>16.7%</td>
<td>25.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td></td>
<td>(1/6)</td>
<td>(2/8)</td>
<td>(0/4)</td>
</tr>
<tr>
<td>Sleeps In My Room</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td></td>
<td>(0/5)</td>
<td>(0/1)</td>
<td>(0/1)</td>
</tr>
<tr>
<td>Requires Medicine To Sleep</td>
<td>0.0%</td>
<td>25.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td></td>
<td>(0/6)</td>
<td>(1/4)</td>
<td>(0/4)</td>
</tr>
</tbody>
</table>

Note: Percentage (Treatment Effectiveness = Number of Participants Reporting Treatment Effectiveness For Specific Symptoms) / Number of Participants Reporting They Attempted Treatment For Symptom
Chapter 5

Discussion

The purpose of this study was to address three primary research questions. The first question investigated the types of specific sleep symptoms experienced by children with autism or PDD as reported by parents. The second research question investigated whether specific types of treatments were tried to treat particular sleep symptoms according to parent report. The third research question examined whether particular sleep symptoms were successfully treated by specific types of treatments according to parent report.

Specific Sleep Symptoms

According to parent report, the present investigation found that the six main symptoms for children with a past or present sleep problem were, 'trouble falling asleep' (62.5%), 'waking to engage in disruptive or self-stimulatory behavior (60.0%)' 'sleeps less than other children their age' (30.0%), 'gets less than 6 hours of sleep in a 24 hour period' (20.0%), 'sleeps in my room now' (17.5%) and requires medication to sleep (17.5%).

A difficulty in the assessment of sleep problems in children with autism or PDD has been the lack of an ideal assessment technique that can be used for children with limited or no language skills. The present study utilized a revised version of the Behavioral Evaluation of Sleep Disorders (Schreck, 1997) which can be used with non-verbal children to investigate individual symptoms. As Schreck (1997) derived the items for the BEDS from the International Classification of Sleep Disorders (1990), all possible childhood sleep symptoms were presumably included in the questionnaire at the beginning of the
present study. Yet, the present investigation has appeared to uncover another group of symptoms not described in the BEDS. These symptoms also do not appear to be included in the International Classification of Sleep Disorders (1990) or the International Classification of Sleep Disorders Revised (1997). The symptoms described as, 'waking to engage in disruptive or self-stimulatory behavior' appear to be qualitatively different from any of the symptoms previously described in the BEDS, as these behaviors do not appear to be merely for attention or avoidance of bedtimes or to be resulting from fear or anxiety. The night behaviors described by parents are similar to the self-stimulatory behaviors engaged in by their children with autism or PDD during the day such as singing, laughing, self-talking, jumping, hand flapping or clapping and wandering away from their rooms. Yet, even though parents reported that many children with autism or PDD were waking up in the night to engage in these disruptive behaviors, the behaviors couldn’t be scored on the BEDS, as they do not exist in the available items.

Many parents reported that they were frustrated with the available items in the BEDS in the present study, and were unwilling to re-classify their child’s symptoms under an available item. They were also unwilling to leave the section blank insinuating that their child had no main sleep symptoms. Instead, 18 participants wrote an intricate description of their child’s problems which were later classified under the heading, 'waking to engage in disruptive or self-stimulatory behavior'. Because the quality of this volunteered information seemed too valuable to discard, it was decided to include the symptoms in the present analysis. Yet, because all of the participants did not have an opportunity to choose these items as their main sleep symptoms, this category may be underreported.
This failure of an assessment technique to ask the right questions to parents to get an accurate picture of a child's sleep problems can be a very costly one to the child. If clinicians do not know what questions to ask parents with regards to specific sleep symptoms, they will be unable to prescribe compatible treatments that match the symptoms the child is experiencing. If parent report questionnaires must be the primary technique used in the assessment of sleep problems for children with autism or PDD, they must be redesigned to accurately represent the range of possible symptoms demonstrated by this population.

Although Stores and Wiggs (1998) describe findings that show good agreement rates between parental sleep diaries and video recordings of their child's sleep, some researchers argue that parents may not be the most reliable reporters of their children's sleep problems, especially if their children are autistic (Hering, Epstein, Elroy, Iancu & Zelnik, 1999). Hering, Epstein, Elroy, Iancu & Zelnik (1999) claim that data describing a child's sleep recorded by parent report vs. an actigraphy reading will show different results. These authors report that parent report questionnaires, "over-diagnose autistic patients with abnormal sleep patterns" (p. 146) perhaps due to a "a bias effect which makes the parents of the autistic children more sensitive to any abnormal event during the night"(p. 146), or because, "towards the late evening, parents of autistic children are more tired, thus they are less tolerant to deviation from quiet sleep"(Hering, Epstein, Elroy, Iancu & Zelnik, 1999, p. 147) Yet, methodological problems in this study raise considerable speculation about these conclusions. For example, only the older, more tolerant children with autism were used in the actigraphy recording portion of the study by Hering, Epstein, Elroy, Iancu and Zelnik (1999). By not including data from the younger,
less tolerant children in the sample in the actigraphy portion of the study, data from parent report questionnaires and the subsequent actigraphy recordings cannot be fairly compared. Since children with autism are often uncooperative in testing situations where recording devises are intrusive or touch their skin, live or videotaped behavioral observations by a clinician may be the ideal assessment tool to competently assess the unique and individualized symptoms shown by children with autism or PDD. A future investigation that examines the unique sleep symptoms of children with autism and PDD is needed.

Minde, Popiel, Leos, Falkner, Parker & Handley-Derry (1993) conducted a study to assess parent’s accuracy of reporting their children’s sleep behavior and their children’s response to a behavioral sleep intervention. They compared parent reports of the children’s sleep behavior with data gathered from an infrared camera positioned in the child’s room all night. They found that while parents of good sleepers were not reliable recorders of their child’s sleep patterns, parents of poor sleepers were very good recorders of their child’s sleep behavior (Minde, Popiel, Leos, Falkner, Parker & Handley-Derry, 1993). These authors found that while the patterns of good and poor sleepers were nearly identical, “the differences arose from the ability of good sleepers to soothe themselves and to go back to sleep without waking anyone in the family” (Minde, Popiel, Leos, Falkner, Parker & Handley-Derry, 1993, p.532). While children with autism may not wake more often than their typically developing peers, the peers are rolling over and going back to sleep without alerting their parents, while children with autism may not have learned this skill. Once awakened, children with autism who have sleep problems may not know how to go back to sleep, and consequently may begin to engage in self-stimulatory or disruptive behaviors which signal parents that the child is awake. This is also a possibility
acknowledged by Hering, Epstein, Elroy, Iancu and Zelnik (1999) as they hypothesize that, "the hyperactive and restless atypical behavior of these children (with autism) may disturb the parents or other persons living with them even if their night wakings are not longer or more numerous than those of normal children, who do not disturb the family even when they are awake at night (p. 146).

Treatments Tried For Specific Symptoms

When asked about the types of treatments that attempted to treat specific sleep problems, parents reported that for the symptoms, 'trouble falling asleep' and 'waking to engage in disruptive of self-stimulatory behavior', they had most frequently tried bedtime routine and extinction. For the symptom, 'sleeps less than other children their age', parents had most frequently tried bedtime routine, extinction and graduated extinction. For the symptom, 'gets less than 6 hours sleep in a 24 hour period, parents report most frequently trying bedtime routine and extinction while for both, 'sleeps in my room now', and 'requires medicine to sleep', parents report trying bedtime routine and melatonin most often. Extinction, graduated extinction, and bedtime routine may have been tried most frequently because these procedures are easy to understand, relatively uncomplicated to administer, and are well known enough to have been suggested by friends, family members or many different professionals. Treatments such as bedtime fading, bedtime fading with response-cost and scheduled awakening may be less common because they may be less well known by the general public, are more complicated to understand and to administer, and require considerable parent or clinician attention throughout the night to implement properly. Using sleep medications such as benzodiazepines, barbiturates, sleep-inducing medications and sleep-related medications may also have been less popular with parents of
children with autism or PDD as parents of neurologically impaired children may be less comfortable administering medication to their children without fully understanding the potential side-effects. Finally, relaxation may be less popular than other treatments for children with language difficulties because many relaxation techniques require the child to use techniques such as visualization that often require complex language. Melatonin may not have been tried by a large number of families because the research on this treatment is relatively new to both parents and professionals.

Treatment Effectiveness

Of the 40 participants who had children with a past or present sleep disorder, many participants reported attempting multiple treatments. For example, 66.7% of participants found melatonin to be an effective treatment, 50.0% had tried bedtime routine and found it effective, 43.5% found extinction effective, 38.5% found bedtime fading effective and 23.5% found graduated extinction effective. Yet, this information on treatment effectiveness is not very helpful in predicting future treatment effectiveness for other children because each participant had a child with a different combination of sleep symptoms.

When treatment effectiveness was examined for specific sleep symptoms, melatonin was frequently reported to be effective for all of the six main symptoms. Extinction was also reported to be effective for the symptom, 'waking to engage in disruptive and self-stimulatory behavior', and bedtime fading was frequently reported to be effective for both the symptom, 'sleeps less than other children their age', and for, 'gets less than 6 hours sleep in a 24 hour period'. While melatonin was frequently reported to
be effective for all of the 6 main sleep symptoms, it must be noted that the number of participants who tried melatonin for each of the sleep symptoms was not very high.

**Treatment Acceptability and Parent Compliance.** A factor that may have affected treatment effectiveness is whether the parent administered the treatment correctly, and for an adequate amount of time. When the patients are children with sleep problems, it usually becomes the job of the child’s parents or caregivers to insure that the treatment plan is being followed consistently and correctly. Researchers have studied both parents that stick with treatments, as well as those who drop out, and have discovered that treatment compliance may be affected by the parent’s feeling of the treatment’s ‘acceptability’ (Reimers & Lee, 1991).

Treatment acceptability has been defined as, “judgments by lay persons, clients, and others of whether treatment procedures are appropriate, fair and reasonable for the problem or client” (Kazdin, 1981). When many equally effective treatments are available, “acceptability for prospective parents may be an important consideration for seeking, initiating, and adhering to treatment” (Rosenburg & Raynes, 1976). For example, parents of children with autism may find pharmaceutical treatments for sleep problems less acceptable as they may worry about effects of medication on their child’s behavior.

The time needed to successfully implement a behavioral intervention affects the treatment’s acceptability. No matter how potentially effective a treatment may be, it needs to be manageable for those implementing the procedure. Researchers that looked at the home environment found that “treatments rated as time consuming or which disrupted the family routine had a negative impact on compliance” (Reimers, Wacker, Cooper and DeRaad, 1992). As parents often have more than one child at home as well as many other
responsibilities, an acceptable sleep treatment must fit in with the lifestyle if it is going to be effective.

If a particular treatment has side-effects that are seen as unacceptable or avoidable, the treatment will be rated as less acceptable. Side effects refers to “ancillary or unintended effects of the procedure that usually affect areas other than those focused on in treatment” (Kazdin, 1981) and can occur in both medical or behavioral treatments. A medical side effect may include headaches, nausea or drowsiness while a behavioral side effect might be aggression, tantrums or escape. Kazdin found that “undesirable side effects associated with treatment, whether reinforcement, punishment or medication, consistently influenced acceptability ratings and stronger side effects were associated with decreased acceptability ratings” (Kazdin, 1981). Side effects of behavioral treatments for sleep disorders may be very important to treatment acceptability as some treatments require the child to be able to cry and scream for many nights before the situation improves which may not be possible for families who are unable to disrupt their close neighbors.

Treatment acceptability is also influenced by the type of treatment approach that is used. For example, parents, children, and staff similarly report that the various interventions for behavioral problems differ in terms of their acceptability. When treatments such as reinforcement, positive practice, time out and medication were compared by Kazdin, French & Sherick’s (1981), parents, children, and staff agreed that reinforcement was the most acceptable treatment, followed by positive practice, medication, and time out.
The severity of the behavior problem that the child is exhibiting is also a variable that affects treatment acceptability. For example, in the study by Frentz and Kelley, “parents rated all treatments significantly higher (more acceptable) when applied to a more severe behavior problem” (Frentz & Kelley, 1986). Furthermore, Kazdin also found that treatments are seen as more acceptable when they are applied to more severe behavior problems than when they are applied to less severe problems, and he also found that more positive treatments were rated as more acceptable (Kazdin, 1984). Parents who are experiencing extensive sleep deprivation may be more likely to try less acceptable treatments if they feel the problem is severe.

Another factor that affects treatment acceptability is the parent’s willingness to implement the treatment. ‘Willingness’ is whether or not the parents are committed to following through with the treatment protocol if it is deemed to be feasible and reasonably compatible with their normal routines. For example, in one study the researchers found that “the families willingness to implement the treatment appeared to have the largest bearing on whether or not the treatment was implemented” (Reimers, Wacker, Cooper & DeRaad, 1992). Since most professionals only act as consultants for treating the sleep problems of children with autism while the parents actually implement the procedures, “treatment efficacy is often dependent on the therapist obtaining cooperation from parents or other adult caregivers” (Witt, Martens & Elliott, 1984). Compliance may be related to the amount of support from others the parent has to help treat the child’s sleep problem.

The final variable that appears to be important in assessing treatment acceptability is treatment effectiveness. Reimers and Wacker (1988) hypothesized that assessing acceptability before implementing a procedure excluded how the attitudes of parents and
teachers changed after they had actually experienced implementing the procedure and had seen if the intervention had worked. They found that, "parental ratings of the effectiveness of the treatment had the largest influence on acceptability" (Reimer & Wacker, 1988). Kazdin also initially hypothesized that "acceptability of a particular treatment may depend on the direct effects of treatment on client performance. Treatments that might otherwise be relatively unacceptable may be evaluated favorably if they are associated with marked therapeutic changes. Alternatively, generally acceptable procedures may be evaluated less favorably if they produce poor outcomes, i.e. do not work" (Kazdin, 1981). Reimer and Wacker emphasize that, "the significant correlations between acceptability and effectiveness may be especially important because it demonstrates the importance of assessing acceptability after the treatment has been implemented. The strong positive correlation between effectiveness and acceptability was present only at one month (not initially), which suggests that a treatment’s effectiveness is highly related to acceptability over time" (Reimer & Wacker, 1988). A parent who implements a less acceptable treatment may describe the treatment as more acceptable after it is over, if the treatment was effective in treating the problem.

Future Research

Nearly seventy seven percent (76.9%) of the participants in this study reported that their child had experienced a past or present sleep problem. While 76.9% is a higher prevalence rate than the 65% found by Hoshino, Watanabe, Yashima, Kaneko & Kumashiro (1984) and the rate of 65.1% found by Taira, Takase & Sasaki (1998) it is important to note that the participants in the present study were volunteers from many
different sources. Parents may have been more likely to volunteer for a study on sleep if their child had actually experienced a sleep problem. Future research is needed in this area using a random sample of children with autism or PDD that does not rely on self-selected parent volunteers. By using an unbiased sampling method, the risk of over-sampling children with sleep problems will be decreased. In addition, future prevalence reports on past or present sleep problems in children with autism or PDD could sample professionals who diagnose and treat sleep problems such as pediatricians, behavioral consultants and family doctors instead of relying primarily on parent report.

As the present study appeared to uncover unique sleep symptoms that closely resemble the self-stimulatory behaviors often engaged in by children with autism and PDD during the day, this finding uncovers a research area that requires more in-depth investigation. DeMyer (1979) similarly reported that typically developing children often woke up for a reason that could be quickly remedied such as to use the bathroom or to get a drink, but the children with autism often woke up to engage in loud, inconsolable and problematic behaviors such as crying, screaming, hysterical laughter, roaming around the house, or violent rocking which often lasted for hours.

In Schreck's study on sleep in children with autism and PDD (1997), she observed the children's behavior in the day and found associations between daytime stereotypies and social and sleep problems. While she did not investigate the children's stereotypies during the night, it would be interesting to conduct another study to see if the child's self-stimulatory behaviors in the day are similar to the behaviors they are demonstrating in the night. If they are similar, and the family has a successful procedure for decreasing the rate
of the behavior during the day, perhaps the same procedure implemented at night would show a similar decrease in the rate of the self-stimulatory and disruptive behaviors.

While many children without sleep problems wake numerous times in the night, they generally turn over and fall back to sleep within seconds. Perhaps children with autism or PDD who have sleep problems are not waking up more often than other children, rather, they are simply not going back to sleep once they have woken. As going to sleep is a learned behavior taught to small children by parents using techniques such as rocking, bedtime routines, bedtime rules, the use of pacifiers, blankets and even punishment for getting out of bed to play or to seek parental attention, perhaps children with autism or PDD may not have learned this skill. Perhaps they do not recognize the feeling of being ‘tired’, they do not recognize all the cues of nighttime around them, and once they have woken up during the night, they are simply entertaining themselves because there is nothing else to do and they do not know how to fall back asleep.

Jan, Freeman & Fast (1999) wrote that, “for falling asleep, the brain requires a decrease or cessation of vigilance and of environmental stimuli such as noise, strong light, or movements. The process is also influenced by variations in temperature, by cerebral functions such as established habits, knowledge of clock time, and by numerous behavioral, social, and nutritional cues” (p.493). Yet, if a child is engaging in self-stimulatory behaviors, if they have limited understanding of clock time and external stimuli that trigger sleep such as light and dark and they have no established habits regarding sleep, all of these factors may impede healthy sleep patterns. In addition, Jan, Freeman & Fast (1999) claim that, “neurological, neurodevelopmental, and neuropsychiatric disabilities predispose children to sleep-wake rhythm disturbances. Disorders such as . . .
autism diminish the ability of these individuals to perceive and interpret a multitude of cues for synchronizing their sleep within the environment” (p.494). Therefore, since children with autism may not be observing the external cues that trigger sleep, they may also not be learning to anticipate and expect sleep in response to these triggers. This is a hypothesis that could be further explored in the future.

When individuals do not recognize the external stimuli that signifies night and sleep, the secretion of melatonin from their pineal gland also may not be stimulated. When oral melatonin is given to children with autism just before bed, perhaps this supplement helps to replace the melatonin that is not being secreted from the pineal gland and consequently helps to regulate the child’s sleep-wake cycle with the environment. Since melatonin appears to help regulate the child’s sleep-wake cycle, behavioral treatments such as creating a strict bedtime routine and wake-up time may also be integral to its success.

Although melatonin was frequently reported to be effective for the most typical sleep symptoms experienced by children with autism or PDD as reported by parents in this study, results must be considered with caution. There were only 15 participants in this study who had tried melatonin. Although 10 participants found melatonin to be an effective treatment for their child’s sleep problem, there is still a great deal of information that remains unknown. There is still a lack of data on the long-term safety of melatonin, on the side effects of prolonged usage, and the ideal dosages for different individuals (Arendt, 1997; Lord, 1998). In addition, in research with animals, possible side effects have been reported such as, “inhibition of reproductive function and the delayed timing of puberty . . . and its interactions with other medications are virtually unexplored” (Arendt, 1997).
Melatonin is not sold in Canada at this time and is typically purchased by parents from the United States. Because it is sold as a natural health product, the purity of the preparation is unknown (Nickel, 1996). Since melatonin has not been approved for sale in Canada, parents often decide to administer it to their child on their own, without physician assistance on the amount and timing of dosages. Medical research and clinical trials on the treatment of sleep problems with melatonin for children with autism and PDD is needed. If found effective through clinical trials, professional advise and supervision is needed from physicians to prescribe and monitor this treatment to ensure that the treatment is the best match for the child’s specific symptoms. Parents need to be educated on how to properly administer melatonin using the correct amount, and at the correct time of day, for each individual child.

Conclusion

This study attempted to describe the types of sleep symptoms that children with autism or PDD were experiencing. Not only did the results show that some symptoms are experienced more frequently than others out of the 107 possible symptoms listed in the Behavioral Evaluation of Sleep (BEDS), this study revealed that these children are also experiencing symptoms that can not be coded in any of the available sleep manuals. The symptoms described as, ‘waking to engage in disruptive or self-stimulatory behavior’ are not found in the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV; American Psychiatric Association, 1994), under sleep disorders, nor are the symptoms described in the International Classification of Sleep Disorders Revised (ICSD-R; American Sleep Disorders Association, 1997). If the symptoms cannot even be coded using the available diagnostic and classification systems for sleep disorders, professionals
do not have a high probability of identifying and treating the symptoms in individual children.

This investigation also looked at whether specific treatments are chosen to treat particular sleep symptoms. While there appear to be a few patterns linking symptoms and treatments tried, most parents have tried so many of the possible treatments that it is difficult to tell if treatments are attempted to match individual sleep symptoms or whether treatments are tried simply because they are easy to implement and appear to be the most acceptable to the parent.

A third goal was to describe through parent report, whether particular sleep symptoms were more successfully treated by specific types of treatments. Patterns of results suggested that that the match between the specific sleep symptoms exhibited by the child, and the type of treatment employed to treat the symptoms may be related to treatment effectiveness. Further research is needed to explore and define the relationships between specific symptoms and their idealistic treatment types.

There were many limitations of this study that must be considered in interpreting the results. Most importantly, this study describes parental reports of effectiveness only and does not represent results from clinical trials in controlled settings. In addition, this study did not investigate the length or combinations of treatments. For example, a treatment such as melatonin may only be effective if is administered in combination with a strict bedtime routine and if the parent does not attend to the child's behavior after bedtime (extinction). These conclusions are unclear at this time. It is also unclear whether the effectiveness of some treatments may last longer than others. For example, families that have found success with a particular treatment at one point in time may find that it
decreases in effectiveness over time as the child gets older or as the environment or family dynamics change. Additional limitations pertain to the sample in this study. As many participants were from F.E.A.T. B.C. which is a group that strongly supports behavioral treatments, these parents may be more supportive of behavioral treatments for sleep problems than parents from another sample. In addition, the questionnaire required proficiency with the English language, so non-respondents may have been families who have English as a second language. Finally, this study did not analyze the data on the children without sleep disorders so the results are specific to the sample used, and do not represent results from a prevalence investigation.

This research contributed to the sleep literature as only children with autism or PDD were included which helped to isolate sleep symptoms specific to this population. Additionally, this investigation looked at a defined age group of children. A future study might examine patterns for more defined age groups to determine if there are any developmental differences in symptoms described or in treatment effectiveness. This study also attempted to operationalize sleep symptoms of children with autism or PDD looked at assigning treatments based on specific symptoms, and not on the child's diagnosis of autism. This investigation identified an area of research that has been largely unexplored, but that may have the ability to affect the quality of life for children with autism or PDD and their families.
References


Appendix A

Glossary of Terms
Glossary of Terms

**Autism:** Also referred to as Autistic Disorder in the DSM-IV Diagnostic and Statistical Manual of Mental Disorders (American Psychological Association, 1994). To receive a diagnosis of Autistic Disorder according to the DSM-IV, a child must meet 6 out of a possible 12 criteria in areas of social development, communication, and activities and interests (American Psychological Association, 1994). Specifically, they must meet 2 criteria in social development, 2 in communication and at least 2 in atypical activities and interests (Siegel, 1996).

**Bedtime Fading:** Keeping the child up so late that they fall asleep on their own, and then fading the bedtime back in small increments until the bedtime at which you want your child to fall asleep at is achieved (Durand, 1998).

**Bedtime Routine:** A consistent and calming series of activities that parent and child engage in before bedtime to help the child relax and wind down. The routine will help the child associate these activities with bedtime and will assist the child’s transition to sleep (Durand, 1998).

**Chronotherapy:** Systematically delaying the child’s bedtime each night while maintaining a regular schedule during waking hours until an age appropriate bedtime is observed (Piazza, Hagopian, Hughes & Fisher, 1998, p. 358).

**Congenital Omphalocele:** A protrusion at birth of part of the intestine through a defect in the abdominal wall (Miller & Brackman, 1978).

**Delayed Bedtime with Response-Cost Component:** Keeping the child up so late that they fall asleep on their own, and then fading the bedtime back in small increments until the bedtime at which you want your child to fall asleep at is achieved (Durand, 1998). If the child does not asleep within a designated time interval after being put in their bed, the child is removed from their bed, redirected to another task, and not permitted to return to their bed until a longer time interval has elapsed. This pattern is repeated until the child falls asleep within a specified time interval after being put in their bed (Piazza & Fisher, 1991).

**Dyssomnias:** A category of sleep disorders that involve problems initiating or maintaining sleep (American Sleep Disorders Association, 1990).

**Electrocardiograph (ECG):** Are used to monitor the child’s cardiac rate and rhythm during sleep.
**Electroencephalograph (EEG):** is used to monitor the activity of the central nervous system during sleep, and can also provide information that differentiates the non-rapid eye movement (NREM) portions of sleep into specific sleep stages (Sheldon, Spire & Levy, 1992). The EEG requires that electrodes are attached to the scalp of the child for the entire duration of the recording period to record the changes in the electrical potentials of cortical neurons (Sheldon, Spire & Levy, 1992).

**Electromyography (EMG):** used to monitor the child’s muscle tone during sleep, and usually involves attaching electrodes to the skin on the child’s chin (Sheldon, Spire & Levy, 1992). The information from this device can be helpful in assessing atypical muscle activity and identifying sleep disorders such as bruxism and REM sleep behavior disorder (Sheldon, Spire & Levy, 1992). Leg movements are measured using leg muscle EMGs (Sheldon, Spire & Levy, 1992).

**Electrooculography (EOG):** records eye movements during sleep and identifies when the child is in sleep stages associated with slow eye movement, and when they have moved into the rapid eye movement stage (Sheldon, Spire & Levy, 1992). The EOG recording involves attaching electrodes to the skin surface on the outer canthi of the eyes, and records the electrical potential difference between the cornea and the retina of the eye (Sheldon, Spire & Levy, 1992).

**Extinction:** Spending increasingly longer amounts of time ignoring the cries and protestations of a child at bedtime (Durand, 1998).

**Graduated Extinction:** Responding to bedtime resistance by letting the child ‘cry it out’ and having no parental response to the disruptive behavior (Durand, 1998).

**Parasomnia:** A category of sleep disorders that involve dysfunctions with sleep stages and partial arousals (American Sleep Disorders Association, 1990).

**Pervasive Developmental Disorder:** Also called Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS) in the DSM-IV Diagnostic and Statistical Manual of Mental Disorders (American Psychological Association, 1994). According to the DSM-IV, a diagnosis of PDD-NOS is given when a child meets fewer than 6 of the 12 criteria necessary for a diagnosis of Autistic Disorder (American Psychological Association, 1994). PDD, NOS is a diagnosis that is given when a child has a less severe form of the behavior described in the criteria for Autistic Disorder or when the child may have problems with communication and social development, but not difficulties with atypical interests and activities (Siegel, 1996).

**R-index:** A measure of quantifying oculomotor activity during REM sleep. It is the ratio of intervals of eye movement (Elia, Ferri, Musumeci & Bergonzi, 1991).
Relaxation Techniques: Teaching the child how to tense and relax their muscles through awareness of their body. Teaching the child how to relax at bedtime and how and when to begin the relaxation exercises (Durand, 1998).

Scheduled Awakenings: Waking the child some time prior to a typical night waking, and then letting them fall back to sleep.

Sleep spindles: bursts of EEG activity that last for 0.5-1.5 seconds in stage 2 NREM sleep. Sleep spindles may occur many times per minute (Whyte & Schaefer, 1995).
Appendix B

Sleep Questionnaire

Part A - Demographic Information and Sleep History

Part B - Behavioral Evaluation Of Sleep (BEDS)

Part C - Treatment Information
PART A  

Child History

Please answer the following background questions about your child with Autism or Pervasive Developmental Disorder:

1) Age: ____________ years ____________ months

2) Gender:
   a) Male
   b) Female

3) What is your child’s diagnosis?
   a) Autistic Disorder (autism)
   b) Pervasive Developmental Disorder Not Otherwise Specified (PDD, NOS)
   c) Other ______________________________

4) Please list any other diagnoses your child may have other than their diagnosis of autism or PDD ________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

5) Please list any current medications taken by your child for any reason ________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________
   ___________________________________________________________________

6) On average, how many hours does your child sleep during a typical night?
   a) 0-2 hours per night
   b) 3-4 hours per night
   c) 5-6 hours per night
   d) 7-8 hours per night
   e) 9-10 hours per night
   f) More than 10 hours per night
7) On average, how many hours would you ideally like your child to sleep during a typical night?
   a) 0-2 hours per night
   b) 3-4 hours per night
   c) 5-6 hours per night
   d) 7-8 hours per night
   e) 9-10 hours per night
   f) More than 10 hours per night

8) On average, what is your child’s typical bedtime? (time they are PUT IN bed)
   a) Between 6 and 7 o’clock at night
   b) Between 7 and 8 o’clock at night
   c) Between 8 and 9 o’clock at night
   d) Between 9 and 10 o’clock at night
   e) Between 10 and 11 o’clock at night
   f) After 11 o’clock at night
   g) My child does not have a steady bedtime

9) On average, what time does your child wake up in the morning?
   a) Before 4 o’clock in the morning
   b) Between 4 and 6 o’clock in the morning
   c) Between 6 and 8 o’clock in the morning
   d) Between 8 and 10 o’clock in the morning
   e) After 10 o’clock in the morning
   f) My child does not have a steady wake-up time

10) Who is filling out this survey?
    a) Mother
    b) Father
    c) Stepmother
    d) Stepfather
    e) Foster parent
    f) Grandmother
    g) Grandfather
    h) Legal guardian
    i) Other

11) Who typically responds to the child during the night?
    a) Mother
    b) Father
    c) Stepmother
    d) Stepfather
    e) Foster parent
    f) Grandmother
    g) Grandfather
    h) Legal guardian
    i) Other
Behavioral Evaluation of Sleep (BEDS)

Please answer the following questions about your child’s past or present sleep habits. If your child has previously experienced a sleep problem but is currently being successfully treated for those symptoms, please answer the following questions about their past sleep behavior (when they were experiencing the sleep problems).

(0) Never (1) Rarely (2) Sometimes (3) Frequently • (4) Always
If statement does not apply answer (0).

1. wakes up screaming during the night for more than 1 minute
2. is sluggish when awakened
3. sleeps more than other children his/her age
4. is disoriented when awakened
5. has trouble falling asleep
6. has a sudden leg jerk when falling asleep
7. plays with toys in bedroom at bed time
8. has headaches
9. can’t move body when waking up or going to sleep
10. doesn’t remember crying or screaming during the night
11. gets less than 6 hours sleep in a 24 hour period
12. complains that bed is uncomfortable
13. plays video games less than 1 hour before going to bed
14. sleeps in my room now
15. watches horror and/or action movies/TV show before bed
16. wakes up screaming during the night and cannot be calmed down
17. engages in violent behaviors while asleep (hits, kicks, punches, tackles)
18. takes frequent naps during the day
19. stops breathing during sleep
20. needs me to read before falling asleep
21. takes a day to “catch-up” on sleep
22. needs something to eat before falling asleep
23. can not be awakened when sleep walking
24. needs a night light to fail asleep
25. sleeps better in a place other than own bed
26. talks in sleep without knowing it
27. complains of jaw pain
28. requires medicine to help sleep
29. has no problem sleeping, when it is quiet outside
30. will stay in bed unless I get him/her up
31. has frequent skin rashes
32. is sleepy during the day
33. sleeps longer or shorter on weekends than weekdays
34. complains that room is not dark enough to sleep
(0) Never (1) Rarely (2) Sometimes (3) Frequently (4) Always
If statement does not apply answer (0).

0 1 2 3 4 35. wakes up screaming and sweating during the night
0 1 2 3 4 36. needs a pacifier to fall asleep
0 1 2 3 4 37. walks in sleep
0 1 2 3 4 38. goes to bed at different times
0 1 2 3 4 39. has nightmares.
0 1 2 3 4 40. acts out dreams
0 1 2 3 4 41. screams during the 2nd half of the night
0 1 2 3 4 42. wakes up crying at night
0 1 2 3 4 43. watches TV in bedroom
0 1 2 3 4 44. wakes up screaming approximately two hours after going to sleep
0 1 2 3 4 45. drinks soda/caffeine before bed
0 1 2 3 4 46. rocks body in sleep
0 1 2 3 4 47. has problems/been upset since a new adult moved into the home
0 1 2 3 4 48. sleep walks about 2 hours after going to sleep
0 1 2 3 4 49. does homework less than 1 hour before going to bed or in bed
0 1 2 3 4 50. has problems/been upset since a divorce or separation in the family
0 1 2 3 4 51. eats 1 hour before going to sleep
0 1 2 3 4 52. sees flashes of light when first going to sleep
0 1 2 3 4 53. does not remember walking in sleep
0 1 2 3 4 54. slept in my room as an infant
0 1 2 3 4 55. is afraid of falling, at bedtime
0 1 2 3 4 56. bangs head in sleep
0 1 2 3 4 57. stalls at bedtime
0 1 2 3 4 58. exercises before bed
0 1 2 3 4 59. looks at books or reads in bed
0 1 2 3 4 60. seems depressed
0 1 2 3 4 61. complains that room is uncomfortable
0 1 2 3 4 62. has problems/been upset since moving to a new home or school
0 1 2 3 4 63. wakes up during violent behaviors
0 1 2 3 4 64. throws temper tantrums at bedtime
0 1 2 3 4 65. has problems/been upset since the death of a family member, friend, or pet
0 1 2 3 4 66. frequently has an upset stomach
0 1 2 3 4 67. rocks head in sleep
0 1 2 3 4 68. wets bed
0 1 2 3 4 69. is not awake when screaming at night
0 1 2 3 4 70. sleeps worse after eating certain foods/beverages
0 1 2 3 4 71. is irritable
0 1 2 3 4 72. reacts slowly when awakened
(0) Never (1) Rarely (2) Sometimes (3) Frequently (4) Always
If statement does not apply answer (0).

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>73.</td>
<td>will sleep for 6 hours or longer at a time</td>
</tr>
<tr>
<td>74.</td>
<td>cries easily</td>
</tr>
<tr>
<td>75.</td>
<td>needs something to drink before falling asleep</td>
</tr>
<tr>
<td>76.</td>
<td>is awakened by loud noises (trains, traffic, etc.)</td>
</tr>
<tr>
<td>77.</td>
<td>speaks slowly when awakened</td>
</tr>
<tr>
<td>78.</td>
<td>chooses own bedtime</td>
</tr>
<tr>
<td>79.</td>
<td>is under emotional stress</td>
</tr>
<tr>
<td>80.</td>
<td>is sad</td>
</tr>
<tr>
<td>81.</td>
<td>complains of aches, pains, or sore eyes</td>
</tr>
<tr>
<td>82.</td>
<td>has difficulty breathing during sleep</td>
</tr>
<tr>
<td>83.</td>
<td>wakes up screaming in the 2nd half of the night</td>
</tr>
<tr>
<td>84.</td>
<td>is afraid of noises in the night</td>
</tr>
<tr>
<td>85.</td>
<td>actively plays before bed</td>
</tr>
<tr>
<td>86.</td>
<td>sleeps in inappropriate places</td>
</tr>
<tr>
<td>87.</td>
<td>grinds teeth at night</td>
</tr>
<tr>
<td>88.</td>
<td>takes medicine during the day that makes him/her sleep worse</td>
</tr>
<tr>
<td>89.</td>
<td>wakes up during the night to eat</td>
</tr>
<tr>
<td>90.</td>
<td>needs to rock to sleep</td>
</tr>
<tr>
<td>91.</td>
<td>seems anxious or scared</td>
</tr>
<tr>
<td>92.</td>
<td>needs a toy, stuffed animal or doll to go to sleep</td>
</tr>
<tr>
<td>93.</td>
<td>needs a blanket to fall asleep</td>
</tr>
<tr>
<td>94.</td>
<td>sleeps poorly without medicine at night</td>
</tr>
<tr>
<td>95.</td>
<td>is afraid to fall asleep</td>
</tr>
<tr>
<td>96.</td>
<td>takes naps without being told</td>
</tr>
<tr>
<td>97.</td>
<td>snores</td>
</tr>
<tr>
<td>98.</td>
<td>eats in bed</td>
</tr>
<tr>
<td>99.</td>
<td>has a new sibling</td>
</tr>
<tr>
<td>100.</td>
<td>sleeps less than other children his/her age</td>
</tr>
<tr>
<td>101.</td>
<td>drinks more than 1 glass of water awakening</td>
</tr>
<tr>
<td>102.</td>
<td>teeth are smooth</td>
</tr>
<tr>
<td>103.</td>
<td>falls asleep before being put to bed</td>
</tr>
<tr>
<td>104.</td>
<td>rubs eyes</td>
</tr>
<tr>
<td>105.</td>
<td>becomes pale or blue during sleep</td>
</tr>
<tr>
<td>106.</td>
<td>is limp or stiff during sleep</td>
</tr>
<tr>
<td>107.</td>
<td>sleeps on a mattress that is less than 3 inches thick</td>
</tr>
</tbody>
</table>

To identify your child's 'MAIN FIVE SYMPTOMS' please refer to the above 107 items you have just completed. Please choose FIVE of the most difficult sleep symptoms your child has experienced. An item marked as (4) always, or (3) frequently, would qualify as the most difficult for your child. If your child experiences more than five symptoms that qualify as problematic (marked as a 3 or a 4), please choose the five most problematic for your child and family. (you may write out the item description, or simply list the item numbers in the five blanks below)

Please list your child's MAIN FIVE SYMPTOMS:

1) ______________________  4) ______________________

2) ______________________  5) ______________________

3) ______________________
Treatment Questionnaire

PART C
For the following questions please circle ONE of the possible responses.

1) Do you feel that your child has ever suffered from a previous or current sleep disorder?

a) NO
   ⇒ My child has NEVER experienced a sleep problem. (If your child has NEVER experienced a sleep problem, please skip to page 13)

b) YES
   ⇒ This is a CURRENT problem for my child (please continue with the next question on page 7)

c) YES-
   ⇒ My child does not have a current sleep problem, but he/she has experienced a PREVIOUS sleep problem in the past. (please continue with the next question on page 7)
PART D

TREATMENT: BOTH PAST AND PRESENT SLEEP PROBLEMS

Please Answer the Following Questions About Your Child’s PAST or PRESENT Sleep Problems. For the following questions please circle ONE of the possible responses.

2) When did your child’s sleep problem(s) first develop?
   a) Before 2 years of age
   b) 2-3 years old
   c) 4-5 years old
   d) 6-7 years old
   e) 8-9 years old
   f) 10-11 years old

3) Compared to other difficulties your child may have had at the time, how problematic was the sleep disorder for your child?
   a) Not a problem
   b) Slightly problematic
   c) Problematic
   d) Very problematic

4) Compared to other difficulties your child had, how problematic was the sleep disorder for the family?
   a) Not a problem
   b) Slightly problematic
   c) Problematic
   d) Very problematic

5) Have your child’s sleep problems been successfully treated by a specific treatment protocol?
   a) No-my child has simply ‘grown out’ of the sleep problems
   b) No-my child’s sleep problems are not improving
   c) Yes-my child’s sleep problems have improved because of a particular treatment

6) Which of the following professionals did you see about your child’s sleep disorder?
   a) Family doctor
   b) Pediatrician
   c) Clinical Psychologist
   d) Psychiatrist
   e) Behavioral consultant
   f) Other _____________________
   g) None of the above
7) How did the professional who treated your child's sleep disorder assess your child's specific symptoms and behaviors? Please circle all that apply.

   a) Parent interview
   b) Parent report questionnaire
   c) Parent report sleep diary (completed by the parent)
   d) Child completed questionnaire
   e) Child interview
   f) Behavioral observation in a clinic (child observed all night in a sleep lab setting)
   g) Behavioral observation at home. (Video taping your child sleep in the home)
   h) Behavioral observation at home. (Clinician watching your child sleep in the home)
   i) Electroencephalograph (EEG) - electrical potential of cortical neurons
   j) Electrocardiograph (ECG) - heart rate during sleep
   k) Measurement of Respiratory Activity
   l) Electrooculography (EOG) - ocular movement
   m) Electromyography (EMG) - jaw and limb movement during sleep
   n) NONE OF THE ABOVE

8) Did your child receive a specific sleep diagnosis by a professional? YES NO

9) If your child did have a specifically diagnosed sleep disorder by a professional, please circle all of the following clinical diagnoses that your child received.

   a) Inadequate Sleep Hygiene sleep disorder
   b) Nocturnal eating and drinking sleep disorder
   c) Limit-setting sleep disorder
   d) Insufficient sleep disorder
   e) Environmental sleep disorder
   f) Sleep-Onset Association Disorder
   g) Adjustment sleep disorder
   h) Food-allergy insomnia
   i) Hypnotic-dependent sleep disorder
   j) Stimulant-dependent sleep disorder
   k) Confusional arousals
   l) Narcolepsy
   m) Night (sleep) terrors
   n) Nightmares
   o) Somnambulism (sleep walking)
   p) Soliloquy (sleep talking)
   q) Sleep Enuresis (wetting the bed)
   r) Sleep apnea
   s) Primary Snoring
   t) Bruxism (teeth grinding)
   u) Rhythmic movement disorder
   v) Sleep starts
   w) REM behavior disorder
   x) Sleep paralysis
   y) MY CHILD DOES NOT HAVE A SPECIFIC DIAGNOSIS
<table>
<thead>
<tr>
<th>Treatment Type</th>
<th>Description of Treatment</th>
<th>Have you tried this treatment to treat your child's sleep problems?</th>
<th>What age was your child when this treatment was tried?</th>
<th>Was this treatment effective?</th>
<th>Which of your child's “Main Five Symptoms” was the treatment effective for?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extinction</td>
<td>Responding to bedtime resistance by letting the child 'cry it out' and having no parental response to the disruptive behavior (Durand, 1998).</td>
<td>#10) a) Yes b) No</td>
<td>#11) a) Before age 3, b) 3-5 years old, c) 6-8 years old, d) 9-11 years old</td>
<td>#12) a) Yes b) No</td>
<td>#13) a) Yes b) No #14) a) Yes b) No #15) a) Yes b) No #16) a) Yes b) No #17) a) Yes</td>
</tr>
<tr>
<td>Graduated Extinction</td>
<td>Spending increasingly longer amounts of time ignoring the cries and protestations of a child at bedtime (Durand, 1998).</td>
<td>#18) a) Yes b) No</td>
<td>#19) a) Before age 3, b) 3-5 years old, c) 6-8 years old, d) 9-11 years old</td>
<td>#20) a) Yes b) No</td>
<td>#21) a) Yes b) No #22) a) Yes b) No #23) a) Yes b) No #24) a) Yes b) No #25) a) Yes</td>
</tr>
<tr>
<td>Bedtime Fading (no Response-Cost)</td>
<td>Keeping a child up late so they fall asleep on their own. Fade their bedtime back in small increments until desired bedtime is achieved (Durand, 1998).</td>
<td>#26) a) Yes b) No</td>
<td>#27) a) Before age 3, b) 3-5 years old, c) 6-8 years old, d) 9-11 years old</td>
<td>#28) a) Yes b) No</td>
<td>#29) a) Yes b) No #30) a) Yes b) No #31) a) Yes b) No #32) a) Yes b) No #33) a) Yes</td>
</tr>
<tr>
<td>Bedtime Fading WITH Response-Cost</td>
<td>Keeping child up late so they fall asleep on their own. Fade bedtime back in small increments until desired bedtime is achieved. If child is not asleep within 15 minutes after being put in bed, they are removed from bed, redirected to another task and not permitted to return to bed until 30 minutes has elapsed. This pattern is repeated until child falls asleep within 15 minutes after being put in bed.</td>
<td>#34) a) Yes b) No</td>
<td>#35) a) Before age 3, b) 3-5 years old, c) 6-8 years old, d) 9-11 years old</td>
<td>#36) a) Yes b) No</td>
<td>#37) a) Yes b) No #38) a) Yes b) No #39) a) Yes b) No #40) a) Yes b) No #41) a) Yes</td>
</tr>
<tr>
<td>Treatment Type</td>
<td>Description of Treatment</td>
<td>Have you tried this treatment to treat your child's sleep problems?</td>
<td>What age was your child when this treatment was tried?</td>
<td>Was this treatment effective?</td>
<td>Which of your child's &quot;Main Five Symptoms&quot; was the treatment effective for?</td>
</tr>
<tr>
<td>------------------------</td>
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<tr>
<td>Bedtime Routine</td>
<td>A consistent and calming series of activities that parent and child engage in before bedtime to help the child relax and wind down. The routine will help the child associate these activities with bedtime and assist the child's transition to sleep (Durand, 1998).</td>
<td>#42) a) Yes b) No</td>
<td>#43) a) Before age 3 b) 3-5 years old c) 6-8 years old d) 9-11 years old</td>
<td>#44) a) Yes b) No</td>
<td>#45) a) Yes b) No</td>
</tr>
<tr>
<td>Relaxation</td>
<td>Teaching the child how to tense and relax their muscles through awareness of their body. Teaching the child how to relax at bedtime and how and when to begin the relaxation exercises (Durand, 1998).</td>
<td>#50) a) Yes b) No</td>
<td>#51) a) Before age 3 b) 3-5 years old c) 6-8 years old d) 9-11 years old</td>
<td>#52) a) Yes b) No</td>
<td>#53) a) Yes b) No</td>
</tr>
<tr>
<td>Scheduled Awakenings</td>
<td>Waking the child some time prior to a typical night waking, and then letting them fall back to sleep.</td>
<td>#58) a) Yes b) No</td>
<td>#59) a) Before age 3 b) 3-5 years old c) 6-8 years old d) 9-11 years old</td>
<td>#60) a) Yes b) No</td>
<td>#61) a) Yes b) No</td>
</tr>
<tr>
<td>Barbiturates</td>
<td>Secobarbital (Seconal) Amobarbital (Amytal) Pentobarbital (Nembutal)</td>
<td>#66) a) Yes b) No</td>
<td>#67) a) Before age 3 b) 3-5 years old c) 6-8 years old d) 9-11 years old</td>
<td>#68) a) Yes b) No</td>
<td>#69) a) Yes b) No</td>
</tr>
<tr>
<td>Treatment Type</td>
<td>Description of Treatment</td>
<td>Have you tried this treatment to treat your child's sleep problems?</td>
<td>What age was your child when this treatment was tried?</td>
<td>Was this treatment effective?</td>
<td>Which of your child's &quot;Main Five Symptoms&quot; was the treatment effective for?</td>
</tr>
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</tr>
</tbody>
</table>
| Benzodiazepines     | Triazolam (Halcion) Quazepam (Doral) Remazepam (Restoril) Flurazepam (Dalmane) Estazolam (Prosom) Rivotrill Clonazepam | #74) a) Yes  
b) No                                                   | #75) a) Before age 3  
b) 3-5 years old  
c) 6-8 years old  
d) 9-11 years old | #76) a) Yes  
b) No                                                   | #77) a) Yes  
b) No                                                   | #78) a) Yes  
b) No                                                   | #79) a) Yes  
b) No                                                   | #80) a) Yes  
b) No                                                   | #81) a) Yes  
b) No                                                   |
| Melatonin           | A hormone supplement used to induce and maintain sleep                                    | #82) a) Yes  
b) No                                                   | #83) a) Before age 3  
b) 3-5 years old  
c) 6-8 years old  
d) 9-11 years old | #84) a) Yes  
b) No                                                   | #85) a) Yes  
b) No                                                   | #86) a) Yes  
b) No                                                   | #87) a) Yes  
b) No                                                   | #88) a) Yes  
b) No                                                   | #89) a) Yes  
b) No                                                   |
| Other Sleep-        | Chlortal Hydrate  
Methylphenidate (Ritalin)  
Zolpidem tartrate (Ambien)  
Pemoline sodium (Cyert)  
Imipramine (Tofranil)  
Trazadone (Desyrel)  
Dimenhydrinate (Gravol) | #90) a) Yes  
b) No                                                   | #91) a) Before age 3  
b) 3-5 years old  
c) 6-8 years old  
d) 9-11 years old | #92) a) Yes  
b) No                                                   | #93) a) Yes  
b) No                                                   | #94) a) Yes  
b) No                                                   | #95) a) Yes  
b) No                                                   | #96) a) Yes  
b) No                                                   | #97) a) Yes  
b) No                                                   |
| Inducing Medications|                                                                                         |                                                                     |                                                       |                               |                                                                                       |                                                                                       |                                                                                       |                                                                                       |                                                                                       |                                                                                       |
| Other Sleep-        | Levodopa and carbidopa (Sinemet)  
Desmopressin acetate                         | #98) a) Yes  
b) No                                                   | #99) a) Before age 3  
b) 3-5 years old  
c) 6-8 years old  
d) 9-11 years old | #100) a) Yes  
b) No                                                   | #101) a) Yes  
b) No                                                   | #102) a) Yes  
b) No                                                   | #103) a) Yes  
b) No                                                   | #104) a) Yes  
b) No                                                   | #105) a) Yes  
b) No                                                   |
| Related Medications |                                                                                         |                                                                     |                                                       |                               |                                                                                       |                                                                                       |                                                                                       |                                                                                       |                                                                                       |                                                                                       |
| Other Treatments    | Please Describe:                                                                        | #106) a) Yes  
b) No                                                   | #107) a) Before age 3  
b) 3-5 years old  
c) 6-8 years old  
d) 9-11 years old | #108) a) Yes  
b) No                                                   | #109) a) Yes  
b) No                                                   | #110) a) Yes  
b) No                                                   | #111) a) Yes  
b) No                                                   | #112) a) Yes  
b) No                                                   | #113) a) Yes  
b) No                                                   |
Appendix C

Web Page and Initial Contact Letter
Appendix D

Parent Recruitment Letter After Initial Contact With Agency
Appendix E

Cover Letter For Questionnaire