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The Sleep Problems Inventory: a measure for the assessment of sleep problems in adults with intellectual disabilities

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THE SLEEP PROBLEMS INVENTORY:  
A MEASURE FOR THE ASSESSMENT OF SLEEP PROBLEMS IN ADULTS WITH INTELLECTUAL DISABILITIES

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
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ABSTRACT

Sleep problems can have a broad impact across the day-to-day functioning of an individual. Persons with intellectual disabilities are at a particular risk for developing sleep problems, with prevalence estimates much higher than is found in the general population. Nonetheless, the assessment of sleep problems in persons with intellectual disabilities has been widely overlooked. The Sleep Problems Inventory (SLEEPY) was created to measure various factors related to sleep problems in persons with intellectual disabilities. The present study represents the first steps in establishing the reliability and validity of the SLEEPY in adults with intellectual disabilities.
INTRODUCTION

Sleep has a broad effect across many of the day-to-day aspects of an individual’s life. Because of the many areas that sleep impacts, these problems can disrupt the functioning of an individual in many domains. Thus, sleep problems can serve to exacerbate minor difficulties or irritations (Schreck, Mulick, & Smith, 2004). However, while sleep problems can lead to day-to-day difficulties and disorders, they are not necessarily the primary cause. In many instances the sleep problem is a result of a medical condition, side effect of medication, poor sleep hygiene, or a psychological disorder (Benca, 2000; Gillin & Drummond, 2000; Smith, Smith, Nowakowski, & Perlis, 2003; Uhde, 2000). A large number of disorders in the DSM-IV-TR (APA, 2000) include sleep problems among the diagnostic criteria.

Sleep problems are a common occurrence. Most people will have a sleep problem at one point in their life, which will go away after a short duration and cause little disruption. However, the prevalence of more significant and longstanding sleep problems is estimated between 5% and 15% (Ford & Kamerow, 1989; Mellinger, Balter, & Uhlenhuth, 1985; Ohayon, Caulet, Philip, Guilleminault, & Priest, 1997). A significant relationship exists between sleep and psychological functioning. Sleep disorders are often associated with emotional disorders or stressful life events (Ford & Kamerow, 1989). Likewise, patients with chronic sleep disorders have been found to be at an increased risk for depression, anxiety disorders, substance abuse disorders, and nicotine dependence (Breslau, Roth, Rosenthal, & Andreski, P., 1996; Ford & Kamerow, 1989). Improvements in mood may often be found when treating the underlying sleep problem (Jacobs, Benson, & Friedman, 1993; Jacobs, Pace-Schott, Stickgold, & Otto, 2004). Because of the diverse areas that sleep impacts, an increased knowledge of the assessment and treatment of
sleep problems has significant potential to aid a myriad of health professionals in assisting their clients.

In an effort to increase the clinician’s ability to identify and diagnose sleep disorders, a number of assessment methods have been developed, including polysomnography, actigraphy, and questionnaires. Two of the most frequently used questionnaires are the Epsworth Sleepiness Scale (Johns, 1991) and the Stanford Sleepiness Scale (Hoddes, Dement, & Zarcone, 1972). The efforts to develop more reliable and valid assessment measures have for the most part been successful and have shown adequate psychometric properties (Herscovitch & Broughton, 1981; Johns, 1994). Nonetheless, the assessment of sleep problems in persons with intellectual disabilities has been widely overlooked. Few measures have been constructed to assess for sleep disorders in adults with intellectual disabilities and only one measure, the Behavior Evaluation of Disorders of Sleep (BEDS; Schreck, 1997/1998), has been constructed to assess for sleep disorders in children with intellectual disabilities. A questionnaire by Simonds and Parraga (1984) has been used in modified forms across a number of studies in persons with intellectual disabilities (e.g. Brylewski & Wiggs, 1999; Didden, Korzilius, van Aperlo, van Overloop & de Vries, 2002; Wiggs & Stores, 1996). However, only one study addressed the psychometric properties of this questionnaire (Hunt & Stores, 1994). One other tool that has been developed to assess for sleep problems in persons with developmental disabilities is the Diagnostic Assessment for the Severely Handicapped (DASH-II; Matson, 1993). The DASH-II is an informant based screening tool for the rapid assessment of psychopathology in persons with developmental disabilities. The DASH-II contains a sleep disorders subscale consisting of 5 items. Initial evaluation of the psychometric properties of the sleep subscale are favorable.
However, in line with the overall purpose of screening for a broad spectrum of psychopathology, the item content of the DASH-II sleep scale is limited.

The paucity of assessment measures for sleep disorders in persons with intellectual disabilities is most striking when considering the prevalence of reported sleep problems in this population, which are estimated at 23% to 51% (Bartlett, Roney, & Spedding, 1985; Quine, 1991). Johnson (1996) notes that the relative lack of research on sleep disorders in persons with intellectual disabilities may be due partially to a lack of valid and reliable assessment measures designed for use in this population. However, whatever the reason, there is no debate about the fact that little attention has been paid to sleep irregularities as applied especially to persons with severe and profound mental retardation.

The present study represents the first step in establishing a measure to assess for sleep problems in adults with intellectual disabilities. While the sleep subscale of the DASH-II may be useful to identify potential problems with sleep as a part of a larger evaluation, a more in depth assessment of sleep problems containing a broader content (e.g., breathing related sleep problems) would do much to advance research and treatment of sleep problems in persons with developmental disabilities. The Sleep Problems Inventory (SLEEPY) was created to measure various factors related to sleep disorders in persons with intellectual disabilities, a little explored area. An important first step in establishing acceptable psychometric properties of this measure is examining the SLEEPY’s factor structure, reliability, and validity.
REVIEW OF LITERATURE

Sleep Disorders

Assessment of Sleep

Sleep has been a topic of philosophical musing since early history. However, it was only in the last century that the study of sleep emerged as a serious scientific endeavor (Dement, 2000). The advent of sleep as a topic of scientific inquiry can be dated to 1930, when Hans Berger demonstrated that the sleeping brain produced electrical rhythms that were distinct from the rhythms produced while awake (Berger, 1930). Berger titled the electrical recordings “electroencephalograms” (EEG), and thus a method to measure and study activity in the sleeping brain emerged. The sophistication of EEG methods has improved dramatically since its inception and it still remains a major component of polysomnography (PSG), the gold standard for establishing the presence of a sleep disorder (Smith, Nowakowski, Soeffing, Orff, & Perlis, 2003). There are primarily four ways that sleep is assessed. They include PSG, actigraphy, direct observation, and self-report (questionnaires, sleep diaries, etc.).

When used for measuring sleep, PSG consists of three measures, EEG, electromyography (EMG), and electrooculography (EOG) (Smith, et al., 2003). All three measures are indices of electrical activity produced by their respective locations (scalp, muscles, and eyes). While EEG is the primary measure, EMG and EOG are useful in determining sleep stage (such as REM sleep). When combined with other measures of cardiac, respiratory, and peripheral nervous system activity, the PSG becomes a very sensitive tool for diagnosing various dyssomnias and parasomnias (Smith et al., 2003). However, PSG is cumbersome and is almost exclusively conducted in a laboratory environment, yet technology continues to improve as new advancements have been integrated into the process. Efforts to develop portable and less intrusive devices for PSG have begun to receive the attention of researchers (Chervin, 2000);
however, entirely different ways of measuring sleep such as actigraphy have also been developed as a means to overcome the cumbersomeness of PSG.

Actigraphy is a useful but often underused measure of sleep (Ancoli-Israel, Cole, Alessi, Chambers, Moorcroft, & Pollak, 2003; Smith, et al., 2003). Simply put, actigraphy is a measurement of activity summated over a number of time intervals. It is assumed that although movement may occur while sleeping or the individual may be inactive while awake, that overall, activity indicates wakefulness and inactivity indicates sleep. In studies with humans, the actigraph is usually worn on the wrist, similar to a wristwatch. One benefit of the actigraph over PSG is its portability. While early models have been somewhat obtrusive, newer models are smaller and may be disguised in the shape of a wristwatch to decrease the awkwardness of wearing the device in day-to-day circumstances. In a critical review of the methodological issues with actigraphy, Tryon (2004) concluded that while studies have found that PSG and actigraphy do not relate well, this variability is not random, but systematic and controllable. Further, Tryon (2004) points out that the reliability coefficients meet or exceed those of commonly used medical or psychological tests. Ancoli-Israel et al. (2003) concluded that actigraphy is a moderately valid and reliable means to differentiate sleep states but becomes less reliable as the severity of sleep problems increase. Further, Ancoli-Israel et al. (2003) commented that while actigraphy is less reliable, it can be used in situations where PSG is not practical. Nonetheless, there remains much that still needs to be done to validate the use of actigraphy to measure sleep problems.

Direct observations are commonly used in residential and inpatient settings. This procedure consists of monitoring an individual for the presence of sleep over a series of intervals. Observable definitions of sleep must be clearly stated as well as the rate of intervals. For the data to show meaningful changes, the intervals should be 30 minutes or less. However, Smith et al.
(2003) point out that as the time between intervals decreases, the compliance and vigilance of direct care staff to reliably observe the individual may decrease. Further, error may be introduced by poorly defined target behaviors. Nonetheless, this procedure is inexpensive and easy to implement. Moreover, adequate training as well as explicit behavioral definitions of the target behaviors may control much of the unreliability.

Self-report measures are a mainstay of clinical sleep assessment (Smith et al., 2003). These assessments may vary from informal questions about sleep quality to validated scales. While commonly used, self-report measures have a number of problems with validity that depend upon the particular aspects of the measure used. For instance, retrospective measures and prospective measures like sleep logs depend upon the ability of the individual to report accurately (Smith et al., 2003). A number of factors may influence the individual’s recall on such scales including primacy, recency, and confirmation bias. Further, they depend upon how well the individual can average their sleeping behavior across a number of days and report on their “overall” sleep. Prospective measures such as sleep diaries are not as dependent upon an individual’s long-term memory or the ability to summate their sleep. However, sleep diaries commonly ask the individual to rate things such as how long it took them to fall asleep. Whether an individual can answer such items accurately is questionable (Smith et al., 2003). While these limitations are significant, self-report measures still provide useful and valid information if constructed properly and used in the appropriate context (Smith et al., 2003).

The methods used to assess for particular sleep disorders is highly dependent upon the disorder in question. For example, the diagnostic tools to evaluate for insomnia will differ greatly from those used in obstructive sleep apnea. PSG may continue to be the gold standard for diagnosing a sleep disorder (Ancoli-Israel et al., 2003). However, this method requires
substantial amounts of time and resources. Many sleep disorders may be identified by more efficient means such as structured interviews and questionnaires. When available, other methods that are more cost effective, less intrusive, and more adaptable to measuring sleep in the natural setting may be preferred.

Classification of Sleep Disorders

The classification of sleep disorders has received a good deal of attention. The two most frequently used classification systems are the International Classification of Sleep Disorders (ICSD) and the DSM-IV-TR. The ICSD, originally published in 1990 by the American Sleep Disorder Association was revised in 2000 with the purpose of updating the ICSD code numbers to match the ICD-10 system. The ICSD was published primarily with the goal of expediting diagnosis and classification for epidemiological purposes. In spite of the similarities between the ICSD and the DSM-IV, there has been much debate over which system ought to be used. Because of the greater number of subdivisions and categories in the ICSD, many sleep-specialists prefer this nosology (Thorpy, 2000). However, while useful for diagnosis or epidemiological information, this degree of subdivision is not usually found in the research literature. Instead, more general terms are often employed.

In the ICSD system, the disorders are broken down into four categories: (1) dyssomnias; (2) parasomnias; (3) sleep disorders associated with mental, neurologic, or other medical disorders; and (4) proposed sleep disorders, disorders with insufficient data to show clear diagnostic guidelines (American Academy of Sleep Medicine, 2000). The ICSD results in 84 distinguishable sleep disorders.

The DSM-IV-TR categories include: (1) Primary Sleep Disorders, which is broken down into dyssomnias and parasomnias; (2) sleep disorders related to another mental disorder; (3)
sleep disorders due to a general medical condition; and (4) substance-induced sleep disorder. While the two classification systems are divided differently, many of the same disorders are included in both, but are simply classified into different sections. While developers of both systems attempt to organize the disorders based upon known etiology, they have arrived at different outcomes. This development may be due in part to efforts to match the ICSD’s coding system to that of the ICD.

Regardless of classification system, historically, sleep disorders not due to a substance or medical condition are separated into two categories: dyssomnias and parasomnias. The dyssomnias consist of problems related directly to the sleep process (i.e. amount, quality, and timing of sleep). The parasomnias consist of problems that occur during sleep or sleep-wake transitions. According to the DSM-IV-TR (APA, 2000) the dyssomnias include Primary Insomnia, Primary Hypersomnia, Narcolepsy, Breathing-Related Sleep Disorder, Circadian Rhythm Sleep Disorder, and Dyssomnia Not Otherwise Specified. The parasomnias include Nightmare Disorder, Sleep Terror Disorder, Sleepwalking Disorder, and Parasomnia Not Otherwise Specified. A detailed discussion of each sleep disorder is beyond the scope of this paper, particularly in light of the high differentiation in the ICSD; however, they will be covered generally, with emphasis on the disorders recognized by both the DSM-IV-TR and ICSD.

**Dyssomnias**

**Insomnia**

Insomnia is one of the most common sleep disorders. Depending on the definition used, prevalence estimates vary from 10-50% (Zorick & Walsh, 2000). Most conservative estimates fall around 10% in a six month time period (Ford & Kamerow, 1989; Simon & VonKorff, 1997). In persons between 20 and 40 years of age, prevalence estimates do not vary by gender.
However, in persons over 65 years of age, women are more likely to have problems with insomnia than men (Zorick & Walsh, 2000). Further, persons over 65 are in general more likely to experience problems with insomnia than younger adults (Ganguli, Reynolds, & Gilby, 1996). Children and adolescents are also more susceptible to having problems with insomnia, with children 6-24 months old having prevalence rates of 20-30% (Lozoff, Wolf, Davis, 1985; Richman, 1981). From the ages of 4-8 these rates decrease to approximately 15% (Zorick & Walsh, 2000). These data suggest that prevalence rates of insomnia follow a developmental course in which persons in early childhood and older adulthood are more likely to experience this problem.

A number of environmental, psychological, and medical factors may cause or lead to insomnia. Factors rarely occur singularly; rather, they occur in concert with one another. For example, Parkinson’s disease may cause insomnia (Garcia-Borreguero, Larrosa, & Bravo, 2003). However, individuals dealing with this medical condition also often experience anxiety and depression, both of which are known to contribute to problems with insomnia. For diagnostic and treatment purposes, teasing apart the various factors contributing to the insomnia is complex and difficult.

For cases in which insomnia occurs in the absence of psychological, environmental, and medical problems, the insomnia is considered to be free-standing and thus is seen as a root problem rather than a symptom of another disorder (Hauri, 2000). The DSM-IV-TR classifies these cases as Primary Insomnia. The ICSD has three classifications for free-standing insomnia: psychophysiological insomnia, sleep-state misperception, and idiopathic insomnia.

Compelling evidence is available to suggest that primary insomnia is fundamentally different from other forms of insomnia in which sleep deprivation is imposed on the individual
as a result of some other disorder. The most significant difference is that persons with primary insomnia appear to be hyperaroused (Hauri, 2000). Likewise, Bonnet and Arand (1995) have shown that persons with insomnia more closely resemble hyperarousal than sleep deprivation.

Because of the many different causes for insomnia, the assessment process must be broad. Insomnia is most commonly diagnosed by history alone (American Sleep Disorder Association, 1995; Chervin, 2000; Reite, Buysse, Reynolds, & Mendelson, 1996). PSG, actigraphy, self report, and direct observations may also all be employed to determine the severity of the insomnia even though not necessary to determine the actual presence of the disorder (Chervin, 2000). The diagnostic process becomes more complicated though when attempting to determine the etiology of the insomnia. In doing so, many other domains need to be assessed, including both psychiatric and medical causes. PSG is useful to assess for physical abnormalities such as BRSD. However, the cause may often simply be inadequate sleep hygiene. Chervin (2000) points out that PSG should not be overused as it may convince the patient that the cause of the insomnia is biological and undermine attempts to effectively treat the insomnia behaviorally.

Insomnia is troublesome and frustrating for many people who experience it frequently. However, it is not particularly the inability to fall asleep that is found distressing, but rather it is the consequences of getting too little sleep that are seen as the problem. Lack of sleep can increase irritability, lead to excessive daytime sleepiness, or impair functioning while at work (Zorick & Walsh, 2000). However, these symptoms may be caused by any sleep disorder that impairs the amount, quality, or timing of sleep.
Hypersomnia

Sleep is often considered a drive state, in much the same way as hunger. As time without food increases, hunger also increases and is reduced by food consumption; likewise sleepiness is also increased by time without sleep and is reduced by sleeping. However, sleep is not simply a singular process of deactivation due to sleep-debt, but rather consists of multiple processes. Borbély (1982) originally proposed a two-factor model in which the drive for sleep consists of homeostatic and circadian-rhythm components. This model has received much support and is still widely held (Cluydts, Valck, Verstraeten, & Theys, 2002). Other models have been proposed by various researchers, which include three or more factors (Folkard & Åkerstedt, 1987). However, systems of sleepiness that rely solely upon systems of deactivation may not capture the whole picture. A system of two opposing processes controlling the sleep-wake state was proposed by Edgar, Dement, and Fuller (1993) in which a drive for sleep consisting of sleep-debt and deactivating chronobiological factors compete with a drive for wakefulness consisting of environmental and activating chronobiological factors. Such a system of various processes competing to both activate and deactivate is more in line with the heterogeneity of problems with sleep.

For most people, sleepiness will wax and wane throughout the day with a decrease in alertness during the mid-afternoon (2:00 pm) and more severely during early morning (2:00 am) (Mitler & Miller, 1996). The drop in alertness during the afternoon corresponds to a peak in body temperature and the drop in the late evening corresponds with a significant drop in body temperature. However, these temperature peaks and drops may vary as there is much heterogeneity among individuals (Cluydts et al., 2002). Excessive daytime sleepiness is a common complaint. As excessive daytime sleepiness becomes more severe it may lead to mild
problems such as inattentiveness or to more serious problems such as motor vehicle accidents. Mild cases of excessive daytime sleepiness may simply be due to poor sleep hygiene. However, more severe cases of excessive daytime sleepiness are frequently associated with obstructive and central sleep apnea, restless leg syndrome, and neurodegenerative diseases (El-Ad & Korczyn, 1998).

Idiopathic hypersomnia (ICSD) or primary hypersomnia (DSM-IV) consists of complaints of severe excessive daytime sleepiness in the presence of normal sleep architecture. The diagnosis of idiopathic/primary hypersomnia depends greatly upon the process of ruling out other sleep disorders such as narcolepsy or obstructive sleep apnea. Much of the diagnosis of hypersomnia relies upon self-reported problems with daytime somnolence. The gold standard for measuring daytime sleepiness is the multiple sleep latency test (MSLT; Mitler, Carskadon, & Hirshkowitz, 2000). The MSLT consists of a series of naps while undergoing PSG to determine how quickly the individual is able to fall asleep. The time until sleep onset is computed as an index of the individual’s sleepiness. While self-report has not been found to correlate well with MSLT (Chervin, Aldrich, Pickett, & Guilleminault, 1997), measures such as the Stanford Sleepiness Scale (Hoddes, et al., 1972) and the Epworth Sleepiness Scale (Johns, 1991) may provide more reliable results.

Narcolepsy is essentially defined the same by both the ICSD and DSM-IV-TR. The DSM-IV diagnostic criteria include irresistible attacks of refreshing sleep that occur daily over at least 3 months and the presence of cataplexy or intrusions of REM sleep during sleep-wake transitions (APA, 2000). Recognition of the disorder dates back to 1880 when Gelineau first coined the term narcolepsy and described it as short episodes of irresistible sleep that were sometimes preceded by falls (Guilleminault & Anagnos, 2000). The disorder was further refined
in 1934 by Daniels who developed the cluster of symptoms commonly known as the “narcoleptic tetrad.” These five symptoms consisted of daytime sleepiness, cataplexy, sleep paralysis, and hypnagogic hallucinations. While substantial progress has been made concerning the etiology of the disorder, one can see from the current ICSD and DSM definitions that not much has changed concerning the disorder’s clinical features.

Onset of narcolepsy is most likely to occur in the mid 20’s with approximately 50% of the known cases being preceded by an abrupt change in the sleep pattern or a severe psychological stressor (Guilleminault & Anagnos, 2000). The prevalence of narcolepsy has been estimated at .02-.06% (Hublin, Partinen, Kaprio, Koskenvuo, & Guilleminault, 1994; Mignot, 1998). However, due to the genetic components of the disorder, prevalence rates may vary significantly by region. A large body of research has been conducted concerning the genetic transmission of narcolepsy. It is reasonable to conclude that there is a strong genetic basis to the disorder (Guilleminault & Anagnos, 2000). Juji, Satake, Honda, and Doi (1984) found that 85% of their sample of persons with definite cataplexy shared a common human leukocyte antigen (HLA) allele on chromosome 6. However, Guilleminault, Mignot, and Grumet (1989) showed that this same genetic marker is also found in 12-38% of the general population. Thus, it is likely that the development of narcolepsy is the possible result of a specific genetic vulnerability combining with environmental and psychological stressors.

A large portion of the process of diagnosing sleep disorders consists of ruling out other causes. Because of the similarity of presentation of symptoms among these disorders, this process may be quite lengthy. Disorders of hypersomnia such as idiopathic hypersomnia or narcolepsy may impair a number of areas related to daytime functioning and sleep. However, as with insomnia, these symptoms are not exclusively due to hypersomnia but may be caused by
other disorders of sleep such as sleep apnea. When evaluating for possible causes of
hypersomnia, breathing related sleep disorder (BRSD) should also be considered.

Breathing-Related Sleep Disorder

BRSD can consist of apneas (breathing cessation), hypopneas (slow or shallow
breathing), and hypoventilation (low oxygen blood levels). Three forms of BRSD are recognized
in the DSM-IV-TR: obstructive, central, and central alveolar hypoventilation. In obstructive
sleep disorder the central nervous systems regulation of sleep breathing is maintained although
breathing is inhibited, usually due to some physical obstruction of the upper airway (Ayappa &
Rapoport, 2003). This form of BRSD is the most common and occurs more frequently in
overweight individuals. Characteristics of obstructive sleep disorder include loud snores and
brief gasps with alternating silence. Snoring can be quite loud and can significantly disrupt the
sleep of bed partners or other persons living in the home.

Central BRSD consists of cessation of sleep breathing without obstruction of breathing
passages. Central BRSD is usually the result of a cardiac or neurological condition. Because of
its presentation, central BRSD is much less noticeable than obstructive BRSD. In alveolar
hypoventilation, low blood oxygen levels and high carbon dioxide levels are present in spite of
normal lung mechanics. Shallow or slow breathing may be the cause. As with obstructive sleep
apnea, obesity is a prime cause.

There are a number of recognized risk factors for developing BRSD, the most frequently
noted include high body mass, craniofacial malformations, and male gender (Jordan & McEvoy,
2003; Redline & Tishler, 2000). The discrepancy in prevalence between males and females may
be due in part to the differing distribution of fat throughout the body between males and females.
In a study evaluating gender differences in sleep disordered breathing, Young (1993) found that
gender differences were eliminated when waist-hip ratio and neck girth were analyzed instead of their body mass index (BMI). However, there is some evidence that female sex hormones may serve a protective role against developing BRSD (Jordan & McEvoy, 2003). Likewise, women appear to have shorter soft-palates, which reduces the potential for collapse of the upper airway during sleep, causing obstruction (Jordan & McEvoy, 2003).

The value of clinical impressions in the diagnosis of BRSD is questionable, showing poor sensitivity and specificity (Hoffstein & Szalai, 1993; Viner, Szalai, & Hoffstein, 1991). Considering the high correlation of BRSD with various physical features of the individual, Kushida, Efron, and Guilleminault (1997) developed a predictive model of obstructive sleep apnea. Their model, which is based upon BMI, neck circumference, and various craniofacial measurements, was used to correctly classify 98% of individuals with obstructive sleep apnea. While their model is an improvement over simple clinical impressions or history taking, PSG remains the most common method of assessment of BRSD and is considered the gold standard (Chervin, 2000). Because of the cost and intrusiveness of PSG in laboratory settings, efforts have been made to develop portable recording devices. However, not much data have been collected concerning the reliability of these devices in regards to laboratory PSG (Chervin, 2000).

**Circadian Rhythm Sleep Disorder**

The synchronization of internal processes such as sleep-wake cycles with the external environment depends upon how well the circadian clock is in tune with the world around us (Baker & Zee, 2000). A number of naturally occurring cues are used to reset or realign the timing of our internal clock with the external environment. These cues are known as zeitgebers, or “time-givers”. Of the known zeitgebers, light has the strongest effect (Avissar, et al., 1999;
Wirz-Justice, 1998). Many other zeitgebers have been identified such as food consumption, temperature, social cues, and physical activity.

By a series of ablation studies in rats, Richter (1967) found that only lesions of the hypothalamus resulted in a loss of circadian rhythm. Because of the known role that light plays in regulating circadian rhythms, it was hypothesized that by tracing projections from the optic nerve, the specific area concerned with regulating circadian rhythms could be identified (Moore & Eichler, 1972). Indeed, such a projection was found to lead to the suprachiasmatic nucleus (SCN; Moore & Eichler, 1972). Various ablation studies have confirmed the SCN’s role in synchronizing sleep with the external environment (Moore & Lenn, 1972; Stephen & Zucker, 1972). However, the specific mechanism by which it does so remains unknown (Harrington & Mistlberger, 2000). Further, a number of other regions such as the pineal gland have been implicated in the process of circadian regulation.

A malleable system of sleep regulation is needed due to naturally occurring variations in the environment such as seasonal changes. Unnatural variations such as late-shift work and traveling through time zones also requires a system that is malleable and able to be reset. However, these unnatural variations may be too severe and sleep problems may arise when the synchronization of internal cycles with external cycles is lost. Desynchronization, or phase shifts, may occur for multiple reasons, which are commonly classified into two categories: (1) the environmental light/dark cycles changes relative to the individual’s internal clock (shift work or time-zone travel) or (2) the individual’s internal clock changes relative to stable environmental cycles (Baker & Zee, 2000).

The essential problem with circadian rhythm sleep disorder is that the individual is unable to sleep when it is desired or socially expected. In circadian rhythm sleep disorder, the
actual process of sleep remains unimpaired, however, the timing of sleep is mismatched with the environment. As with many sleep disorders, the presenting complaint is often insomnia or excessive daytime drowsiness. However, in circadian rhythm sleep disorder further investigation will show that the problem is not necessarily with falling asleep, but rather the timing of sleep onset. As with most sleep disorders, PSG is the gold standard for the diagnosis. Actigraphy and self-report of problems are also helpful in determining the specific characteristics of the disorder.

Parasomnias

Non-REM Parasomnias

Sleep-walking, sleep terrors, and confusional arousal are typically grouped together because they almost exclusively occur during NREM sleep, have similar genetic patterns, and are more common in children (Broughton, 2000). Indeed, the ICSD recognizes this grouping as a category, however the DSM-IV-TR does not categorize them but simply lists each as an individual parasomnia. These disorders also occasionally overlap with one another with aspects of confusional arousal being present in both sleep terrors and sleep-walking (Broughton, 2000).

As may be implied by its title, confusional arousal consists of periods of confusion after arousal from sleep, most commonly during slow wave sleep. While the ICSD recognizes this particular disorder, the DSM-IV-TR does not provide a specific diagnostic code. Little has been done concerning epidemiological studies of confusional arousal. Likewise, little is known concerning the pathophysiology. However, factors that may deepen sleep such as youth, medication, or sleep deprivation may increase the frequency of occurrence (Broughton, 2000). Confusional arousal usually does not impair the individual as long as objects are not left near the bed such as water glasses that may be broken and cause injury.
Sleep terrors consist of abrupt awakenings from sleep with loud screams or crying as well as autonomic arousal and feelings of intense fear. Both the ICSD and DSM-IV-TR recognize sleep terrors as a disorder. Sleep terrors occur primarily in children, with one to six percent experiencing the disorder (Broughton, 2000; Kales, Kales, Soldatos, Caldwell, Charney, & Martin, 1980). The condition is found far less frequently in adults with less than one percent experiencing the disorder. There appears to be a strong genetic component to sleep terrors (Kales, Soldatos, Bixler, Ladaa, Charney, Weber, & Schweitzer, 1980). However, the pathophysiology remains unknown (Broughton, 2000). As with confusional arousal, while unpleasant and distressing, sleep terrors rarely cause injury nor serve as signs of other more serious disorders.

According to the ICSD, sleep-walking consists of the individual arising from a deep sleep, usually slow wave sleep, and engaging in a series of complex behaviors, resulting in getting out of bed and walking. In spite of previously held notions that sleepwalking was a significant sign of other pathology, it usually causes minimal harm and will resolve itself if allowed to “run itself out” (Broughton, 2000). Sleepwalking is common in children with three to four percent having frequent sleepwalking episodes (Kales, Soldatos, Caldwell, Kales, Humphrey, Charney, & Schweitzer, 1980). As with sleep terrors, there appears to be a genetic component, with roughly 80% of sleepwalkers having a significant family history (Kales, Soldatos, Caldwell, et al, 1980).

REM Parasonmias

REM sleep behavior disorder (RBD) and nightmares are the two most commonly researched REM sleep disorders. Nightmares are a common occurrence for most individuals and lifetime prevalence may be assumed to approach 100% (Nielsen & Zadra, 2000). While some
debate continues over what constitutes a nightmare, it is commonly held that nightmares are frightening dreams that awaken the individual. Nightmares are more common in children and decrease with age. However, it is not uncommon for nightmares to occur in adulthood, with estimates ranging from 8-25% (Nielsen & Zadra, 2000).

REM sleep behavior disorder (RBD) consists of the loss of atonia associated with REM sleep and excessive motor movements related to dream content. In RBD, injury may occur to the individual or bed partner as often the movements reflect punching or kicking motions. The atonia seen during REM sleep is primarily the result of inhibition of motor activity by the pontine centers of the peri-locus ceruleus, which in turn causes the medulla to hyperpolarize the motor neurons of the reticulospinal tract (Mahowald & Schenck, 2000). As the central nervous system develops during infancy, the REM atonia becomes more stable and movement during REM sleep decreases. Any impairment in the structures regulating the inhibition of motor activity may result in RBD. Chronic cases are usually related to neuromaldevelopment or neurological damage. Acute problems of RBD have been observed in persons taking excessive amounts of caffeine, tricyclic antidepressants, monoamine oxidase inhibitors, and various antipsychotics (Mahowald & Schenck, 2000). Because of the association with Parkinson’s disease and dementia, individuals with chronic cases should be evaluated by a neurologist to rule out these disorders.

Sleep Bruxism

Sleep Bruxism (SB) is defined by the ICSD as a stereotyped movement disorder characterized by grinding or clenching of the teeth during sleep. The disorder is differentiated from daytime clenching and grinding of teeth in that it takes place while sleeping and thus is believed to not be under volitional control. There is evidence to suggest a psychological component in that SB increases following stressful days or in anticipation of stress (Funch &
Gale, 1980; Rugh & Solberg, 1975). SB can lead to severe wearing away of the teeth as well as damage to the bone and muscles of the jaw. This problem may result in significant tooth and jaw pain, as well as temporal area headaches. SB does not usually occur every time the individual sleeps but rather has a good deal of fluctuation (Lavigne & Manzini, 2000). SB is usually not noticed unless the individual’s bed partner is disturbed by the grinding noises or the individual’s dentist observes the tooth wear (Lavigne & Manzini, 2000). While SB is usually the primary diagnosis, it may occur secondary to a medical condition. For example, withdrawal from neuroleptics or neuroleptic induced dyskinisia may cause non-volitional jaw movements that persist during sleep. In such a case, the SB would be secondary to the dyskinisia (Micheli, Pardal, Gatto, Asconapé, Giannaula, & Parera, 1993; Bassett, Remick, Blasberg, 1986). Due to the inherent difficulty in observing SB and the individual’s frequent lack of awareness of the occurrence of SB, prevalence estimates are preliminary. Estimates of frequent SB in the general population range from 5-20% (Glaros & Rao, 1977). However, infrequent teeth grinding during sleep is fairly common, occurring in 85-90% of the population (Bader & Lavigne, 2000). It is only when the SB causes severe tooth wear or disturbs the sleep of the individual or their bed partner that it becomes clinically significant.

The etiology of sleep problems is diverse. Many disorders of sleep may result in similar symptoms. Various mental disorders or medical conditions may also lead to sleep problems. Because these various factors work in concert with one another, a thorough evaluation must also consider the role that mental disorders or medical conditions may play in sleep disturbances.

Mental Disorder or Medical Condition

Sleep disorders due to another mental disorder or medical condition are often not diagnosed or are simply overlooked. The diagnosis of these sleep disorders is often difficult due
to the inclusion of sleep disturbance as a criteria for other mental disorders such as Major Depressive Disorder or Generalized Anxiety Disorder. However, even when due to another disorder, the sleep disturbance may become of such a magnitude that it takes on a life of its own and warrants a second diagnosis. For the diagnosis of sleep disorders related to another mental disorder or medical condition, the ICSD provides much more definitive categories than the DSM-IV-TR, which simply calls for the clinician to specify which disorder is the primary cause of the sleep disturbance. The ICSD list of mental disorders includes psychosis, mood disorders, anxiety disorders, panic disorders, and alcoholism. The ICSD list of neurologic disorders includes cerebral degenerative disorder, dementia, parkinsonism, fatal familial insomnia, sleep-related epilepsy, electrical status epilepticus of sleep, and sleep-related headaches. The list of other medical disorders includes: sleeping sickness, nocturnal cardiac ischemia, chronic obstructive pulmonary disease, sleep-related asthma, sleep-related gastroesophageal reflux, peptic ulcer disease, and fibromyalgia. With its specific categories, the ICSD system is more readily adapted to compiling epidemiological and statistical information.

As can be seen from the long list of mental and medical disorders that the ICSD includes, sleep disturbances may arise from disparate sources. No one particular health professional will receive all referrals that may be related to a sleep disorder. Physicians, psychologists, psychiatrists, neurologists, and nurses all need to be aware of the impact that sleep problems may have on the disorders that define their specialty. A brief review will be provided of those disorders that are the most commonly reported in persons with intellectual disabilities. These conditions include depression, anxiety, and epilepsy.
Anxiety and Depression

When discussing sleep disorders in the context of anxiety and depression, much of the research becomes blurred. This problem is due in part to the overlap of disorders and sleep problems that are often conceptualized as symptoms of depression and anxiety (Ware & Morin, 1997). Further, considering the high prevalence of anxiety and mood disorders across the lifespan, little research has been done concerning their impact on sleep or vice-versa (Uhde, 2000). Nonetheless, the available research does indicate a significant relationship between sleep and these disorders (Benca, 2000; Uhde, 2000).

Relaxing before bedtime is a significant step in settling before sleep onset. However, many individuals with anxiety disorders report worrying and thinking about problems after laying down to sleep (Uhde, 2000). This situation may pose a significant problem to the process of winding-down (Spielman, Conroy, & Glovinsky, 2003). Indeed, 50% to 70% of persons with generalized anxiety disorder report problems with sleep and 30% report moderate to severe problems (Anderson, Noyes, & Crowe, 1984; Uhde, Tancer, & Gurguis, 1990). Additionally, intrusive thoughts and ruminations have been shown to disrupt sleep in person with obsessive compulsive disorder, with these individuals showing fragmented and restless sleep (Insel, Gillin, Moore, Mendelson, Loewenstein, & Murphy, 1982; Uhde, 2000). Post-traumatic stress disorder (PTSD) poses a particular problem to sleep, particularly in having trouble initiating sleep or with recurrent nightmares. Further, the individual with PTSD may develop a conditioned fear to sleep if the trauma occurred while they were sleeping, such as a house-fire or burglary (Uhde, 2000).

Since sleep problems are a diagnostic criteria for mood disorders, the high association of insomnia and depression should not be surprising. Mellinger, Balter, and Uhlenhuth (1985) found that persons with serious insomnia complaints were much more likely (three times more
likely) to report depression than those with only minor complaints of insomnia. While conventional wisdom holds that depression causes impairment in sleeping, there is increasing evidence that impaired sleep may also cause depression. For example, Ford and Kamerow (1989) found that individuals whose sleep disturbances persisted between baseline assessment and a 1-year follow-up were much more likely to have developed a new major depressive disorder. A similar study (Breslau et al., 1996), which did not include sleep disturbances as a criteria for depression, also found that sleep disturbances were a significant risk for developing a depressive disorder. Similarly, treating sleep disturbances have been shown to be effective in reducing anxiety and depression (Jacobs et al., 1993)

A number of theories have been proposed to account for the role that sleep plays in anxiety and depression. These theories consider REM suppression, cholinergic-aminergic imbalance in REM sleep regulation and problems with the circadian regulation of sleep/wake cycles. While no one theory is able to explain the various symptoms, sleep and anxiety and sleep and depression appear to be significantly linked (Benca, 2000). Examining these links may lead to more effective treatments for sleep disorders as well as for depressive and anxiety disorders.

**Epilepsy**

Many individuals who experience nocturnal seizures are not aware of the seizure activity at all, but rather present with complaints of sleep fragmentation, poor sleep quality, and daytime tiredness (Provini, Plazzi, Montagna, & Lugaresi, 2000). Many nocturnal seizure disorders will remit without treatment; this is particularly the case in children (Pressman, Gollomp, Benz, & Peterson, 1997). Seizure activity and sleep disorders appear to be significantly related to one another. Sleep deprivation has been shown to increase seizure activity (Shouse & Mahowald, 2000). However, seizures may also increase the incidence of sleep disorders. To further
complicate the picture, anticonvulsants have a significant impact on REM sleep, and epileptic
discharges have been known to exacerbate periodic limb movements (Pressman et al., 1997).

Some parasomnias such as arousal disorders are often misdiagnosed as nocturnal
seizures. Indeed, there is a good deal of overlap between sleep and epileptic phenomena
(Eisenman, & Attarian, 2003). For example, normal occurrences in sleep such as hypnic jerks,
which involve motor, visual, auditory, or somethetic sleep starts may be confused as seizure
activity (Shouse & Mahowald, 2000). However, these events may also be the only manifestation
of a seizure disorder (Fornazzari, Farcnik, Smith, Heasman, & Ichise, 1992). Additionally,
disorders of arousal such as REM sleep behavior disorder, nightmares, periodic limb movement
disorder, nocturnal panic attacks, and enuresis may have significant overlap with seizure
disorders. Differential diagnosis is extremely difficult. Standard practices to assess for seizures
such as EEG recordings may be obscured by normal sleep phenomena. In light of the
complicated diagnostic picture and the common comorbidity of sleep and seizure disorders, an
awareness of both sleep and seizure disorder manifestations is necessary (Shouse & Mahowald,
2000). The clinician needs to be vigilant in exploring both possibilities, especially in such cases
where the phenomena may lead to injury.

Sleep Disorders in Persons with Intellectual Disabilities

Prevalence and Classification Issues

The prevalence of sleep problems in persons with intellectual disabilities appears to be
much higher than in the general population (Brylewski & Wiggs, 1998; Brylewski & Wiggs,
1999; Stores, Stores, & Buckley, 1996; Wiggs & Stores, 1996). For example, Bartlett, Roney,
and Spedding (1985) conducted a study in which 80% of the parents of children with intellectual
disabilities reported one or more difficulties related to sleep. Didden et al. (2002) reported
settling, night waking, and early waking as the most common of the severe problems reported in children with intellectual disabilities. Quine (1991) also reported a high prevalence of sleep problems with 51% of the sample having settling problems and 67% having problems with waking during the night. Further, Stores et al. (1996) found that children with intellectual disabilities were much more likely to have a sleep problem than typically developing children. Thus, it is apparent that persons with intellectual disabilities appear to be particularly vulnerable to sleep problems.

Most studies published concerning sleep problems in persons with intellectual disabilities have been with children (Didden & Sigafoos, 2001; Espie & Tweedie, 1991). Quine (1991) and Clements, Wing, and Dunn (1986) both found sleep disorders to be more common in children under 5 than children over 5. The period of sleep problems experienced in the early development of typically developing infants might apply to persons with intellectual disabilities. Indeed, Bartlett et al. (1985) indicated that those children with intellectual disabilities in their study appeared to be significantly slower at “growing-out” of sleep problems than were typically developing children. Few studies have been published concerning the prevalence of sleep problems in adults with intellectual disabilities. Brylewski and Wiggs (1999) evaluated 205 adults with intellectual disabilities for sleep problems. They reported the most frequent sleep problem to be night waking, which occurred in approximately half of their sample.

A number of individuals with intellectual disabilities suffer from brain damage or neuromaldevelopment. Neurological impairments such as severe locomotor disability, blindness, and epilepsy were found to be predictors of sleep problems in persons with mental retardation (Lindblom, Heiskala, Kaski, Leinonen, Nevanlinna, Iivanainen, & Laakso, 2001). Further, damage to the structures that regulate REM sleep (pontine and forebrain), circadian rhythms
(suprachiasmatic nucleus), and activation and arousal (ascending reticular formation) will likely lead to disorders of these sleep systems. Indeed, REM sleep phase is one area in which abnormalities may be found between persons with intellectual disabilities and the general population (Grubar, 1983).

Breathing problems are an area that is of particular risk for persons with intellectual disabilities. Problems related to breathing may result from any physical abnormality that compromises an individual’s ability to breathe easily such as craniofacial abnormalities, scoliosis of the spine, and disorder of the upper airway. Stores et al. (1996) found that children with Down’s syndrome were particularly vulnerable to breathing related sleep problems. These differences are most likely due to the physical differences found in Down’s syndrome, particularly concerning craniofacial development.

In addition to physical abnormalities, the problem of discerning the etiology of sleep problems is further complicated by the prevalence of medication use in this population. Lipman (1970) found that psychotropic medications were taken by 51% of persons living in a residential facility. A high prevalence of psychotropic use among persons with intellectual disabilities not living in institutions has also been reported. Aman, Sarphare, and Burrow (1995) reported the prevalence of receiving psychotropic medications to be 27% among persons with intellectual disabilities living in community group homes. The most common psychotropics were neuroleptics and anticonvulsants. Common side effects included sedation, daytime fatigue, REM disturbance, and disturbed nocturnal sleep (Hoeppner, Garron, & Cartwright, 1984; Wetter, Lauer, Gillich, & Pollmächer, 1996). Medication use may account for a number of the reports of sleep problems among these individuals. However, no systematic studies evaluating the role of psychotropic drug use on sleep problems in this population have been conducted.
Another factor that requires consideration is that a large number of individuals with intellectual disabilities suffer from seizure disorders. The abnormal brain activity associated with seizures has the potential to alter a number of sleep systems. However, Espie and Tweedie (1991) point out that this has been widely overlooked by researchers evaluating sleep disorders in persons with intellectual disabilities. The frequent misdiagnosis of parasomnias as seizures and vice-versa is further complicated in this population, who have a much higher incidence rate of both seizure and sleep disorders (Deb & Joyce, 1999; Shepard, & Hosking, 1989; Steffenburg, Hagberg, & Kylerman, 1996). The cyclical nature of sleep and seizure disorders only further serves to increase the risk for persons with intellectual disabilities to develop sleep problems.

Persons with intellectual disabilities are a population warranting significant inquiry concerning sleep problems. However, relative to the enormous body of research on sleep disorders in the general population, these problems in persons with intellectual disabilities have been overlooked. Of those studies that have been concerned with sleep problems in persons with intellectual disabilities, most only looked at sleep in children. Indeed, the only measure specifically designed to evaluate sleep problems in this population, the BEDS, is designed for use with children (Schreck, 1997/1998).

Treatment of Sleep Disorders in Intellectual disabilities

The treatment of sleep disorders is highly specific to the particular symptom manifestation. While there is a good deal of discussion concerning whether behavioral or pharmacological treatments should be used as first line treatments, a recent meta-analysis by Smith, Perlis, Park, Smith, Penington, Giles, and Buysse (2002) found both approaches to be equally efficacious. Identifying specific environmental and behavioral variables may lead to simple but effective treatments, without the risk of side-effects. However, Didden and Sigafoos
(2001) point out the general lack of well-controlled treatment studies in persons with intellectual disabilities. Nonetheless, there is a growing body of research available to suggest the efficacy of a number of treatments (Lancioni, O’Reilly, & Basili, 1999).

**Light therapy**

Light therapy is a relatively easy and inexpensive method for treating sleep problems such as insomnia or circadian rhythm disorder. Light therapy may consist simply of exposure to bright natural or artificial light. Light therapy takes advantage of the strong role that light plays as a zeitgeber. Exposure to bright lights is a well-established treatment in the general population. However, little has been done to explore the effectiveness of this treatment in persons with intellectual disabilities. The available evidence does indicate though that light therapy may be effective with this population. For example, Short and Carpenter (1998) report on the case of a 34 year-old with profound mental retardation that had problems with fragmented sleep and daytime drowsiness. Following unsuccessful treatment attempts with sleep hygiene as well as hypnotic medication, a regimen of exposure to direct sunlight for 2 hours each morning was initiated. After two weeks of light therapy, his sleep stabilized and followed a normal pattern. More recently, Altabet, Neumann, and Watson-Johnston (2002) presented three case studies in which light therapy was effectively used to treat sleep problems. They also noted a decrease in irritability as measured by the Aberant Behavior Checklist (Aman & Singh, 1985) and depression as measured by the Diagnostic Assessment for Severe Handicaps (Matson, 1993).

Light therapy is a promising intervention for treating various sleep problems in persons with intellectual disabilities. However, much still needs to be done to determine for which particular sleep problems it is effective. Likewise, more controlled studies are needed before one can accurately gauge its effectiveness.
Chronotherapy

Chronotherapy was first developed as a treatment for delayed sleep phase syndrome. Basically, each day the individual’s bedtime is pushed back by one to two hours. This is continued until the appropriate bedtime is reached. In an evaluation of four congenitally blind children with circadian sleep-wake rhythm disorder, Okawa and colleagues (1987) found that chronotherapy was effective at entraining only one of the four children’s sleep cycles, with two of the children’s sleep cycles responding to hypnotic medications following the failure of chronotherapy. However, there is evidence showing improvement in sleep problems in persons with intellectual disabilities when treated with chronotherapy. For example, Piazza, Hagopian, Hughes, and Fisher (1998) report on the use of chronotherapy to effectively reduce sleep problems in an 8 year-old girl with autism. Chronotherapy was originally designed based upon the belief that the endogenous sleep-wake cycle in humans followed a 25-hour clock and that it would be the easiest approach to resetting the person’s sleep time to the desired schedule. However, later research has shown that the internal clock actually follows a cycle just over 24 hours (24.18), reducing the overall rationale for pushing the bedtimes later rather than earlier (Stepanski & Perlis, 2003). Chronotherapy may be effective in some cases; however, considering the overall efficacy of this approach, other less disruptive methods such as light therapy may be preferred.

Sleep Hygiene

Sleep hygiene consists of day-to-day habits that either improve or degrade the quality and amount of sleep for an individual. Many different sleep hygiene lists have been constructed for research or clinical purposes, however, sleep hygiene lists do not vary dramatically and usually consist of the same core items. These items include: getting up at the same time each day,
keeping your bedroom free from light and noise, avoiding caffeine during the day and particularly in the evening, and avoiding long daytime naps. Good sleep hygiene practices may be of particular concern for persons living in residential care facilities, who often do not have much influence over their daily routines or sleeping environments. Likewise, daytime napping is often a frequent problem. While studies evaluating the use of sleep hygiene in persons with intellectual disabilities as the sole treatment are virtually nonexistent, it has been used as a component in a few studies. For example, Espie and Wilson (1993) report on the use of “optimal scheduling” to improve sleep problems in 5 persons with intellectual disabilities. This procedure was found to improve the overall sleep of the individuals in their study. However, results of their study are limited by an AB design. In another study, Gunning and Espie (2003) found that by using a combination of treatment components, which were individually tailored for each of their 12 participants, sleep problems were effectively treated. The treatment components used in their study included optimal scheduling, sleep hygiene, stimulus control, relaxation, light therapy, and cognitive behavioral therapy.

Sleep hygiene is a basic treatment for good sleep habits. It is usually considered an adjunctive treatment though, requiring other more effective techniques to treat most sleep problems (Smith, et al., 2003). Nonetheless, it is a necessary consideration when dealing with persons with intellectual disabilities, who often do not have much personal control over these decisions. By caretakers making sleep hygiene a factor when determining schedule and environmental changes, the overall sleep quality for many of the individuals in their care may improve.
Faded Bedtime

Faded bedtime procedures have been found to be an effective intervention for bedtime resistance and frequent night waking in children (Kuhn & Elliott, 2003). Fading usually consists of altering the bedtime daily by 30 minutes based upon the child being able to fall asleep within 15 minutes. If the child does not fall asleep within 15 minutes, they are removed from bed and kept awake for a period of an hour. This procedure has been found to be relatively effective in reducing bedtime resistance and frequent night waking in persons with intellectual disabilities. For instance, Piazza and Fisher (1991) evaluated the use of bedtime fading and response cost for reducing sleep problems in 4 children with intellectual disabilities. Using a multiple-baseline across-subjects design, they found that sleep disturbances were significantly reduced as well as levels of appropriate sleep being improved. More recently, Piazza, Fisher and Sherer (1997) compared the efficacy of faded bedtime with response cost to bedtime scheduling. They found that sleep improved significantly more for the children in the faded bedtime with response cost group than in the bedtime scheduling group.

Functional Analysis

Functional analysis is a useful tool to determine the environmental contingencies that cause and maintain behavior. The functional analysis approach is dependent upon the assumption that behavior is learned and maintained by environmental conditions. Much research has been done that validates this assumption (Bachman, 1972; Carr, 1977; Iwata, Dorsey, Slifer, Bauman & Richman, 1994), indicating that even maladaptive behaviors, such as self-injurious behavior (SIB) may also be learned. While it is less likely that some sleep disorders such as BRSD are operantly controlled, other sleep problems such as frequent night wakenings and disturbances are readily affected by behavioral reinforcement (Didden, Curfs, van Driel, & de Moor, 2002).
There is increasing evidence for the use of functional assessment in the treatment of sleep problems in persons with intellectual disabilities. For example, Didden, Curfs, Sikkema, and de Moor (1998) conducted functional assessments for 6 boys with intellectual disabilities. Results of the functional analyses found that parent or caretaker attention maintained nighttime disruptions for 4 of the boys, anxiety for 1 of the boys, and a combination of seizure activity and attention for 1 boy. Extinction procedures were found effective at reducing nighttime disruptions maintained by attention. For the child in whom nighttime disruptions were maintained by anxiety, systematic desensitization was found effective. In a similar study, Didden et al. (2002) conducted individual functional analyses for 3 children and 1 adult with intellectual disabilities who were experiencing sleep problems. Using a multiple-baseline design, they found nighttime disruptions that were maintained by attention to be successfully reduced by extinction. Further, in a multiple-baseline design across subjects, Durand, Gernert-Dott, and Mapstone (1996) found that a combination of graduated extinction and consistent bedtime routines were successful at reducing nighttime wakenings and disturbances.

Considering the functional variables that may maintain sleep problems is a useful step in devising effective treatments for sleep problems in persons with intellectual disabilities (Didden et al., 2002). However, most studies found nighttime disruptions to be maintained by social attention. While it is improbable that social attention maintains all occurrences of nighttime disruptions, studies evaluating the prevalence of the various maintaining variables may be able to identify particular variables that occur frequently, thus streamlining the assessment and treatment process.
Pharmacological Treatments

Pharmacological interventions are designed to primarily address one of two problems, excessive daytime sleepiness or insomnia. First line treatment for excessive daytime sleepiness is to target the underlying cause, which should be determined by a thorough evaluation. However, when treatment of the underlying cause is unsuccessful or not possible, psychostimulants may be a viable option. Psychostimulants that act on the sympathetic nervous system are termed sympathomimetic, and include amphetamine derivatives such as dexamphetamine and methylphenidate. Historically the only non-sympatheomimetic psychostimulant popularly used was caffeine, however, a relatively new psychostimulant, modafinil, falls into this class. Methylphenidate is the most commonly prescribed psychostimulant (Challman & Lipsky, 2000), however, it is likely that a large portion of prescriptions for methylphenidate are not to treat daytime sleep disorders but other disorders such as Attention Deficit Hyperactivity Disorder. While the specific mechanism of action for modafinil are unclear, it has a benign side effect profile when compared to dexamphetamine and methylphenidate, which have a high abuse potential (Jasinski, 2000). Recently, modafinil has received a considerable amount of attention from researchers and is rapidly becoming the drug treatment of choice for excessive daytime sleepiness (Banerjee, Vitiello, & Grunstein, 2004). However, no controlled studies of modafinil in persons with intellectual disabilities have been conducted.

Most pharmacological treatments for sleep disorders have addressed insomnia. While new agents are under development, all currently approved hypnotics act on the gama-aminobutyric acid (GABA)- benzodiazepine receptor complex and are still considered the drug class of choice to treat insomnia (National Institute of Mental Health, 1984). In a survey of psychiatrists and internist, Silberman (1998) found a generally negative view of using
benzodiazepines for sleep problems. Likewise, prescription hypnotic use appears to be decreasing (Mendelson, et al., 2004). In a 20-year review, Balter and Uhlenhuth (1991) report a drop from 3.5 to 2.5% in persons who had been prescribed a hypnotic sleep agent. Further evidence of the decline in hypnotic prescriptions can be seen in the 10-year review by Schweitzer and Walsh (1998), who found a 20% decline in the use of hypnotic agents to treat sleep problems.

While the use of hypnotic agents may be decreasing, there has been a dramatic increase in off-label use of antidepressants and anxiolytics (Mendelson et al., 2004). Further, the frequency with which over-the-counter medications are used to treat sleep problems should not be underestimated. Johnson, Roehrs, Roth, and Breslau (1998) found that alcohol and over-the-counter sleep aids were the most common methods used to treat sleep problems. Antihistamines and alcohol are readily available for most adults and do not require the time or expense of a doctor’s visit, which may account for their frequency of use over other sleep inducing agents.

Few researchers have examined the use of pharmacological treatments for sleep problems in persons with intellectual disabilities. Despite the widespread use of these agents in persons with intellectual disabilities and the high prevalence of sleep problems in this population, little has been done to generalize the results found in general population studies to an understanding of the effectiveness of pharmacological treatments for persons with intellectual disabilities. What research exists appears to pertain almost exclusively to melatonin.

Melatonin is a well-established treatment for sleep problems in the general population that has received increasing attention for use in persons with intellectual disabilities. Melatonin administration has the opposite effect of exposure to bright light in that it advances the onset of sleep when taken in the evening whereas light exposure pushes sleep onset back (Lack &
There is some evidence suggesting the efficacy of melatonin administration in persons with intellectual disabilities. Jan, Espezel, and Appleton (1993) reported on 15 case studies in which melatonin treatment was found to significantly improve sleep. Likewise, Palm, Blennow, and Wetterberg (1997) found that melatonin treatment was effective for treating disturbed circadian sleep-wake rhythms in eight children. However, similar results have not been found in more rigorous experimental designs. For instance, in a series of 6 double-blind single-subject experiments, Camfield, Gordon, Dooley, and Camfield (1996) report a general lack of response to melatonin. While some benefit was found as far as increasing overall sleep, the amount of increase was not clinically significant enough for the families of the participants to consider the long-term use of melatonin (Camfield et al., 1996). There is substantial evidence from studies of melatonin administration in the general population to expect melatonin administration to be effective in persons with intellectual disabilities. However, in light of the finding by Camfield et al. (1996), it is clear that more rigorous experimental studies are needed.

Considering the overall effectiveness of pharmacological interventions to treat sleep problems in the general population, it is unfortunate that so little has been done to evaluate its use in persons with intellectual disabilities. This is particularly striking in light of the comparatively high use of psychotropic medications in this population. One cannot simply assume that these interventions will have the same effects in persons with intellectual disabilities as has been found in the general population. More experimentally sound studies focusing on the use of these treatments in persons with intellectual disabilities are needed.
RATIONALE

Sleep, a process often taken for granted, can disrupt many different areas of a person’s day-to-day living if significant problems develop (Breslau et al., 1996; Ford & Kamerow, 1989). Persons with intellectual disabilities frequently have a number of additional medical and psychological conditions, occurring at a much greater rate than in the general population. Indeed as discussed here, sleep disorders appear to occur at a much higher rate than in the general population based on available evidence (Stores et al., 1996). However, since most of these studies did not use measures designed for persons with intellectual disabilities, solid conclusions are tentative despite the serious potential for poor quality of life for these persons. Indeed, using scales that have been designed for use in the general population has multiple limitations when applied to persons with intellectual disabilities (Favell, Realon, & Sutton, 1996; Green, Gardner, & Reid, 1997). First, the format of most of these measures does not fit well. Almost all of the questionnaires that have been designed to assess sleep disorders in the general population rely on self-report. Many persons with intellectual disabilities are nonverbal and unable to report on issues such as sleep quality or duration, and even for those persons with some verbal skills, the likelihood of being able to comprehend the questions is highly unlikely. These issues are particularly true for those in the severe and profound range of mental retardation. Further, of those who are verbal, their verbal skills are usually poor and thus render any assessment based solely on self-report as incomplete and in need of supplemental sources of information.

In response to these limitations, the SLEEPY was designed to be administered in an indirect format, thus allowing the clinician to inquire about an individual’s sleep behavior without the constraints of the individual’s ability to self-report. Further, the items on the SLEEPY were developed after an extensive review of reported sleep problems in persons with
developmental disabilities. Thus, the content of the SLEEPY is designed to specifically target
sleep problems as they appear in persons with developmental disabilities. While the BEDS
(Schreck, 1997) and the DASH-II (Matson, 1993) have been developed to assess for sleep
problems in this population, the BEDS was designed for the assessment of sleep problems in
children. Little is known concerning the developmental course of sleep problems across the
lifespan for individuals with developmental disabilities. It is likely that the type of sleep
problems will differ as the individual ages, as is seen in the general population. The DASH-II has
been developed to screen for psychopathology in adults. However, as is the nature of screening
instruments, the content is limited and designed to alert care-providers to areas that require
further inquiry. The SLEEPY was designed to serve as a systematic method to be used as that
second line of inquiry or as a stand-alone assessment for possible sleep problems.

Nonetheless, for such a scale to have utility, its reliability and validity need to be
established. The present study reports on the development of the SLEEPY and serves as an initial
effort to evaluate its reliability and validity. In particular, an item analysis was conducted to
remove any items with poor reliability or low endorsement. Secondly, the factor structure of the
remaining items was evaluated to develop subscales of the SLEEPY. Further, the test-retest and
inter-informant reliability of the subscales were evaluated. Finally, the validity of the SLEEPY
was evaluated in two ways. First, scores on the SLEEPY were compared to scores on the DASH-
II sleep subscale. Secondly, responses to SLEEPY items were compared to direct behavior
observations for a 24-hour period.

The development of a scale to reliably and validly assess sleep problems in this
population is of considerable importance. Such a scale has the potential to do much to improve
the quality of life for individuals with developmental disabilities who have suffered from sleep
problems that have gone unnoticed. Further, research in the epidemiology and treatment of sleep problems in persons with developmental disabilities has been hindered by the absence of systematic means of assessment.
METHOD

Participants

All participants were recruited from Pinecrest Developmental Center (PDC) in Pineville, Louisiana. PDC is a residential developmental center that provides services for approximately 580 individuals with intellectual disabilities. Residents at PDC present with a variety of physical and intellectual disabilities. Most of the individuals at PDC function in the range of severe and profound mental retardation.

The SLEEP Problems InventorY (SLEEPY) is an indirect measure of sleep problems that is designed to be administered in an interview format with a staff member who is familiar with the day-to-day behavior of the individual. At PDC, each direct care staff member (group leader) provides services for three to four individuals. Thus, the same person may serve as an informant for up to four different individuals. Institutional Review Board approval for this project was obtained through a previous proposal entitled: “Norming Psychological Assessment Battery for Treatment Plans”.

A total of 400 participants were recruited. These individuals were randomly selected from the overall population of residents at PDC. The sample of 400 participants consisted of 216 males and 184 females. Age ranged from 18 to 87 years (mean = 50.61 SD=13.36). Deafness was present in 25 individuals (6.3%), blindness in 54 (13.5%), seizure disorder in 149 (37%), 226 were nonverbal (56.5%), and 136 were non-ambulatory (34%). The majority of the participants functioned within the range of profound mental retardation (75%). Table 1 displays the demographic information for the entire sample of 400 participants.
Table 1

Demographic Characteristics of Participants

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<tr>
<td>22-45</td>
<td>129</td>
<td>32.3</td>
</tr>
<tr>
<td>46-65</td>
<td>213</td>
<td>53.3</td>
</tr>
<tr>
<td>66+</td>
<td>55</td>
<td>13.8</td>
</tr>
<tr>
<td>Level of Mental Retardation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>5</td>
<td>1.3</td>
</tr>
<tr>
<td>Moderate</td>
<td>21</td>
<td>5.3</td>
</tr>
<tr>
<td>Severe</td>
<td>41</td>
<td>10.3</td>
</tr>
<tr>
<td>Profound</td>
<td>301</td>
<td>75.3</td>
</tr>
<tr>
<td>Unspecified</td>
<td>32</td>
<td>8</td>
</tr>
</tbody>
</table>

Inter-Informant Reliability

For a scale to have utility, staff and others familiar with the client must be able to generally agree on which sleep items do and do not occur. In an effort to assess for error variance due to differences among direct-care staff reports, 20% of the overall sample received independent administrations of the SLEEPY by the same interviewer with an additional staff member who had known the participant for at least 6 months and reported knowing well the daily behavior of the participant. Because the SLEEPY is scored on an interval scale, the most appropriate measure of inter-informant reliability is the Pearson product-moment correlation (Haynes & O’Brien, 2000). Correlations were computed between raters in regards to severity as well as for dichotomous scores (endorsement of the item occurring or not).

Participants were randomly selected from the overall participant pool of 400 individuals. The demographics from the inter-informant sample reflect those of the overall study sample. Demographic information for the inter-informant sample is shown in Table 2.
Table 2

Demographic Characteristics of Participants in the Inter-Informant Sample

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>44</td>
<td>54.3</td>
</tr>
<tr>
<td>Female</td>
<td>37</td>
<td>45.7</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-21</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>22-45</td>
<td>22</td>
<td>27.2</td>
</tr>
<tr>
<td>46-65</td>
<td>44</td>
<td>54.3</td>
</tr>
<tr>
<td>66+</td>
<td>14</td>
<td>17.3</td>
</tr>
<tr>
<td><strong>Level of Mental Retardation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>2</td>
<td>2.5</td>
</tr>
<tr>
<td>Moderate</td>
<td>2</td>
<td>2.5</td>
</tr>
<tr>
<td>Severe</td>
<td>7</td>
<td>8.6</td>
</tr>
<tr>
<td>Profound</td>
<td>66</td>
<td>81.5</td>
</tr>
<tr>
<td>Unspecified</td>
<td>4</td>
<td>4.9</td>
</tr>
</tbody>
</table>

Test-Retest Reliability

In order to assess for error variance due to time sampling, 20% of the overall sample of participants received a second administration by the same interviewer with the same informant following a 1-2 week interval. The error variance between administrations may be influenced by a number of factors including non-standardized administration, environmental changes, and changes in the informant such as mood or level of arousal (Anastasi & Urbina, 1997). Regardless of the source of variance, the more susceptible a measure is to changes in variables other than that of the target construct, the less useful that measure becomes. Test-retest reliability was computed between raters in regards to severity. The reliability coefficient is an index of agreement between subsequent administrations of a measure by the same person (Anastasi & Urbina, 1997). For the present study, the reliability coefficient was computed by the Pearson product-moment method.

Participants for the test-retest sample were randomly selected from the overall participant pool of 400 individuals. The demographics from the test-retest sample also reflect those of the
overall population. However, subjects selected for the test-retest sample had slightly more males than females, which is the opposite of the overall sample. Demographic information for the test-retest sample is shown in Table 3.

Table 3
Demographic Characteristics of Participants in the Test-Retest Sample

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Frequency</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>35</td>
<td>43.8</td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>56.3</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-21</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>22-45</td>
<td>24</td>
<td>30</td>
</tr>
<tr>
<td>46-65</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>66+</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Level of Mental Retardation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>1</td>
<td>1.3</td>
</tr>
<tr>
<td>Moderate</td>
<td>7</td>
<td>8.8</td>
</tr>
<tr>
<td>Severe</td>
<td>9</td>
<td>11.3</td>
</tr>
<tr>
<td>Profound</td>
<td>57</td>
<td>71.3</td>
</tr>
<tr>
<td>Unspecified</td>
<td>6</td>
<td>7.5</td>
</tr>
</tbody>
</table>

Measures

Rating Scales

Over the past 10 years, rating scales have emerged as a viable means of assessing for disorders or measuring skills in persons with intellectual disabilities (Matson & Bamburg, 1998; Matson, LeBlanc, Weinheimer, & Cherry, 1999). Typically, they are administered in an interview format with a person who is familiar with the individual such as a direct-care staff member or a parent. Rating scales used in the present study included the SLEEPY and the DASH-II.

SLEEPY

The SLEEPY is a measure designed to assess for symptoms of sleep disorders in persons with developmental disabilities. The items on the SLEEPY were constructed by reviewing
reports of particular symptoms of sleep disorders in persons with developmental disabilities in published studies over the past 20 years. The SLEEPY was designed to be administered in an interview format to a person who is familiar with the day-to-day behavior of the individual being assessed. Items on the SLEEPY consist of statements about sleep-related behaviors of the individual (i.e. “Will fall asleep if not otherwise occupied”). Each item of the SLEEPY is rated on a three-point scale concerning the accuracy of the statement as well as the duration of the behavior. The SLEEPY consists of both the questionnaire and a score sheet.

The SLEEPY is designed to serve two purposes. First, to act as a screening device that alerts care providers to the possible presence of a sleep disorder, with the goal of leading to more accurate referrals for the less efficient but more definitive procedures such as polysomnography. The second goal of the SLEEPY is to provide areas for possible immediate intervention.

Diagnostic Assessment for the Severely Handicapped-II (DASH-II)

The DASH-II is an 84-item, informant-based screening tool designed to provide information for the diagnosis of psychopathology for persons within the severe and profound range of mental retardation. The scale is comprised of subscales representing 13 diagnostic categories: (1) anxiety, (2) depression, (3) mania, (4) autism and other pervasive developmental disorders, (5) schizophrenia, (6) stereotypies and tics, (7) self-injurious behavior (8) elimination disorders, (9) eating disorders, (10) sleep disorders, (11) sexual disorders, (12) organic syndromes, and (13) impulse control and other miscellaneous behaviors. All items are rated on frequency, duration, and severity on a 0-2 Likert scale.

Behavior Observations

Sleep data was collected using momentary time-sampling (MTS) with 30-minute intervals. Each participant was observed individually for a period of 2 minutes. The observations
continued for a 24-hour period, resulting in 48 observations per participant. During the observation period the observer recorded the behavior of the participant as well as various environmental variables. Operational definitions for the target behaviors consisted of 1) sleeping: defined as eyes closed, all movement or vocalizations appear sleep related; 2) snoring: defined as audible breathing difficulties causing harsh snorting noises; 3) out of bed: not in bed for any reason, regardless of sleep status; 4) in bathroom: defined as in bathroom regardless of activity or sleep status; and 5) bruxism: defined as audible grinding or clicking noises while sleeping. Environmental variables consisted of 1) temperature, as measure by a thermometer, 2) sound level, as measured by a decibel meter; and 3) level of light, defined as dark, no light; dim, partial light; or light, room lights on or in direct sunlight. These target behaviors and environmental variables were selected to correspond to various items on the SLEEPY.

A second independent observer recorded data in order to compute the inter-informant reliability of the behavior observations. For the inter-informant reliability observations, both observers entered the room and observed the individual at the same time. Inter-informant reliability data were collected on 20% of the sleep log participants. While a second observer was available to collect reliability data for 100% of the sleep log sample, inter-informant observations were limited to 20% in an effort to reduce any disturbance that the observations may have caused to the participants. Agreement was defined as an interval in which both the primary and secondary observer recorded the same occurrence of a behavior. Agreement between observers were computed by dividing the number of agreements by the number of agreements plus disagreements, then multiplying by 100 (Alberto & Troutman, 2003). Due to unforeseen schedule changes among the participants in the sleep log sample, the two data collectors for the daytime period were required to both serve as primary observers at different
locations. Thus, calculations of the inter-informant reliability for the sleep log observations were only available for the nighttime observations. Inter-informant reliability for the nighttime observations was 100%.

**Procedures**

The SLEEPY was administered to direct-care staff by master’s-level clinicians. Informants were selected based upon extensive experience with the participant (i.e., each informant must have worked with the respective study participant for at least six months). In most circumstances, the person who was the most qualified to serve as an informant was the individual’s group leader. Further, the items on the SLEEPY are designed to measure sleep problems that may occur throughout the entire 24-hour period. Because of the different times in which sleep problems may occur, a single informant may not be able to report accurately concerning behaviors that primarily occur when they are not present. For this reason, the initial items on the SLEEPY were divided into two sections: Morning/Day and Evening/Night. Informants responded to the items that corresponded to the time-period in which they primarily cared for the participant. Items from the remaining time-period were completed by an additional informant who primarily cared for the participant during that time-period. The SLEEPY is administered in an interview (masters level psychologist), interviewee (direct care staff) format. If the participant had been selected for the inter-informant reliability sample, an additional SLEEPY was administered to another informant. If the participant had been selected for the test-retest reliability sample, the same interviewer administered an additional SLEEPY to the same informant following a 1-2 week interval.
Factor Analysis

Factor analysis is commonly used in scale development as a means to construct subscales. This procedure serves to simplify data by grouping together variables that are related to one another. Factor analysis is a useful procedure for summarizing information obtained from individual variables. While a useful tool, this procedure may not be appropriate or useful in all situations, as discussed by Guilford (1952). There are a number of issues to bear in mind when considering a factor analysis, among these are the minimum sample size needed, how many factors to extract, and which extraction method is to be used.

For the present study, a total sample size of 400 was used. The SLEEPY consists of an initial item pool of 72 items, many of which sample the same domain. While this ratio (5.5:1) is sufficient to meet the minimum criteria set by a number of researchers (e.g. Gorsuch, 1983), the expected factor correlations were unknown, and thus the stability of the factor solution may be compromised. However, as the SLEEPY underwent an item analysis to remove unreliable or unendorsed items prior to the factor analysis, the ratio of participants to items was much higher than the 5:1 guideline.

For the exploratory factor analysis, the number of components to retain was determined by computing a parallel analysis. Following the parallel analysis, an exploratory principal components analysis was conducted, setting the number of factors to extract to that determined by the parallel analysis. Items were assigned to the factor with the greatest loading. To be included in a subscale, item loadings had to be above 0.4 (Gorsuch, 1983).

As the staff at PDC typically serve more than one individual at a time, it was expected that the same person may have served as an informant for more than one questionnaire. It may be argued that questionnaires using the same informant may not be sufficiently independent to
appropriately run a factor analysis. A lack of independence poses the potential to introduce systematic bias into the results of the analysis. Further, without examination, the stability of the factor solution may not be assumed (Gorsuch, 1983). To evaluate for a lack of independence and to evaluate the replicability of the factor structure found by the exploratory analysis, a second exploratory analysis was conducted. For the second exploratory analysis, only one questionnaire per informant was used. The second exploratory analyses included 201 completed questionnaires.

Construct Validity

In establishing the validity of a measure, it is important to show that it both measures the intended construct as well as not measuring unintended constructs. This is known as convergent and discriminant validity (Anastasi & Urbina, 1997; Campbell & Fiske, 1959). The multi-trait multi-method system as described by Campbell and Fiske (1959) is difficult to conduct concerning a measure such as the SLEEPY. While an appropriate comparison measure, the DASH-II, has been developed, the broad scope of this measure may limit comparisons to the SLEEPY. Second, because of the widespread effect that sleep problems may have on the functioning of an individual, a variety of domains may be related to elevations on the subscales of the SLEEPY. Thus domains that traditionally conceptualized as unrelated such as autistic behavior may indeed have sleep problems as significant predictors (Schreck, Mulick, & Smith, 2004). Further, as discussed earlier, sleep problems may significantly impact depression, anxiety, and challenging behaviors (Brylewski & Wiggs, 1999; Didden et al., 2002). Because of this widespread impact, it is difficult to suggest which domains should not be related to sleep problems, indeed, to do so may be premature considering the available literature.
To evaluate the validity of the SLEEPY, responses to the DASH-II sleep items were compared to the corresponding SLEEPY items. Pearson product-moment correlations were computed between the subscales and corresponding items on the SLEEPY with the DASH-II sleep items.

In order to evaluate the predictive validity of the SLEEPY, responses to SLEEPY items were compared directly to behavioral observations. Participants were classified into categories for each relevant item of the SLEEPY. Scores of 0 were classified as “No”, 1 as “Maybe”, and 2 as “Yes”. These classifications were then compared to the corresponding data from the sleep log observations. For the sleep log groups, participants were classified in regards to if they had been observed engaging in the corresponding target behavior. Correct and incorrect classification rates were then computed for each relevant item of the SLEEPY.
RESULTS

Item Analysis

Each item on the SLEEPY was evaluated for overall variance of responses. Clark and Watson (1995) recommend the elimination of items in which virtually all of the respondents endorse or deny. In an overview of the development process of measures of this nature, Hagino (2002) reports that the cut-off of 80 percent is commonly used. However, Clark and Watson (1995) give the guideline of 95 percent. For the present study, any item that 90 percent or more of the informants answered “no” to was removed from the final questionnaire prior to the factor analysis. A total of 26 items were removed due to low endorsement. The items removed due to low variance are listed in Table 4.

While item elimination due to low endorsement is important to streamline assessment and reduce unstable correlations (Comrey, 1978), it is important not to eliminate construct-relevant items even when endorsement is low (Clark & Watson, 1995). This is particularly the case when the expected base-rate of the construct is low. Four items fell within this category in that they met the 90 percent or more criteria for removal but were not removed due to clinical importance and expected low base-rate of “yes” responses. These items include: 44. Has trouble breathing while sleeping, 57. Stops breathing while sleeping, 65. Gags or chokes while sleeping, and 68. Awakens during the night gasping for breath.

Table 4

<table>
<thead>
<tr>
<th>SLEEPY Item</th>
<th>% “No”</th>
</tr>
</thead>
<tbody>
<tr>
<td>3. Complains of headaches in the morning</td>
<td>97</td>
</tr>
<tr>
<td>24. Smokes cigarettes before going to bed</td>
<td>98</td>
</tr>
</tbody>
</table>

(Table 4 continued)
<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>30.</td>
<td>Complains of loud noises during the night</td>
<td>97</td>
</tr>
<tr>
<td>31.</td>
<td>Uses tobacco before going to bed</td>
<td>97</td>
</tr>
<tr>
<td>32.</td>
<td>Complains of light disturbing sleep</td>
<td>98</td>
</tr>
<tr>
<td>33.</td>
<td>Complains of others disturbing him/her while sleeping</td>
<td>95</td>
</tr>
<tr>
<td>34.</td>
<td>Complains that the bedroom is too hot/cold</td>
<td>97</td>
</tr>
<tr>
<td>35.</td>
<td>Eats a large snack before bed</td>
<td>91</td>
</tr>
<tr>
<td>41.</td>
<td>Cries during the night</td>
<td>94</td>
</tr>
<tr>
<td>45.</td>
<td>Sleeps in another’s bed</td>
<td>99</td>
</tr>
<tr>
<td>46.</td>
<td>Does not want to sleep in his/her own bed</td>
<td>98</td>
</tr>
<tr>
<td>48.</td>
<td>Sleepwalks</td>
<td>100</td>
</tr>
<tr>
<td>49.</td>
<td>Talks while sleeping</td>
<td>98</td>
</tr>
<tr>
<td>52.</td>
<td>Is afraid of noises at night</td>
<td>98</td>
</tr>
<tr>
<td>53.</td>
<td>Is afraid to fall asleep</td>
<td>99</td>
</tr>
<tr>
<td>55.</td>
<td>Requires medication to fall asleep</td>
<td>98</td>
</tr>
<tr>
<td>56.</td>
<td>Sleeps poorly without medication</td>
<td>97</td>
</tr>
<tr>
<td>60.</td>
<td>Rocks himself/herself to sleep</td>
<td>93</td>
</tr>
<tr>
<td>61.</td>
<td>Awakens complaining of nightmares</td>
<td>99</td>
</tr>
<tr>
<td>62.</td>
<td>Has a lengthy bedtime routine</td>
<td>95</td>
</tr>
<tr>
<td>64.</td>
<td>Requires medication to sleep through the whole night</td>
<td>98</td>
</tr>
<tr>
<td>66.</td>
<td>Has difficulty falling back to sleep when awoken during the night</td>
<td>91</td>
</tr>
<tr>
<td>69.</td>
<td>Moves legs while sleeping</td>
<td>91</td>
</tr>
<tr>
<td>70.</td>
<td>Moves arms while sleeping</td>
<td>92</td>
</tr>
<tr>
<td>71.</td>
<td>Makes loud noises while sleeping</td>
<td>95</td>
</tr>
<tr>
<td>72.</td>
<td>Has roommate who snores loudly</td>
<td>90</td>
</tr>
</tbody>
</table>

**Item Test-Retest Reliability**

Items were further evaluated for stability over time. Pearson product-moment correlation coefficients were computed for each SLEEPY item between administrations for the test-retest.
sample. Items with coefficients below 0.5 were removed from the questionnaire before the factor analysis. A total of 15 items were removed due to low correlation coefficients. The items removed due to poor reliability are listed in Table 5.

Table 5

Items Removed due to Reliability Below 0.5

<table>
<thead>
<tr>
<th>SLEEPY Item</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Is sluggish when awoken</td>
<td>.428</td>
</tr>
<tr>
<td>12. Difficult to awaken in the morning</td>
<td>.390</td>
</tr>
<tr>
<td>20. Goes to bed earlier than his/her peers</td>
<td>.338</td>
</tr>
<tr>
<td>22. Sleeps more than 10 hours a day</td>
<td>.417</td>
</tr>
<tr>
<td>26. Drinks caffeinated beverages within 4 hours of bedtime</td>
<td>.350</td>
</tr>
<tr>
<td>38. Snores loudly</td>
<td>.349</td>
</tr>
<tr>
<td>39. Wakes up frequently during the night</td>
<td>.449</td>
</tr>
<tr>
<td>42. Has difficulty relaxing before bed</td>
<td>.457</td>
</tr>
<tr>
<td>43. Yells during the night</td>
<td>.398</td>
</tr>
<tr>
<td>47. Grinds teeth while sleeping</td>
<td>.248</td>
</tr>
<tr>
<td>51. Has difficulty relaxing at night</td>
<td>.435</td>
</tr>
<tr>
<td>54. Awakens during the middle of the night</td>
<td>.467</td>
</tr>
<tr>
<td>63. Awakens shortly after falling asleep</td>
<td>.372</td>
</tr>
<tr>
<td>65. Gags or chokes while sleeping</td>
<td>-.018</td>
</tr>
<tr>
<td>67. Does not keep a regular sleep schedule</td>
<td>.220</td>
</tr>
</tbody>
</table>

In reviewing the remaining items, it was noted that the majority of the items written to address environmental factors that could cause or exacerbate sleep problems had been removed during the previous two steps of item analysis. Thus, it was decided to remove the remaining items designed to address environmental factors. In total, 5 items were removed for this reason.
These items include: 6. The bedroom is brightly lit before he/she awakes, 21. Sleeps with night-light, 27. Gets woken up by noise, 28. Bedroom is noisy while he/she is sleeping, 29. Sleeps with room lights on. Following the item elimination, a total of 26 items remained.

Factor Analysis

To determine the number of components for the factor analysis, a parallel analysis was conducted. However, this is not a standard analysis available in the most popular statistical programs (SPSS & SAS). Fortunately, O’Connor (2000) provides the SPSS syntax necessary to conduct this analysis. The syntax may also be downloaded from the following internet address: http://flash.lakeheadu.ca/~boconno2/nfactors.html. Results of the parallel analysis indicated that a 4-factor model was the most appropriate.

An exploratory factor analysis was conducted using SLEEPY item scores for the total sample of 400 participants. A principal components analysis with varimax rotation and holding the number of factors to 4 as determined by the parallel analysis (O’Connor, 2000) accounted for 43.8% of the observed variance. A secondary principal components analysis using promax rotation found the same factor structure as the initial analysis that used varimax rotation, indicating that the factors are likely orthogonal (Gorsuch, 1983).

Items were assigned to the factor with the greatest loading. However, item 19 was not assigned to a factor due to an undifferentiated pattern of loading (Gorsuch, 1983). Likewise, item 40 was not assigned to a factor due to failure to meet the minimum loading of .4. Items 10, 15, and 16 did not meet the minimum criteria of .4 to be assigned to a factor. However, as their factor loading approached this level and met the commonly used but less stringent criteria for factor loadings of .3 (e.g. Schreck, Mulick, & Rojahn, 2003) as well as considering that the item
content matched the apparent theme of the factor, they were interpreted as meaningful to their respective factor (Gorsuch, 1983). See table 6 for specific factor loadings.

From viewing table 6, it is evident that Items that loaded on the first factor primarily consisted of daytime somnolence such as taking naps during the day, falling asleep at least once during the day and appearing drowsy during the day. Thus, the first factor was titled “Daytime Somnolence”. The second factor has the highest loadings with items concerning lack of sleep, nighttime wakening, arising extremely early in the morning, and getting out of bed during the night. Thus, factor two was titled “Sleep Maintenance”. Items loading on the third factor consisted of problems with waking-up and sleeping longer than others. Thus the third factor was titled “Hypersomnia”. Items loading on the fourth factor were concerned exclusively with breathing related sleep problems, thus this factor was titled “Breathing Related Sleep Problems”.

Table 6

Factor Loadings and Percent Variance for Exploratory Analysis

| Factor 1: Daytime Somnolence (17.5%) |
|-------------------------------|------------------|
| Item # | Item                          | Factor Loading |
| 1      | Takes naps during the day      | .757            |
| 2      | Falls asleep when bored        | .798            |
| 4      | Will fall asleep if not otherwise occupied | .741          |
| 7      | Appears sleepy during the day  | .686            |
| 8      | Falls asleep at least once during the day | .824          |
| 14     | Appears drowsy during the day  | .644            |
| 15     | Is inactive during the day     | .388            |

| Factor 2: Sleep Maintenance (11.9%) |
|-------------------------------|------------------|
| Item # | Item                          | Factor Loading |
| 17     | Awakens extremely early in the morning | .681          |
| 18     | Gets out of bed early          | .738            |
| 23     | Sleeps less than 6 hours a day | .479            |
| 25     | Is very active before bedtime  | .452            |
| 36     | Wakes up frequently to go to the bathroom | .364          |
| 37     | Drinks fluids before going to sleep | .393          |
| 50     | Disrupts other’s sleep         | .519            |
| 58     | Repeatedly gets out of bed     | .702            |
| 59     | Refuses to go to bed           | .579            |

(Table 6 continued)
Factor 3: Hypersomnia (7.7%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Gets out of bed later than his/her peers</td>
<td>.671</td>
</tr>
<tr>
<td>10</td>
<td>Is disoriented (confused) when awoken</td>
<td>.437</td>
</tr>
<tr>
<td>11</td>
<td>Wakes up looking tired</td>
<td>.557</td>
</tr>
<tr>
<td>13</td>
<td>Sleeps longer than most of his/her peers</td>
<td>.701</td>
</tr>
<tr>
<td>16</td>
<td>Is irritable during the day</td>
<td>.361</td>
</tr>
</tbody>
</table>

Factor 4: Breathing Related Sleep Problems (6.8%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>44</td>
<td>Has trouble breathing while asleep</td>
<td>.738</td>
</tr>
<tr>
<td>57</td>
<td>Stops breathing during sleep</td>
<td>.867</td>
</tr>
<tr>
<td>68</td>
<td>Awakes during the night gasping for breath</td>
<td>.819</td>
</tr>
</tbody>
</table>

In an effort to evaluate the stability of the factor structure, a second exploratory analysis was conducted. For this analysis, one questionnaire was randomly selected from each informant, such that, only one questionnaire per informant was used. The total number of participants for this analysis was 201. Table 7 presents the factor loadings.

Table 7

Factor Loadings and Percent Variance for Second Exploratory Analysis

Factor 1: Daytime Somnolence (17.3%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Takes naps during the day</td>
<td>.760</td>
</tr>
<tr>
<td>2</td>
<td>Falls asleep when bored</td>
<td>.781</td>
</tr>
<tr>
<td>4</td>
<td>Will fall asleep if not otherwise occupied</td>
<td>.732</td>
</tr>
<tr>
<td>7</td>
<td>Appears sleepy during the day</td>
<td>.632</td>
</tr>
<tr>
<td>8</td>
<td>Falls asleep at least once during the day</td>
<td>.838</td>
</tr>
<tr>
<td>10</td>
<td>Is disoriented (confused) when awoken</td>
<td>.416</td>
</tr>
<tr>
<td>14</td>
<td>Appears drowsy during the day</td>
<td>.630</td>
</tr>
</tbody>
</table>

Factor 2: Sleep Maintenance (11.8%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>Awakens extremely early in the morning</td>
<td>.677</td>
</tr>
<tr>
<td>18</td>
<td>Gets out of bed early</td>
<td>.750</td>
</tr>
<tr>
<td>23</td>
<td>Sleeps less than 6 hours a day</td>
<td>.528</td>
</tr>
<tr>
<td>25</td>
<td>Is very active before bedtime</td>
<td>.429</td>
</tr>
<tr>
<td>36</td>
<td>Wakes up frequently to go to the bathroom</td>
<td>.392</td>
</tr>
<tr>
<td>37</td>
<td>Drinks fluids before going to sleep</td>
<td>.363</td>
</tr>
<tr>
<td>50</td>
<td>Disrupts other’s sleep</td>
<td>.438</td>
</tr>
<tr>
<td>58</td>
<td>Repeatedly gets out of bed</td>
<td>.698</td>
</tr>
<tr>
<td>59</td>
<td>Refuses to go to bed</td>
<td>.504</td>
</tr>
</tbody>
</table>

(Table 7 continued)
Factor 3: Breathing Related Sleep Problems (6.2%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>44</td>
<td>Has trouble breathing while asleep</td>
<td>.763</td>
</tr>
<tr>
<td>57</td>
<td>Stops breathing during sleep</td>
<td>.896</td>
</tr>
<tr>
<td>68</td>
<td>Awakes during the night gasping for breath</td>
<td>.829</td>
</tr>
</tbody>
</table>

Factor 4: Hypersomnia (8.2%)

<table>
<thead>
<tr>
<th>Item #</th>
<th>Item</th>
<th>Factor Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Gets out of bed later than his/her peers</td>
<td>.707</td>
</tr>
<tr>
<td>13</td>
<td>Sleeps longer than most of his/her peers</td>
<td>.760</td>
</tr>
<tr>
<td>15</td>
<td>Is inactive during the day</td>
<td>.435</td>
</tr>
<tr>
<td>16</td>
<td>Is irritable during the day</td>
<td>.380</td>
</tr>
</tbody>
</table>

Subscale Inter-Rater Reliability

20 percent of the overall sample of participants were selected to receive a second administration of the SLEEPY using a different staff member as the informant. Pearson product-moment correlations were conducted among SLEEPY subscale and total scores for each administration. Overall, correlations between informants were moderate. Due to a lack of variance on the BRSP subscale among the participants chosen for the inter-rater sample, a reliability coefficient was unable to be computed. Results of subscale correlations between informants are presented in table 8.

Table 8

<table>
<thead>
<tr>
<th>Subscale</th>
<th>r</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: Daytime Somnolence</td>
<td>.568</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 2: Sleep Maintenance</td>
<td>.527</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 3: Hypersomnia</td>
<td>.729</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 4: BRSP</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Total Score</td>
<td>.725</td>
<td>&lt;0.000</td>
</tr>
</tbody>
</table>

Subscale Test-Retest Reliability

To assess for consistency of informant responses to SLEEPY items over time, 20% of the overall sample received a second administration of the SLEEPY with the same informant following a one to two week interval. Pearson product-moment correlations were computed for
each subscale and the total score between each administration. Correlations were again moderate.

Results of subscale and total score correlations between administrations are presented in table 9

Table 9

SLEEPY Subscale Test-Retest Reliability Correlation Coefficients.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>r</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: Daytime Somnolence</td>
<td>.744</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 2: Sleep Maintenance</td>
<td>.636</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 3: Hypersomnia</td>
<td>.731</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Factor 4: BRSP</td>
<td>.779</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>Total Score</td>
<td>.732</td>
<td>&lt;0.000</td>
</tr>
</tbody>
</table>

Validity

To evaluate the validity of the SLEEPY, Pearson product moment correlations were computed between the subscales of the SLEEPY and the sleep scale items of the DASH-II.

Further, the SLEEPY total score was correlated with the DASH-II sleep scale items. Due to lack of variance among responses to the DASH-II item “sleepwalks”, the correlation coefficient was not computed. Results of item correlations between DASH-II sleep scale items and SLEEPY subscales are presented in table 10.

Table 10

Pearson Product Moment Correlation Coefficients for DASH-II Items and corresponding SLEEPY Subscales.

<table>
<thead>
<tr>
<th>DASH-II Item</th>
<th>SLEEPY Subscale</th>
<th>r</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. Has difficulty staying awake during the day.</td>
<td>Daytime Somnolence</td>
<td>.574</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>19. Wakes up frequently during the night.</td>
<td>Sleep Maintenance</td>
<td>.414</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>39. Has difficulty getting to sleep.</td>
<td>Sleep Maintenance</td>
<td>.268</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>79. Wakes up crying or screaming.</td>
<td>Sleep Maintenance</td>
<td>.181</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>14. Has difficulty staying awake during the day.</td>
<td>Total Score</td>
<td>.475</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>19. Wakes up frequently during the night.</td>
<td>Total Score</td>
<td>.372</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>39. Has difficulty getting to sleep.</td>
<td>Total Score</td>
<td>.140</td>
<td>&lt;0.000</td>
</tr>
<tr>
<td>79. Wakes up crying or screaming.</td>
<td>Total Score</td>
<td>.186</td>
<td>&lt;0.000</td>
</tr>
</tbody>
</table>
In order to evaluate the predictive validity of the SLEEPY, responses to SLEEPY items were compared directly to behavioral observations. Table 11 presents the classification of individual SLEEPY items compared to behavioral observations. Results are reported in regards to the number and percent of participants classified by each method.

Table 11

Classification rates for SLEEPY items Compared to Behavioral Observation

<table>
<thead>
<tr>
<th>SLEEPY Item 1</th>
<th>Observed asleep during the day</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Takes naps during the day</td>
<td>No</td>
<td>11 (61%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>2 (11%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>5 (28%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 2</th>
<th>Observed asleep during the day</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls asleep when bored</td>
<td>No</td>
<td>10 (56%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1 (6%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>7 (39%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 4</th>
<th>Observed asleep during the day</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Will fall asleep if not otherwise occupied</td>
<td>No</td>
<td>11 (61%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1 (6%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>6 (33%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 5</th>
<th>Out of bed after wake-up</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gets out of bed later than his/her peers</td>
<td>No</td>
<td>25 (96%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1 (4%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 8</th>
<th>Observed asleep during the day</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls asleep at least once during the day</td>
<td>No</td>
<td>7 (39%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>4 (22%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>7 (39%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 17</th>
<th>Out of bed before wake-up</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Awakens extremely early in the morning</td>
<td>No</td>
<td>17 (71%)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
<td>7 (29%)</td>
</tr>
</tbody>
</table>

(Table 11 continued)
<table>
<thead>
<tr>
<th>SLEEPY Item 18</th>
<th>Out of bed before wake-up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Gets out of bed early</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 23</th>
<th>Less than 6 hours of sleep</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Sleeps less than 6 hours a day</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 44</th>
<th>Snored during the observation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Has trouble breathing while asleep</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SLEEPY Item 58</th>
<th>Observed out of bed during night</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Repeatedly gets out of bed</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Maybe</td>
</tr>
</tbody>
</table>
DISCUSSION

A major limitation in understanding sleep problems in persons with developmental disabilities is the relative lack of reliable and valid assessment tools (Didden & Sigafoos, 2001; Johnson, 1996). The present study was an initial effort to develop a tool for the identification of sleep problems in persons with developmental disabilities. As a part of this process, the psychometric properties of the SLEEPY were examined. In particular, the factor structure, inter-rater reliability, test-retest reliability, and construct validity of the SLEEPY were evaluated. Based upon the results of these analyses, the following conclusions are available.

Factor Structure

An exploratory factor analysis of the SLEEPY using varimax rotation yielded a 4-factor solution. Twenty-four items were grouped into the following factors (1) Daytime Somnolence, (2) Sleep Maintenance, (3) Hypersomnia, and (4) Breathing Related Sleep Problems. These factors address four primary areas in which sleep problems may occur. The purpose in developing this instrument was to provide a means to rapidly assess individuals with developmental disabilities for sleep problems. By providing information concerning these specific domains in which sleep problems may occur, the SLEEPY may meet this purpose and allow clinicians to more quickly determine the area in which to invest more robust but costly assessment methods.

A second exploratory factor analysis was conducted using only one questionnaire per informant to evaluate the stability of the factor structure. Overall, the factors showed good stability. However, three items changed in their factor loadings. Item 10, which was originally assigned to the Hypersomnia subscale, loaded higher on the Daytime Somnolence subscale. Likewise, item 15, which loaded highest on the Daytime Somnolence subscale for the
exploratory analysis loaded highest on the Hypersomnia subscale on the second exploratory analysis. Further, item 11, which was assigned to the Hypersomnia subscale by the exploratory analysis loaded on too many factors to warrant assignment to any particular factor found by the second exploratory analysis.

While the overall factor structure of the SLEEPY did not significantly change between analyses, the instability of these three items is cause for some concern. It is noteworthy that items 10 and 15 did not meet the criteria of factor loadings above .4 but were retained due to apparent homogeneity with the theme of the factor and because they met the less stringent criteria of similar measures (Schreck et al., 2003). The decision to retain these items may have been an error. However, the instability of the factor loadings for these three items may have been a result of an insufficient sample size for the second exploratory principal components analysis (DeVellis, 1991). Future confirmatory principal component analyses on independent administrations of the SLEEPY should help to clarify this issue.

Reliability

Inter-rater reliability coefficients for the SLEEPY total score and subscales fell within the moderate range. While reliability coefficients were not as robust as one might hope, results suggest that informants may reliably report on the day-to-day sleep behavior of the participants for the total score and the Hypersomnia subscale. The Daytime Somnolence and Sleep Maintenance scales showed moderate inter-rater reliability. From these data, it is evident that the person chosen to serve as an informant on the SLEEPY may significantly impact an individual’s Daytime Somnolence and Sleep Maintenance scores. As the individuals who live at PDC are primarily cared for by one person per shift, the secondary informant was most likely less informed about the participant’s day-to-day behavior than the primary care provider. While
criteria were in place to control for the reduced familiarity of the secondary informants with the participant, the assumption that another informant whose duties focus on other individuals would be familiar enough to serve as a knowledgeable informant may have been wrong. Regardless of the source of error, the Daytime Somnolence and Sleep Maintenance subscales should be interpreted cautiously and care should be used to insure that informants are adequately familiar with the individual’s day-to-day behavior.

Test-retest reliability coefficients also fell in the moderate range, suggesting that while they may be susceptible to some variation across a one to two week period, informant responses are fairly stable over time. It is questionable if the difference observed between administrations is true variance or not. While it is presumed that sleep problems will be fairly stable across a two-week period, the lack of studies evaluating sleep problems in persons with developmental disabilities obscures our knowledge of what the true variance is. Thus, it is difficult to discern if the moderate correlations are a threat to the ability of the SLEEPY to reliably measure sleep problems over time. Further research is needed to clarify this issue. In particular, future studies using direct behavior observations across a number of weeks would help to clarify the issue of whether or not sleep problems are stable within this population.

Validity

The DASH-II sleep subscale consists of items that are worded and administered in the same manner as SLEEPY items. Most of the correlation coefficients, while statistically significant, were in the low range. It may be the case that for some items, the questions were phrased in such a way that the informant might have perceived them differently (i.e. DASH-II item 14. “Has difficulty staying awake during the day” and SLEEPY item 4.” Will fall asleep if not otherwise occupied”). Another explanation for this relatively low correlation coefficient may
be the period of time that is queried by the different measures. For items on the SLEEPY, the
informant is instructed to consider the past month and then is asked to rate how accurate the
statement is. Whereas the DASH-II instructs informants to consider the past two-weeks and to
rate how frequently the behavior has occurred. The different criteria will result in the DASH-II
having a smaller window in which the sleep problem may have occurred. Further, the DASH-II
instructs informants to report the frequency of the behavior. In contrast, the SLEEPY items ask
the informant to respond concerning the accuracy of the statement. These two methods differ
significantly. One method relies upon recall of behavior while the other relies upon the
informants overall perception of behavior. Informants responding to the DASH-II items reported
fewer sleep problems than they did on the SLEEPY items. The lower rate of endorsement on the
DASH-II may be due to informants’ inability to recall specific occurrences or apprehension of
over endorsement.

Classification decisions using SLEEPY item scores were compared to classifications
made using direct observations over a period of 24 hours. The classification rates of the SLEEPY
can be interpreted in regards to type 1 and type 2 errors, that is, rejecting the null hypothesis
when it is true (type 1) and retaining the null hypothesis when it is false (type 2). Overall, the
SLEEPY showed very low rates of false positives. However, the occurrence of false negatives
was much higher. Thus, individual SLEEPY items showed good specificity when compared to
behavioral observations but questionable sensitivity.

Regarding specific behavioral observations, the sleep log data “observed asleep during
the day” corresponded to the following SLEEPY items: 1. takes naps during the day, 2. Falls
asleep when bored, and 4. Will fall asleep if not otherwise occupied. The most generally worded
of these items, number 1, showed the highest sensitivity, falsely rejecting only 9% of those
individuals who were observed sleeping during the day. However, the more specifically worded, items of 2, 4, and 8, showed poorer sensitivity, falsely rejecting 54, 36, and 27% of those individual’s who were observed sleeping during the day. It is likely that staff are unsure of the particular cause for napping during the day such as boredom or lack of activities and thus are reluctant to answer in the affirmative to specific causes.

Concerning the observation of “not out of bed after wake-up”, three individuals were observed to not be out of bed. Of these three participants, item 5 misclassified two as not having problems with getting out of bed later than their peers. Similar to the observation “not out of bed after wake-up” the behavior observation “out of bed before wake-up” showed poor correspondence with SLEEPY items 17 and 18. Five participants were observed to get out of bed before the morning staff woke-up their peers. Of these five, items 17 and 18 misclassified 100% as not having problems with awakening early in the morning and getting out of bed early. One explanation for this poor sensitivity is that daytime staff may not arrive early enough to answer these items accurately. Awaking and helping the residents to get ready in the morning are among the final duties of the night staff at PDC. Thus, the daytime staff should not be informants for items 17 and 18.

The SLEEPY item 44 “has trouble breathing while sleeping” showed poor sensitivity when compared to the number of participants who were observed snoring during the behavior observations. Eleven participants were observed snoring for at least one interval throughout the 24-hour observation. Informants responded “no” on item 44 for all eleven of these participants. It may be the case that the informants did not consider snoring as troubled breathing. Considering that item 38 “snores loudly” was removed due to poor reliability, it is questionable if phrasing item 44 to more specifically match the observation of snoring would improve the sensitivity.
Further, Hoffstein and Szalai (1993) reported that clinicians who commonly see patients with sleep problems showed poor sensitivity to breathing related sleep problems. Thus, it should not be surprising informants in the current study, who were not trained in the diagnosis of sleep problems, also showed poor sensitivity.
CONCLUSION

The SLEEPY was designed as a measure to efficiently assess for sleep problems in persons with developmental disabilities. This initial effort presents data on the factor structure, reliability, and validity of the SLEEPY. The factor structure of the SLEEPY resulted in four domains of sleep problems. The same factors were found by a second exploratory principal components analysis. While three items changed in regards to their factor loadings, the overall factor structure of the SLEEPY appeared stable. Adequate inter-rater reliability was shown for the Hypersomnia and BRSP subscales of the SLEEPY. Likewise, the total score showed adequate inter-rater reliability, indicating that informants generally agreed on the overall level of sleep problems in participants. However, the Daytime Somnolence and Sleep Maintenance subscales showed questionable reliability. Thus, care should be used in selecting appropriate informants. To meet this need, future research should evaluate which characteristics are important when considering what constitutes a qualified informant.

Adequate test-retest reliability was found for all of the subscales and the total score of the SLEEPY. Thus, they showed adequate stability for their ratings of sleep problems over time. Multiple-week objective monitoring (such as behavior observations, actigraphy or PSG) of sleep problems should help elucidate the true variability of sleep problems among persons with developmental disabilities. Future test-retest reliability evaluations should be interpreted in light of any new findings.

Evaluation of the validity of the SLEEPY showed mixed results. Comparisons to direct behavioral observations found SLEEPY items to have excellent specificity but low sensitivity to sleep problems. It is worth noting that the informants under-reported sleep problems rather than over-reported. The low sensitivity of the SLEEPY may reflect the degree to which direct care
staff were aware of the less overt sleep behaviors of the participants. Behaviors of long duration such as daytime napping showed better classification rates than other behaviors such as snoring, which may occur covertly and only be notice by direct care staff if they happen to check-in on the individual at that point in time. Indeed, in a study on the relationships between sleep organization, sleep disorders and epilepsy, Bruni, Cortesi, Giannotti, and Curatolo (1995) found that parents missed a high number of brief awakenings relative to PSG.

While the present study found low sensitivity for the SLEEPY to detect sleep problems as measured by behavior observations, results are similar to those reported by Espie et al. (1998) who compared caregiver reports of sleep in sleep-diaries to EEG. Espie et al. (1998) found caregiver report to over-estimate sleep length by approximately 1 hour. Further, the only caregiver variable that predicted the participants’ as appearing “refreshed” upon awakening was an early bedtime, not the number of nighttime awakenings or sleep latency. Thus in both the present study and the results reported by Espie et al. (1998) and Bruni et al. (1995), caregiver report was found to under-report sleep problems but to be significantly related to objective measures of sleep.

The present results concerning informant-report of sleep problems are interesting when compared to findings concerning self-reported sleep problems. Self-reported sleep diaries typically overestimate sleep problems in relation to objective measures of sleep (Tyron, 2004). When using caregivers to report on sleep problems, the opposite trend occurs and sleep problems are underreported relative to objective measures (Espie et al., 1998). It is likely that the low sensitivity of the SLEEPY when compared to behavior observations is due to the caregiver’s tendency to underestimate sleep problems. Perhaps with caregiver training to attend to more
sleep related variables as well as coaching to lower the informant’s threshold for what constitutes problem sleep may increase the sensitivity of the SLEEPY.

Informant based questionnaires offer rapid and less costly means to assess for sleep problems in persons with developmental disabilities. However, indirect assessments are often less valid than direct observations (Johnston & Pennypacker, 1993). The utility of informant based questionnaires is dependent upon the reliability of the informants used to answer items (Smith, et al., 2003). The present study assessed the psychometric properties of the SLEEPY using participants from a large developmental center in Louisiana. Further research is needed to evaluate the psychometric properties of the SLEEPY using different informant populations. For example, it is likely that parents who live with their child with developmental disabilities would have a much better understanding of their child’s daily behavior, particularly in light of their exposure to their child on a 24-hour basis.

On the whole, these data are promising. The results of the present study indicate that further studies evaluating the reliability and validity of the SLEEPY are warranted. The most significant limitation of the SLEEPY appears to center on the degree to which informants may reliably and accurately report on various sleep problems. This issue should be the primary focus of future research.
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