

Do Better Nights Mean Better Days? An Examination of a Behavioural Sleep Treatment  
Program on Health-Related Quality of Life on School-Aged Children

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## **Abstract**

The present study was designed to determine if successful treatment of sleep problems results in improved health-related quality of life (HRQL) for school-aged children both with and without Disruptive Behaviour Disorders. The main hypothesis was that improved sleep would result in improved HRQL (physical, social, and emotional/behavioural health, as well as family well-being). The current study analyzed data collected from a larger sleep study, *Better Nights, Better Days: Treatment for Sleep Difficulties*, a module of the Family Help Program at the IWK Health Centre in Halifax, Nova Scotia. The current study demonstrated that the behaviourally-based sleep intervention of the larger study improved the overall sleep of its child participants, which in turn improved the HRQL. These results indicate that HRQL improves in children whose sleep problems were reduced after completion of a behavioural treatment delivered via distance. This was particularly the case in the psychosocial health domain, which is comprised of scores on subscales from the CHQ-PF50 and measures children's functional health and well-being. Results of the current study are in keeping with the extant body of literature which indicates that treatment of sleep difficulties can lead to improved health across multiple domains of a child's life.

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## Introduction

Sleep problems are frequently found in young children, with estimates of prevalence ranging from 25 to 50 percent in typically developing children and up to 95 percent in children with developmental and behavioural disorders (Roanne, Piazza, Bodnar, & Zimmerman, 2000; Lecendreux, Konofal, Bouvard, Falissard, & Mouren-Simeoni, 2000). Despite the high prevalence, little is known regarding the relationship between sleep difficulties and the quality of life for children in the areas of the health and well-being within physical, emotional, and social domains (Hart, Palmero, & Rosen, 2005).

Sleep is a functional part of our human survival; sleep is necessary in order to function properly throughout the day. Sleep disorders can have detrimental effects on a child's cognitive, social, and physical development if not addressed, especially when considering critical periods of brain maturity (Ferber, 2006; Sadeh, 2003). Furthermore, disrupted sleep patterns in children have significant effects on the well-being of parents and the entire family.

Most current research examines the impact of sleep problems on specific areas of an individual's functioning, including behaviour, learning/cognitive functions (e.g., problem-solving strategies, memory), and psychological development (e.g., depression, anxiety). Few studies, however, have looked at the impact of sleep disturbances on social and emotional development, and health outcomes, or what is also referred to as health-related quality of life (HRQL) (Mindell, 2004; Hepner & Sechrest, 2002). HRQL has been defined as the physical, social and emotional aspects of a patient's well-being that are relevant and important to the individual (Hepner & Sechrest, 2002).

The only study on the impact of sleep on HRQL in relatively healthy children is by Hart et al. (2005) who compared children coming to a pediatric sleep disorders clinic to a normative sample of children in order to determine if the former group would have a poorer HRQL, and whether HRQL is associated with particular sleep diagnosis and sleep behaviours. The researchers used the *Child Health Questionnaire – Parent Form 50* (CHQ-PF50) to compare HRQL between children with and without sleep problems. Results of the study demonstrated that children with sleep disorders showed significantly poorer functioning across all HRQL domains as assessed by the CHQ-PF50 (i.e., general health, change in health, physical functioning, bodily pain, limitations in school work and activities with friends, general behaviour, mental health, self-esteem, time and emotional impact of the parent, and limitations in family activities), with the exception of the scale on family cohesion. This current study aims to explore whether successful treatment of sleep problems results in improved HRQL in children and their families.

### **Review of Literature**

#### *What we know about sleep*

It is still not fully understood why we need sleep, what causes one to sleep, or the purpose that sleep serves (Ferber, 2006). What research does tell us is that sleep is associated with changes in the brain's chemical environment and in its cellular and electrical activity (Ferber, 2006). Sleep serves as a restorative function for our body and mind. It regulates and maintains stress hormone secretions (epinephrine and cortisol) in times of fight or flight. Sleep maintains communication between centres of the brain, through coordinating the firing of nerve cells in compatible frequencies, for higher order cognitive abilities (Bates, Viken, Alexander, Bayers, & Stockton, 2002; Ferber, 2006).

Sleep can be divided into two distinct states: 1) REM (rapid eye movement) sleep; and 2) Non-REM sleep. During REM the body has little movement, breathing and heart rate are irregular, body temperature regulation becomes impaired, and the body uses more oxygen and increases blood flow and hormone release (Ferber, 2006). One usually recalls dreams if awoken during this state. Some researchers, as cited in Ferber (2006), believe that REM sleep has important psychological functions in that dreaming allows one to process daytime emotional experiences and transfer recent memories into longer-term storage, but this hypothesis has remained largely unproven.

Non-REM sleep provides most of the restorative properties for body and mind. In this state, individuals usually lay quietly, with a regular heartbeat and breathing pattern. Non-REM sleep can further be divided into four distinct stages that range from drowsiness (stage 1) to a very deep sleep or slow-wave sleep (stage 4), and such stages can be identified in the laboratory by examining brain activities, eye movements, and muscle tone (Stores, 1996; Anders & France, 1997; Ferber, 2006).

#### *Normative Sleep Patterns for Children*

Sleep requirements are different across the age span. Ferber (2006) lists approximate sleep lengths for children of a certain age (see Appendix A), with 10 hours being typical of elementary school-aged children. Most people (95 percent) arouse every three to four hours during the night. For the first months of infancy, these arousals require parental response (Middlemiss, 2004). As the infant grows older, night arousals requiring parental attention are less frequent, especially if child has learned how to self-soothe (Middlemiss, 2004).

Normative sleep patterns in children vary according to age, health, and stage of development. Infants' first years of sleep can be characterized as Active Sleep (AS) and Quiet Sleep (QS), with AS being similar to REM, and QS being similar to non-REM sleep stages. REM sleep is the earliest stage to form, making up half of full-term infants' sleep (Ferber, 2006).

During sleep an individual will cycle back and forth between REM and non-REM ("sleep cycles"). Once non-REM has developed its four distinct stages and most of the child's sleep time is consolidated into a single nighttime period, the sequence of sleep stages settles into a relatively consistent cyclical pattern that remains throughout life (Ferber, 2006). As a child grows from a newborn to an adolescent, the length of the sleep cycle increases from 50 to 90 minutes and the total REM sleep and the amount of time spent in REM sleep decreases until it reaches adult levels (Ferber, 2006). REM sleep makes up about 25 percent of a child's total sleep, this percentage will decrease as the child becomes older (Ferber, 2006).

Newborns will enter REM at sleep onset until about 3 months of age, and then begin to enter non-REM at sleep onset. Young children plunge into stage IV of non-REM sleep fairly quickly and gradually cycle through all the other stages of non-REM. A child typically remains in stage IV of non-REM for about one to two hours. Children experience several brief arousals during the night that could last for a few seconds or several minutes, with brain waves showing abrupt change in states of deep sleep, light sleep, drowsiness, and waking (Ferber, 2006).

## *Sleep Disorders*

Sleep disorders can typically be classified into two categories: 1) Parasomnias, and 2) Dyssomnias.

*Parasomnias.* Parasomnias are disorders that disrupt sleep after it has been initiated. They are disorders of arousal, partial arousal, or sleep stage transitions; they intrude on the sleep process but do not usually result in complaints of sleepiness (Mindell, 1993). Such disorders include, but are not limited to, sleep terrors, sleepwalking, sleep enuresis (i.e., bed-wetting) and sleep bruxism (i.e., grinding of the teeth).

*Dyssomnias.* This category of sleep disorders result in either difficulty in initiating or maintaining sleep, or excessive sleepiness. Dyssomnias are known to impair wakefulness (Mindell, 1993). The *International Classification of Sleep Disorders: Diagnostic and Coding Manual* (ASDA, 1990) further classifies dyssomnias into three groups according to the origin of the disorder: (1) intrinsic dyssomnias (i.e., causes from within the body); (2) extrinsic dyssomnia/protodyssomnia, (i.e., external causes); and (3) circadian rhythm dyssomnia (i.e., the inappropriate timing of sleep within the 24-hour day) (Anders & Eiben, 1997). Extrinsic dyssomnias are the most common disorders in the pediatric age; however, full diagnostic criteria for such dyssomnias are rarely met at this age (Anders & Eiben, 1997). Such dyssomnias include problems such as bedtime resistance, frequent night waking, and sleep-onset delay.

According to the DSM-IV, the criteria for a diagnosis of dyssomnia, also referred to as primary insomnia, include difficulty falling asleep, remaining asleep, or not receiving restorative sleep for a period no less than one month. The disturbance in sleep

must cause significant distress or impairment in social, occupational, or other important functions and cannot appear exclusively during the course of another mental or medical disorder or during the use of any medications or substances

(<http://allpsych.com/disorders/sleep/insomnia.html>).

#### *Potential Causes of Sleep Disorders*

It is often hard to determine what causes a sleep disorder, even with a full medical and family history. Sleep disorders have multifactorial causes and can be associated with medical and neurological disorders, such as epilepsy, asthma, obstructive sleep apnea, psychiatric conditions (such as anxiety, trauma, and depression), and behavioural and emotional problems (Anders & Eiben, 1997). Many factors have been hypothesized as the source of extrinsic dyssomnias, including nutrition, milk allergy, marital conflict, and maternal psychopathology (Anders & Eiben, 1997). Parent-child interactions at bedtime (Anders & Eiben, 1997) have also been correlated to extrinsic dyssomnias. Ferber (1985; 2006) and Anders and Eiben (1997) both state that infants who fall asleep outside their cribs but are then placed into their cribs by parents will have more difficulty returning to sleep on their own if they wake during the night. This is thought to be due to being disoriented with their surroundings; often resulting in the child requiring a repetition of the initial routine in the middle of the night to return to sleep. In contrast, infants who initially fall asleep in their crib are more likely to return to sleep on their own and self-calm if they wake during the night.

#### *Prevalence of Sleep Problems and Treatment Barriers*

Sleep difficulties are one of the most common concerns reported by parents to their child's physicians and pediatricians (Kuhn & Elliott, 2003; Owens et al, 2002). It

has been estimated that sleep problems occur in 20 to 30 percent of children in the first three years of life (Sadeh, 2003); 25 to 30 percent of preschoolers (Wiggs; 2004); and 15 to 37 percent of school-aged children (Owens et al, 2000). Many children exhibiting sleep problems often go undiagnosed, and, therefore, remain untreated. There are several explanations for the lack of recognition and treatment of sleep disorders in children.

Many health professionals and childcare practitioners (e.g., psychologists, nurse practitioners, early interventionists, child and youth care workers), and the educational system that they come from, often neglect sleep science (Kantrowitz & Springdale, 2003). A 2001 study conducted by Chevin and colleagues found that fewer than 15 percent of children with sleep problems had information related to sleep patterns recorded on their medical charts, and only 4 percent of the 830 children studied had received effective treatment for their sleep problems (Kantrowitz & Springdale, 2003). Treatment that is offered by professionals to parents of children with sleep problems is often ineffective due to the lack of education and intervention options that exists for the wide range of sleep disorders (Robinson & Richdale, 2003).

Secondly, many professionals and parents believe that some children are just “poor sleepers” by nature, and may not need as much sleep as other children of the same age, or may grow out of their poor sleeping habits. Ferber (2006) states that virtually all children without a major medical or neurological disorder have the ability to sleep well. When parents and professionals believe that a child is by nature a poor sleeper, then the thought of possible treatment is nonexistent, and the child will continue to develop poor sleeping habits, leaving both the child and family suffering (Ferber, 2006).

Children with behavioural problems, such as ADHD, have an overall poorer sleep quality than their typically developing peers (Bates et al, 2002; Corkum et al., 1998; Lecendreux et al, 2000). In many instances sleep is overlooked in children with developmental or behavioural disorders due to the fact that their disorder or disruptive daytime behaviours overshadows their poor sleeping behaviour. The child's sleep problem may just be seen as a mere consequence of the child's more general condition, or is seen as less significant of a problem than their disruptive daytime behaviours (Wiggs & France, 2000).

Furthermore, parents may not seek help for their child's sleep problems due to the lack of availability of services or treatment programs. There are few pediatric sleep services and most of the sleep research to date has involved adult participants. In fact, there are no pediatric-specific sleep clinics in the whole of Atlantic Canada. When sleep treatments do become available, many parents tend not to enroll due to barriers such as cost, travel time, geographical location of the clinic, and waitlists (Corkum & Mullane, 2004).

#### *Impact of Sleep on Child's Health-Related Quality of Life*

*Social and Emotional Well-Being.* Sleep deprivation impacts one's mood, behaviour, and learning. Mindell (2004) states that mood disturbance is the most often identified result of inadequate sleep, not only just exhibiting a negative mood following a sleepless night, but also an inability to regulate mood, which in turn may result in long-term implications to one's emotional health.

Research demonstrates that there is an association between sleep disturbances and disruptive daytime behaviours in children that include aggression, lethargy, irritability,

self-injurious behaviour, lowered concentration, tiredness, attachment to routines, lower quality interactions with caregivers, and tantrums (Thackeray & Richdale, 2002).

According to Kantrowitz and Springdale (2003), there is growing evidence that chronic lack of sleep in children can lead to obesity, contribute to depression, and may mimic symptoms of attention-deficit/hyperactivity disorder (ADHD).

A child's social development is greatly affected by the amount of sleep that they receive. Sleep deprivation negatively affects a child's ability to control their emotions, can cause aggressive outbursts, leaving them feeling too tired to actively participate in social play with their peers, and can disrupt their speech and cognitive functioning (Thackeray & Richdale, 2002). This, in turn, disrupts their ability to make and maintain peer relationships. Peer relations are critical to develop as they allow for more interpersonal experimentation, reinforce appropriate behaviour, and aid in developing the child's sense of self and belonging in life (Hetherington, Parke, & Schmuckler, 2003).

*Physical Health.* Sleep deprivation has many negative physical affects to the normal functioning of one's immune system, through its altering blood levels of immune cells and important infection fighting proteins (i.e., cytokins) ([www.about-sleep-disorders.com](http://www.about-sleep-disorders.com)). Lack of sleep increases the quantity and quality of sickness in children, resulting in more sick days from school, again interfering with both learning and social development ([www.about-sleep-disorders.com](http://www.about-sleep-disorders.com)).

*Family Functioning and Well-Being.* A child's sleep problems not only affect their own personal development and functioning, but it also affects the health of the parent, parenting ability and other aspects of family life. According to the Family Systems Theory, the family is a natural social system, with its own rules, roles,

communication patterns, and power structure (Ingoldsby et al, 2004). Each family member both influences and is influenced by other members of their unique group. Emotions and interactions cannot be understood in isolation, they make sense only in the context of the social world in which they live (Ingoldsby et al., 2004).

There are a number of studies that have shown that child adjustment problems are related to family stress and functioning, especially parenting (Owens-Stively et al., 1997; Quine, 1992; Sadeh, 2000; Zuckerman, 1987). Bates et al.'s (2002) study examined the hypothesis that family factors and child sleep may be jointly involved in the development of adjustment problems (Bates et al., 2002). They found that children with recorded disrupted sleep schedules based on sleep diary data had less positive and more negative adjustment in preschool, and that sleep irregularity accounted for the variation in adjustment independent of variation in family stress and family management.

Mothers of children with sleep problems also report not receiving enough sleep, which in turn may cause poor health, depression, marital strain, and an inability to care for other children and family members (cited in Wiggs, 2004). Tired parents may be unable to think of rational ways for coping with their child's abnormal sleep patterns and disruptive behaviour associated with sleep deprivation, and therefore may potentially resort to physical punishment of the child (Quine, 2001). Studies have found that teaching parents effective strategies to manage their child's sleep problems improves the emotional state of the parent, confidence in their parenting abilities, and parent-child interactions (Eckerberg, 2004; Thome & Skuladottir, 2005).

Thome and Skuladottir (2005) explored the effects of a family-centered intervention for sleep problems in infants and the resulting changes in parents' level of

distress. Results demonstrated that both mothers and fathers experienced high level of distress before intervention, with no significant difference between mother and father, and parental distress decreased in both mothers and fathers significantly after intervention.

### *Measurements of Sleep*

In order for one to assess pediatric sleep problems, measures need to be obtained from the child and their parents. Sleep measures can be categorized as either objective or subjective. Objective measures (e.g., polysomnography, actigraphy) capture physiological sleep information which is not directly observable, while subjective measures (e.g., sleep diaries, retrospective questionnaires) focus on observable aspects of sleep. It has been shown that parents are extremely accurate in reporting their child's sleep patterns and behaviours (Honomichl et al., 2002). Many studies on sleep use a combination of such measures in order to gather an accurate picture of the child's sleep patterns and behaviours, and assess family functioning related to sleep disorders.

*Polysomnographs.* Polysomnographs (PSG) is considered the gold standard for evaluating sleep. It involves the measurement of a number of physiological and behavioural variables during an overnight sleep study. PSG examines one's physiological state of sleep and are usually required in the investigation of daytime sleepiness and suspected sleep apnea, and may help in the diagnosis of certain parasomnias (e.g., nightmares) (Stores, 1996). It usually focuses on abnormalities in REM sleep (e.g., increased muscle twitches, discrete bursts of eye movements), and undifferentiated sleep in which features of non-REM and REM sleep are intermixed (Malow, 2004). PSG can detect prolonged sleep times, early wake times, and frequent

interruptions in sleep (e.g., excessive limb movements) (Malow, 2004). PSG serves as a helpful check on the accuracy of sleep complaints, which can be used in evaluating treatment options.

*Actigraphs:* Actigraphs are computerized devices that one wears on his/her wrist similar to a watch, and it measures body movements during sleep. It can distinguish sleep stages from wake stages, as well as collect information about the quality of one's sleep, such as total length of sleep, number of arousals, and the length of arousals. Actigraphs cannot distinguish between the different stages of sleep. The advantage of the actigraph is that it is a non-invasive sleep measuring tool that the child can wear in his/her home environment.

*Sleep Diaries.* Sleep diaries are standardized, calendar-style weekly forms on which parents record specific sleep-related events on a daily basis, such as times that the child went to bed, fell asleep, number of night awakenings, and time the child woke up (Honomichl, Goodlin-Jones, Burham, Gaylor, & Anders, 2002).

*Parent-Report Questionnaires.* Parent-report questionnaires can provide a comprehensive evaluation of sleep problems in children and how these affect different aspects of development and everyday life. Specific questions regarding the age in which the sleep problem began, under what circumstances, child's medical history, how the sleep problem is affecting the child, the parent, and family, and cultural context of the family are several examples of areas that are often examined. These structured questionnaires serve as useful complementary instruments to sleep diaries and objective sleep measures (Anders & Eiben, 1997).

### *Sleep Interventions*

There are many intervention methods used to treat sleep problems, which can be classified into three main types: 1) pharmaceutical treatments; 2) circadian rhythm interventions; and 3) behavioural treatments (Thackeray & Richdale, 2002). Very often a combination of the three intervention methods will be used.

*Pharmaceutical.* There are a wide range of pharmaceutical treatments available, including both prescription and over-the-counter medications. Pharmaceutical interventions, such as sedative antihistamines or chloral hydrates, and melatonin are the most frequently used treatments for sleep problems in children (Wiggs, 2004). Children with behaviour problems, such as ADHD, or children with an intellectual or pervasive developmental disorder are more likely to take medication for sleep problems than their typically developing peers (Malow, 2004). For example, there is some research which has found that children with autism have an abnormally low level of the hormone melatonin, a key regulator of circadian rhythms (Malow, 2004). There is growing evidence that supplementation of melatonin promotes sleep, as well as “resets” the circadian clock (Malow, 2004). Jan et al. (1994), cited in Roane et al. (2000), used oral dosages of melatonin on nine child participants with developmental disabilities and found improvements in the children’s sleep, and when taken off the melatonin, the children relapsed to prior sleep difficulties.

*Circadian Rhythms.* Some sleep problems are associated with dysfunctions in the circadian rhythm or sleep/wake cycle. Circadian rhythms are “biological cycles that repeat about every twenty-four hours... including patterns of sleeping and waking, activity and rest, hunger and eating, and fluctuations in body temperature and hormone

release” (Ferber, 1985: p33). The three most common circadian sleep disorders encountered in children are advanced sleep phase syndrome (ASPS); delayed sleep phase syndrome (DSPS); and irregular sleep/wake pattern (Kuhn & Elliott, 2003). Several therapies in conjunction with behavioural treatments are common in regulating one’s circadian clock to achieve a regular process of sleeping and functioning. For example, light therapy in combination with chronotherapy has been found to be helpful for children with circadian rhythm abnormalities (Malow, 2004). Chronotherapy systematically delays children’s bedtime by gradually adjusting the child’s bedtime and corresponding sleep/wake cycle until desired sleep patterns are achieved (Roane et al., 2000). The use of light therapy can aid in reaching a particular sleep/wake pattern. For example, the use of 10, 000 lux of light for one to three hours in the morning can help in resetting one’s circadian clock resulting in an earlier bedtime (Malow, 2004).

*Behavioural Intervention Strategies.* Behavioural methods and sleep-hygiene programs have been deemed safe and effective alternatives to medications for treating sleep problems in children. Also, parents tend to favour behavioural strategies over medication. Both behavioural and pharmaceutical treatments for sleep demonstrate short-term efficacy, but the effects of behavioural approaches are seen as more durable in the long-term (Ramchandani, Wiggs, Webb, & Stores, 2000; Wiggs, 2004).

Pharmaceutical interventions raise concerns of side effects, tolerance, and rebound of sleeplessness upon discontinuations in parents (Wiggs, 2004). Also, as stated earlier, it has been shown that educating parents about sleep and behavioural methods designed to combat sleeping problems yield higher success rates, improved parents’ sense of

competence, improves parent-child relationships, and reduce parental and family stress (Wiggs, 2004)

One key feature of behaviour programs is promoting good sleep hygiene. Sleep hygiene refers to appropriate sleep habits and should be used in conjunction with a positive bedtime routine in order to promote better sleep behaviours. These habits should include a regular sleep schedule that encompasses going to bed and waking up at the same time every night and day, including weekdays and weekends. Children should also maintain good nutrition; avoid caffeine and other stimulant drugs, and should engage in regular physical exercise during daytime hours. The child's bedroom environment should be quiet and comfortable, and should contain no stimulating toys, television, or computer/video games. Behavioural treatments include such methods as sleep restriction (e.g., restricting the total amount of time in bed to the total amount of time asleep, and not allowing the child to fall asleep before scheduled bedtime or stay asleep past the scheduled wake time), bedtime fading (e.g., setting the child's typical bedtime later to increase probability of rapid sleep onset), graduated extinction (e.g., putting the child to bed and gradually ignoring any disruptions until the child falls asleep on his/her own), and positive routines (e.g., brushing teeth, changing into pajamas, reading a bedtime story) (Christodulu & Durand, 2004; Roane et al., 2000).

#### *Considerations for the Implementation of a Behavioural Sleep Intervention*

*Context of the Family.* Several variables need to be considered when designing and implementing a sleep intervention: child temperament; parenting factors (e.g., discipline style, education level); and environmental factors (e.g., family composition, physical environment) (Mindell, 2004). Additionally, the cultural context of the family

and their beliefs about appropriate sleep practices are also important in delivering sleep services and programs. Acceptance and practices of co-sleeping, for example, need to be integrated into management recommendations and decisions (Mindell, 2003).

Mindell and Owens (2003) state that one of the most important components in developing and delivering a successful sleep treatment program is consistency. Once the desired bedtime is reached and appropriate behaviour is achieved by the child, the child and family should stick with the set program on a nightly basis, as even one night of late stories or a movie early on in the sleep treatment program can reset the child's internal clock back to previous non-adaptive times. It usually takes several months before the child's schedule can become a little more flexible without causing significant damage (Mindell & Owens, 2003).

#### *Current Study*

Although there has been some research regarding the effectiveness of behavioural treatments for child sleep problems in improving sleep quality, behaviour, and cognitive functioning, there is little research examining changes in overall health-related quality of life (e.g., social, emotional, and physical domains). The current research study investigates how a behavioural sleep treatment program, which is being delivered through a sleep research program at the IWK Health Centre, enhances a child's overall health-related quality of life.

The primary hypothesis of the current study is that improved sleep will result in increased health-related quality of life in the child and family. To test this hypothesis, the current study examined change in the severity of a child's sleep disorder, as well as corresponding changes in quality of life domains that pertain to the child's physical,

social, and emotional well-being and the well-being of the family at three time points: 1) prior to the behavioural sleep intervention, 2) two months after randomization (which is when the intervention would have been completed), and 3) at a six-month follow-up.

## Method

### Participants

Participants were derived from data collected from a larger Sleep Treatment program, *Better Nights, Better Days: Treatment for Sleep Difficulties*, conducted at the Family Help Program at the IWK Health Centre in Halifax under the direction of Dr. Penny Corkum and Dr. Patrick McGrath. This study is one of the modules of the Family Help program, which provides behaviourally-based, manualized treatments via distance (i.e., phone, internet) for children with common mental health problems (e.g., anxiety, disruptive behaviour disorders). Family Help is provided to parents who live within the Halifax Regional Municipality and rural communities throughout Nova Scotia. This manualized evidence-based treatment is conducted over the phone by paraprofessionals (“coaches” with specific training) under the supervision of health professionals (See Appendix B for a detailed description of the larger study).

The current study examined the two groups of children who participated in the larger study and who had completed all aspects of their participation in the larger study. Children who participated in the larger study had been randomized into two groups. The first group, labeled the Family Help Group, consisted of children who have received the behavioural sleep treatment, while the second group, labeled the Waitlist Control group, included children who were put on a six-month waitlist for the treatment. Prior to

randomization, all participants were screened using the exclusion/inclusion criteria set by the Family Help program, Sleep Treatment Module (See Appendix B).

The current study was approved by the IWK Research Ethics Board as an amendment to the larger study (see Appendix C - *Approval of IWK Amendment*), and The University Research Ethics Board of Graduate Studies of Mount Saint Vincent University (See Appendix D – *Approval of UREB of Graduate Studies of Mount Saint Vincent University*). The larger study is funded by the Nova Scotia Health Research Foundation (NSHRF) (Appendix E – Consent Form of larger study).

#### Measures

Questionnaire data was collected in order to examine the participants: 1) demographic characteristics, 2) sleep difficulties, and 3) health-related quality of life.

##### *1) Demographic Information*

Demographic information of child participants included age, gender, ethnicity, diagnosis of a DBD, and socio-economic status of the family. Primary caregivers provided study staff with this information during the recruitment stage over the telephone. Children in the study had to have been between the ages of 5 to 12 and in grades primary to six in order to be considered for the sleep study program.

Children diagnosed with a Disruptive Behaviour Disorder (DBD) including attention deficit hyperactivity disorder, oppositional defiant disorder, and conduct disorder were included in the study. A diagnosis of a DBD was based on the Kiddie-SADS-Present and Lifetime Version (K-SADS-PL), which was collected via telephone by study staff during the intake assessment of the larger study. The K-SADS-PL is a diagnostic interview designed to obtain severity ratings of psychiatric symptoms, and

assess current and lifetime history of psychiatric symptoms which can occur in children. Children who obtained clinical scores for any mental health disorder (not including the disruptive behaviour disorders – ADHD, ODD and CD) were excluded from the larger study.

Socio-economic information was collected by staff of the larger study. The social status of families was calculated by using Hollingshead *Four Factor Index of Social Status* (Hollingshead, 1975). This measure is constructed out of three basic concepts: 1) differentiated and unequal status exists in our society, 2) occupation and level of education of an individual are primary factors indicative of one's social status, as well as sex and marital status, and 3) such factors combined present a reliable and meaningful estimate of status positions on individuals and families in society (Harrison, 1975). The Hollingshead Index provides a score comprised of the highest level of completed education and current occupation held for each contributing member of the household, summed and divided by two. The combined score for the two contributing household members is assigned as the status score of the family. If there is only one contributing member (e.g., single-parent household), then only their education and occupation is taken into consideration.

The status of the scores of an individual or family is estimated by multiplying the scale value for education by a weight of three, and multiplying the scale value of occupation by a weight of five, then adding both scores together. Computed scores range from a high of 66 to a low of 8. It is assumed that the higher the score of a family, the higher their social status in society.

Validity of the Hollingshead Index of social status was tested using the National Research Centre (NORC). The occupational groups based on the Hollingshead Index were compared with “prestige” scores developed by the NORC for use in its General Social Survey. The Pearson Product Coefficient of Correlation between the nine-step occupational scale and the NORC prestige score was very high ( $r = .93$ ). The coefficient of determination is  $r^2 = .86$ , indicating acceptable validity.

2) *Children’s Sleep Habits Questionnaire (CSHQ)* (Owens et al., 2000).

The *CSHQ* is a 45-item parent-report sleep measure, on which parents rate a wide variety of children’s sleep behaviours and problems. Of the 45 items, 32 are grouped into eight subscales relating to a number of key sleep domains: 1) Bedtime Resistance; 2) Sleep-Onset Delay; 3) Sleep Duration; 4) Sleep Anxiety; 5) Night Wakings; 6) Parasomnias; 7) Sleep-Disordered Breathing; and 8) Daytime Sleepiness. As well, there is a Total Sleep Disturbance Scale, which is a summation of the eight subscales.

Parents are asked to recall sleep behaviours that occur in their children during a typical recent week. Items are rated on a three-point scale: “usually” if the sleep behaviour occurred five to seven times per week; “sometimes” for two to four times per week; and “rarely” for zero to one time per week. High scores in each sleep domain are indicative of more disturbed sleep. Parents are also asked to give a numerical value for typical bedtime, morning wake-time, and sleep duration.

The *CSHQ* appears to have adequate validity and reliability. Data has been collected on a sample of 495 elementary school children (community sample), and on a clinical sample from a pediatric sleep clinic (Owens et al., 2000). In the community sample, Owens et al (2000) assessed internal consistency reliability and test-retest

reliability. The internal consistency of the entire community sample was 0.68 and in the clinical sample it was 0.78. Test-retest reliability was assessed in a volunteer sample of 60 parents from the community sample who responded to a request to complete a second rating of the *CSHQ* at a two-week interval. The correlations for the subscales of the *CSHQ* ranged from 0.62 to 0.79, indicating acceptable test-retest reliability.

Validity of the *CSHQ* compared the clinical sample to the community sample for each of the items and the subscales. The correlations for the subscales in Owens et al. (2000) study ranged from 0.62 to 0.79.

The current study, the Total Sleep Disturbance Score was used as a general measure of change in sleep over the duration of the study. This score is the most reliable and valid and provided a general evaluation of the effectiveness of the sleep intervention.

### 3) *Child Health Questionnaire – Parent Form 50 (CHQ-PF50) (Landgraf et al., 1996)*

The *CHQ-PF50* is a widely used parent-report measure that assesses children's physical, emotional, and social functioning status and well-being (Landgraf, Abetz, & Ware, 1996). The *CHQ-PF50* is a validated measure that assesses the quality of life in children 5 to 18 years of age. The *CHQ-PF50* consists of 50 items and 12 subscales (i.e., Physical Functioning, Bodily Pain, Role/Social – Limitations due to Emotion/Behaviour, Role/Social – Limitations due to Physical Functioning, Global Health, Behaviour, Mental Health, Self-Esteem, Family Activities, Family Cohesion, Parent Impact – Time, Parent Impact – Emotion) (see Appendix F). Total scores of each scale are rated from 0 (worst health) to 100 (best health). Total scores are calculated by taking the average score of responses, subtracting 1, dividing that number by the possible number of responses and multiplying by 100. Higher scores indicate better HRQL.

The 12 individual subscales were combined to form five domain scores, including 1) physical, 2) emotional, 3) behavioural, 4) social, and 5) family. These domain scores were computed based on research conducted by Williams et al. (2001) who grouped subscales into four domains: 1) Physical Health (Physical Health Scale, Bodily Pain and Discomfort Index), 2) Emotional Health (Self-Esteem Scale, Mental Health Scale), 3) Behavioural Health (Behaviour and Global Behaviour Scale), and 4) Social Health (Role/Social limitations scales, Family Cohesion Scale, and Family Activities Scale). The current study made similar groupings in defining HRQL domains, but added an additional health dimension, Family Health, which grouped the family scales and parental impact scales together. Mean scores of the subscales were added together for each assessment point; therefore higher scores indicated better HRQL in that domain.

Two summary scores, Physical and Psychosocial, were computed from differentially weighted subscale scores which are transformed into T scores with a mean of 50 (see Appendix G). These summary scales are based on extensive research that used factor analysis to specify the weights to be given to each of the subscales (Hepner & Sechrest, 2002; Waters et al., 2000). Four scales have been found to load the strongest on the Physical Summary score: 1) Physical Functioning Scale, 2) Role/Social - Limitations due to Physical Health, 3) General Health Perceptions Scale, and 4) Bodily Pain and Discomfort Index. Four scales that load the strongest on the Psychosocial Summary score include: 1) Role/Social – Limitations due to Emotion/Behaviour, 2) Mental Health Scale, 3) Self-Esteem Scale, and 4) Behaviour Scale. Both parental impact scales load on both of the summary scores, but are heavily weighted on the Psychosocial Summary

score than the Physical Summary score. Neither the Family Activities Scale nor the Family Cohesion Scale is included in the summary scores.

The *CHQ-PF50* questionnaire was tested as a part of a national study, which provided normative data. Extensive data regarding the development, reliability, and validity of the measure for boys and girls of different ages and cultures, and with parents of differing levels of education, marital status, and work status are presented in the *CHQ-PF50* manual. The measure has been found to have excellent psychometric properties.

The *CHQ-PF50* demonstrates excellent internal consistency for the Physical and Psychosocial Summary scores (0.84 and 0.97). Very good internal consistency was also found across the majority of individual items and scales. Only six items had item-scale internal consistency values lower than 0.4, and two scales had alpha coefficients less than 0.7 (i.e., General Health = 0.6, and Parental Impact – Emotional = 0.68). In normative and chronic illness samples, the internal consistency of subscales scores ranged from 0.56 to 0.98 in both samples. Concurrent, convergent, and discriminant validity of the *CHQ-PF50* are also good.

The two summary scores (Physical and Psychosocial) were the primary variables used in the current study because they best capture the impact that sleep behaviours may have on functioning and other areas related to health and quality of life, as well these two scores have the best validity and reliability of all HRQL scores.

#### Procedure

The behavioural sleep treatment is protocol and evidence-based and was delivered by paraprofessionals (“coaches” with specific training) under the supervision of health professionals. The treatment is comprised of five sessions with one being delivered each

week (See Appendix B for more details about the intervention). All participants completed baseline assessment measures after a comprehensive intake assessment was conducted to determine eligibility to participate in the study. Once baseline data was collected, participants were either randomized to the Family Help group, which is a six week behavioural sleep treatment, or to the Waitlist Control group, in which participants were required to wait six months before starting the treatment program. Both groups completed a two-month “end-of-treatment” assessment (which occurred after treatment for the Family Help group), and then again six months from the randomization date. Parents of children in the Family Help group were to continue with the sleep treatment strategies during the time between the end-of-treatment and the six-month follow up assessment.

#### Data Analysis

The *Statistical Package for Social Sciences (SPSS 14.0)* was used to conduct all statistical analysis. The results of the current study are presented in three sections: 1) sample characteristics, 2) the effects of treatment on sleep, and 3) an evaluation of changes in health-related quality of life after the treatment of sleep difficulties.

The first set of analyses included t-tests and chi-square tests to determine if the groups differed across demographic variables. The second set of analysis was a repeated measure ANOVA to explore whether the behavioural sleep treatment used in the larger study had a positive effect on improving sleep amongst child participants in their overall score of sleep disturbance (data collected from the *CSHQ*). The third set of analysis consisted of repeated measure ANOVAs used to determine if the treatment was effective in improving health-related quality of life (data collected from the *CHQ-PF50*). Both the

second and third set of analysis used data collected from baseline assessment, end of treatment (two-month), and six-month follow-up assessment time points.

Eta-square calculation was also used to determine the percentage of the variability of the dependent variables (e.g., change in overall sleep disturbance, change in the individual subscales and summary scores of the *CHQ-PF50*, and change in the HRQL domains) that can be explained by the independent variable, or the behavioural sleep treatment (see Table 1).

## Results

### *1) Sample Characteristics*

There were 30 children that were to be included in the current study (15 in the Family Help group and 15 in the Waitlist Control group); however, two children in the Family Help group were unable to complete their final six-month follow-up within the necessary timeframe. Therefore, the final sample consisted of 13 children in the Family Help group and 15 in the Waitlist Control group.

In order to determine whether the two groups differed across various demographic variables, t-test and chi-square tests were conducted. Results of the t-tests for age and socio-economic status and the chi-square tests for gender, DBD, and ethnicity found that there was no significant difference in any of the five demographic variables between the two groups. This indicates that the randomization process successfully resulted in two equivalent groups in terms of these demographic variables (see Table 2).

The ages of child participants ranged from 6 to 12, with an overall mean age of 9.50 years (SD = 1.94). The mean age for the Family Help group was 8.92 (SD = 2.02) and the Waitlist Control group was 10.07 (SD = 1.83); the groups were not significantly

different on this variable ( $t(26) = -1.57, p = .13$ ). The groups also did not differ in regard to the socio-economic status of the participating parent and spouse/partner based on the Hollingshead *Four Factor Index of Social Status* ( $t(23) = -.62, p = .54$ ). The average SES for both groups fell in the middle SES range.

The distribution of gender in the Family Help group was 9 females (69.2%) and 4 males (30.8%), whereas the Waitlist Control group consisted of 8 females (53.3%) and 7 males (46.7%), again there was no statistically significant difference between groups ( $X^2(1, N = 28) = .74, p = .39$ ). There were 8 children in total that were diagnosed with DBD, 3 in the Family Help group (23.1%) and 5 in the Waitlist Control group (33.3%), with the groups not being statistically different on this variable ( $X^2(1, N = 28) = .36, p = .55$ ). The majority of the children were Caucasian ( $n = 27$ ), with the only non-Caucasian child (representing African Canadian ethnic background) being randomized to the Waitlist Control group ( $X^2(1, N = 28) = .90, p = .54$ ).

## 2) *Effects of Treatment on Sleep*

Based on the Total Sleep Disturbance Scale scores of the *CSHQ*, the children in the Family Help group ( $n = 13$ ) obtained an average score of 52.69 ( $SD = 8.72$ ) at baseline, 44.77 ( $SD = 6.61$ ) at the two-month assessment, and 43.23 ( $SD = 7.36$ ) at the six-month assessment. Children in the Waitlist Control group ( $n = 15$ ) had a mean of 48.67 ( $SD = 6.78$ ) at baseline, 47.33 ( $SD = 10.29$ ) at the two-month assessment, and 46.40 ( $SD = 8.28$ ) at the six-month follow-up. There was a significant main effect of time ( $F(2,25) = 19.98, p < .001, \eta^2 = .62$ ) as well as a group by time interaction ( $F(2,25) = 7.59, p = .003, \eta^2 = .39$ ) (See Graph 1). Contrast analyses indicated that the greatest

change in the group by time interaction was between the baseline and two-month assessment points for the Family Help group.

In looking at individual case reports, all 13 participants that received treatment improved in their overall sleep, meaning that on the CSHQ they went from the clinical range or near clinical range at baseline to a non-clinical or near non-clinical range at the six-month assessment period. The 15 participants that were in the Waitlist Control group, seven participants improved in their overall sleep, four remained the same, and four became worse.

### *3) Evaluation of changes in the Health-Related Quality of Life*

*Psychosocial Summary Scores.* Of the 13 child participants that received the behavioural sleep treatment, the mean Psychosocial Summary score of *CHQ-PF50* was 49.94 (SD = 8.04) at baseline, 52.39 (SD = 5.59) at the two-month assessment, and 55.79 (SD = 3.55) at the six-month follow-up. The Waitlist Control group scores were 52.98 (SD = 6.49) at baseline, 53.04 (SD = 7.49) at two-month assessment, and 51.70 (SD = 8.73) at six-month follow-up (see Graph 2). There was no main effect of time ( $F(2,25) = 2.15, p = .14, \eta^2 = .15$ ), however, there was a group by time interaction ( $F(2,25) = 6.33, p = .006, \eta^2 = .34$ ). Contrast analyses indicated that the greatest change in the group by time interaction was between the two-month and six-month assessment points for the Family Help group.

Individual case report summaries showed that of the 13 Family Help participants, ten improved in Psychosocial Summary scores from baseline to six-month assessment, and four remained the same. Of the 15 participants in the Waitlist Control group, eight increased their Psychosocial Summary score from baseline to six months, five decreased,

and two remained the same. However, of the eight participants in the waitlist group that increased, four of them also demonstrated improvement in their overall sleep.

*Physical Summary Score.* On the Physical Summary score of the *CHQ-PF50* the Family Help group obtained a mean score of 54.27 (SD = 10.56) at baseline, 55.13 (SD = 5.28) at the two-month assessment point, and 53.19 (SD = 10.25) at the six-month follow-up. The Waitlist Control group had a mean score of 51.16 (SD = 13.08) at baseline, 51.50 (SD = 13.64) at the two-month assessment, and 55.03 (SD = 8.29) at the six-month follow-up (see Graph 3). There was no main effect of time ( $F(2,25) = .28, p = .77, \eta^2 = .02$ ) or group by time interaction ( $F(2,25) = .75, p = .49, \eta^2 = .06$ ).

Individual case report summaries indicated that of the Family Help participants ( $n = 13$ ), nine increased in their Physical Summary scores from baseline to six-month assessment, one remained the same, and three decreased their scores. Of the 15 participants in the Waitlist Control Waitlist Control group, five improved the Physical Summary scores from baseline to six-month assessment (three of which improved in their overall sleep), eight decreased in score, and two remained the same.

*HRQL Domains of the CHQ-PF50.* HRQL is defined as one's physical, social, emotional, and behavioural health, as well as the health of the entire family. The current study grouped the scales of the *CHQ-PF50* into five separate domains to represent each area of HRQL (see Appendix H). Results revealed that there was no significant group by time interactions in the children's HRQL physical, social, or behavioural domains. However, for both the HRQL Emotional and Family domains there were trends in the direction of improvement (Emotional domain:  $F(2,25) = 2.62, p = .095, \eta^2 = .17$ ; Family domain:  $F(2,25) = 2.71, p = .086, \eta^2 = .18$ ) (Graphs 4, 5, 6, 7, and 8). It is also important

to note that both groups appeared to improve over time in all HRQL domains with the Family Help group's mean scores appearing to improve more than the Waitlist Control group's mean score in all domains except physical.

The percent of variance of interaction between group effects for the HRQL were quite low (see Table 1).

*Individual CHQ-PF50 Scales.* No statistically significant main effects of time or group by time interactions were found for the majority of the individual scales of the *CHQ-PF50*. There was one exception which was the Global Health Scale for which there was a significant group by time interaction ( $F(2,25) = 6.93, p = .004, \eta^2 = .36$ ). There was also a trend towards significant results in the Change in Health Perception Scale for the group by time interaction ( $F(2,25) = 3.27, p = .06, \eta^2 = .21$ ). For the Role/Social – Limitations due to Emotion and Behaviour Scale there was also a Waitlist Control trend found for a main effect of time ( $F(2,25) = 3.18, p = .06, \eta^2 = .20$ ) and group by time interaction ( $F(2,25) = 2.62, p = .09, \eta^2 = .17$ ). The Global Behaviour Scale had a significant main effect of time ( $F(2,25) = 4.05, p = .03, \eta^2 = .03$ ), as did the Family Activities Scale ( $F(2,25) = 6.08, p = .007, \eta^2 = .33$ ), but no group by time interaction.

Percent variance ( $\eta^2$ ) for the interaction effect between data sets were also calculated to examine any missed features of the data and to make sure that certain assumptions about the data were correct. The percent of variance for the interaction between the group effects on the individual subscales of the *CHQ-PF50* ranged from 2.0 to 44.0 percent (see Table 1).

*Relationship Between Improved Sleep and HRQL.* The Family Help group demonstrated significant improvement on the Total Sleep Disturbance Scale of the *CSHQ*

and in the Psychosocial Summary scale of the *CHQ-PF50*. The relationship between these two variables was examined by computing a change score for each measure (baseline score minus six-month score) and then conducting a Pearson correlation. It was found that the two variables were significantly related ( $r = .41$ ,  $p = .03$ ).

### Discussion

Findings of the current study suggest that successful treatment of sleep disorders improve some areas of HRQL. In the larger study, *Better Nights, Better Days: Treatment for Sleep Difficulties*, children who were experiencing sleep difficulties in the areas of sleep onset and/or bedtime resistance were randomly assigned to a behavioural treatment (Family Help group or Waitlist Control group. Parent reports of the children's sleep and HRQL were gathered at baseline (prior to group randomization), at two months (after the sleep treatment was completed), and at six months. Comparisons across the three time points and between the two groups were made and it was found that sleep and some aspects of HRQL improved for the children that received the sleep intervention.

It has been demonstrated that children with sleep problems score lower on measures of HRQL than children without sleep problems (Hart et al., 2005). HRQL is an individual's subjective sense of well-being and functioning within physical, emotional, behavioural, and social domains, as well as the overall well-being of the family unit. HRQL is important to assess in children seeking treatment for sleep disturbances because it examines the efficacy of a treatment from the perspective of multiple domains of functioning of the child and family. Changes in HRQL can provide a greater incentive to parents (or primary caregivers) to continue with the treatment of treating sleep disturbances in children (Hart et al, 2005).

Despite the importance of HRQL, there is no research which has evaluated whether it improves with treatment of sleep disorders. The current study was designed to address this question; it was hypothesized that children with improved sleep would experience better HRQL. However, before examining this specific hypothesis, it was necessary to ensure that the two groups were similar in terms of demographic variables and level of sleep disturbances.

The two groups were well matched on demographic characteristics and level of sleep disturbances, which lends support to the external validity of the current study. Therefore, significant findings indicating improved HRQL in the group which received treatment for their sleep problems are more likely to be the result of the sleep intervention rather than a discrepancy in sample characteristics between the groups.

From the literature, it has been shown that behavioural interventions for child sleep problems are effective. Furthermore, it has also been shown that educating parents about sleep and using behavioural methods for child sleep disorders improves parents' sense of competence, parent-child relationships, and reduces parental and family stress (Wiggs, 2004). The larger study's behavioural sleep intervention was found to be very effective in reducing sleep problems in the sample of elementary school-aged children based on the parent report questionnaire (*CSHQ*).

A number of studies have found that sleep disorders can negatively impact a child's daytime functioning (e.g., behaviour problems, irritability, mood, lower quality of interactions with caregivers and peers). Therefore the main purpose of the current study was to examine if improved sleep led to improvements across HRQL domains (i.e., physical, social, emotional, behavioural, and family well-being).

The *CHQ-PF50* was used in the present study to assess HRQL. The *CHQ-PF50* is a quality of life measure for pediatric health outcomes, specifically assessing children's physical, emotional, and social well-being, as well as assessing the impact of a child's health on parents/caregivers and family cohesiveness. The two summary scores of the *CHQ-PF50*, Physical and Psychosocial, are computed from subscales that are differentially weighted. These two summary scales are considered to have excellent psychometric properties.

Results from the *CHQ-PF50* collected at baseline, at two-months, and at six-months found that the overall psychosocial functioning of children in the Family Help group significantly increased compared to the Waitlist Control group. Thackeray and Richdale (2002) found an association between sleep disturbances and disruptive daytime behaviours (e.g., aggression, lowered concentration, irritability, lethargy, tantrums, and lower quality interactions with caregivers), therefore it is logical to reason that better sleep results in better psychosocial functioning.

There was no significant difference in the Physical Summary Scale scores between the two groups. The scales associated with a child's physical health and functioning (e.g., Physical Functioning Scale, Bodily Pain Index, Role/Social – Limitations due to Physical Health) were very high (i.e., positive) for children in both groups at baseline, and remained high throughout all other assessment points (see Table 2). The subscales that comprise the Physical Summary score include subscales related to limitations in the activities that children may experience due to health problems and bodily pain. Although sleep improved in the treatment group, it did not appear to directly change a child's ability to play or interact physically with others, nor did it change the

child's experience of direct physical pain or discomfort. The items of the *CHQ-PF50* that inquire about one's physical health mostly ask about the child's physical limitations due to "health problems," or quality and frequency of bodily pain, discomfort, and illness for the child. Sleep problems in children may not be seen as a direct cause of physical limitations or pain by parents simply due to the fact that sleep is not always considered to be associated with disruptive daytime behaviour, attention, concentration, and focusing problems in school, or associated with poor immune systems. Alternatively, it could be that there was a ceiling effect on this scale which reduced the possibility to find differences between groups.

When subscales of the *CHQ-PF50* were combined into five HRQL domains (e.g., physical, social, emotional, behavioural, and family well-being; see Appendix D), the current study found a trend towards improvement in the emotional and family HRQL domains for the treatment group.

The trend towards an increase in the HRQL - Family Domain for the treatment group is understandable given that child adjustment problems have been found to be related to family stress and functioning. The impact that sleep deprivation has on one's overall psychosocial functioning (e.g., emotion, behaviour) would have to affect the parent's well-being, the well-being of other family members, and the quality of the relationship and time spent between the parent and child.

Although many of the individual subscales of the *CHQ-PF50* were found to improve with time, there was no specific improvement noted in the treatment group compared to the waitlist group on the vast majority of subscales. While not statistically significant, it is important to note that the child participants in the Family Help group

improved their mean score in all individual subscales over time, with the exception of the Physical Functioning Scale and Bodily Pain and Discomfort Scale. The lack of significant findings could stem from the fact that the sample sizes were small (Family Help group: n = 13; Waitlist Control group: n = 15), which may have reduced the power of the study to detect whether the sleep intervention affected individual subscales.

The study by Hart et al. (2005) compared the HRQL in children with sleep disorders to children without sleep disorders and found that children with sleep disorders showed significantly poorer functioning across all HRQL domains. The current study's aim was to see whether HRQL improves once sleep has improved, and our results have demonstrated that with improved sleep comes significant improvements in Psychosocial Summary scores, Global Health Scale, and a trend towards an increase in the domains of Emotional and Family well-being. Such a finding is comparable to the results found by Hart et al (2005) in that children with clinical sleep disturbances scored significantly lower on all subscales and summary scores on the *CHQ-PF50* than children in the normative sample, with the largest effects found in Parental Impact – Emotional Scale, Family Activities Scale, and Psychosocial Summary score.

Some of the results in the current study were only significant at the six-month follow-up and not at the two-month assessment point. This finding is similar to the results of Mindell's (2004) article in which it was noted that it usually takes several months before a child's sleep becomes regulated and is not dramatically affected by changes in routine. Although the children in the Family Help group were finished the intervention sessions by the two-month assessment, it seems that it may take more time for the changes to become actualized.

As with any research study, there are always limitations or weaknesses to address. Firstly, as previously mentioned, the current study's sample is relatively small, which decreases the power for certain analyses and limits generalizability. The current study only obtained 13 children who received and complied with the behavioural sleep treatment program of the larger study, and 15 children who were randomized to the Waitlist Control group. Although the sample size used by the current study ( $n = 28$ ) is small, generalizability can still be extracted. In using a repeated measure ANOVA for data analysis, it controls for individual differences while making it possible to separate the variance that has resulted from the manipulation of the treatment factor from that arising from individual differences. Results of the current study did have the power to detect change in sleep as well as in some areas of HRQL. The results can be generalized to a typically developing elementary school-aged population.

Secondly, given that parents sought out help for their child's sleep problem, they may have been biased in their reporting of their child's sleep and HRQL both before and after the sleep treatment. A third limitation is that all the measures used in the current study (i.e., *CSHQ*, *CHQ-PF50*) were measures of parents' perceptions of children's HRQL rather than child-reported HRQL. A child-report evaluating their health perceptions may present a more comprehensive picture of the HRQL. Lastly, the HRQL domains were constructed by the researcher based on theory of HRQL and previous research. However, these domain scores were not validated and may not have good psychometric properties.

### *Future Implications for Parents and Professionals*

Management of child sleep problems is very important because of the high prevalence of sleep problems and widespread positive benefits that are associated with early interventions. Currently, professional sleep education is lacking (Wiggs, 2004). More sleep-related education for health and childcare practitioners as well as parents is needed so that sleep disorders are detected and treated as early as possible to prevent the adverse effects of sleep disruption on the health-related quality of life for the child and family. As the current study found, with improved sleep comes greater improvement in the child's psychosocial quality of life. In assessing HRQL both prior to a treatment and upon completion of treatment, one can examine the efficacy of a treatment and whether improved sleep impacts HRQL. Assessing HRQL can help parents, childcare providers, and healthcare professionals to understand the importance of treating sleep disturbances in children.

It is critical for health care practitioners and child and youth care workers in the community to provide preventative and intervention services for child sleep problems. Effective treatment of sleep problems in children can create social capital for individuals and families, and therefore lead to more positive social outcomes. Having programs for families results in the child and family feeling more connected and supported, and they develop a sense of belonging, which in itself enhances one's social, emotional, and psychological well-being. Also, research has shown family-centered sleep interventions for children leads to lower levels of distress in parents (Thome & Skuladottir, 2005).

Every child has the right to live and be supported in a healthy environment for their optimal development. Addressing health related issues, such as sleep problems, and

recognizing their adverse effects are the responsibility of the parent and associated members to the child in order for that right to be achieved.



Table 1: The Effect Sizes of Partial Eta-Square on the Dependent Variables

Measure	Main effect of time	Interaction
CSHQ Total Score	.62	.39
GlbH	.03	.36
PF	.01	.03
RSEB	.20	.17
RSPF	.07	.05
BP	.01	.18
BES	.15	.11
GlbB	.25	.09
MHS	.18	.14
SELF	.30	.44
GenH	.12	.06
ChgH	.01	.21
PE	.04	.08
PT	.07	.11
FAS	.33	.02
FCS	.12	.10
PHYS	.02	.06
PSYC	.15	.34
HRQLPH	.09	.15
HRQLEM	.21	.17
HRQLBE	.22	.08
HRQLSO	.15	.04
HRQLFM	.22	.18

Abbreviations: GlbH – Global Health Scale; PF – Physical Functioning Scale; REB – Role/Social Limitations due to Emotion/Behaviour; RP – Role/Social Limitations due to Physical Health; BP – Bodily Pain and Discomfort Scale; BE – Behaviour Scale; GlbB – Global Behaviour Scale; MH – Mental Health Scale; SE – Self-Esteem Scale; GH – General Health Perceptions; ChgH – Change in Health Perception; PE – Parental Impact – Emotion; PT – Parental Impact – Time; FAS – Family Activities Scale; FCS – Family Cohesion Scale; Psc. – Psychosocial summary score; Phys. – Physical summary score; HRQLPH – Health-Related Quality of Life Physical Domain; HRQLEM – Health-Related Quality of Life Physical Emotional Domain; HRQL BE – Health-Related Quality of Life Physical Behavioural Domain; HRQLSO Health-Related Quality of Life Physical Social Domain; HRQLFAM – Health-Related Quality of Life Physical Family Domain

Table 2

Comparison of Sample Characteristics in Study Sample

Sample details	Family Help(FH)				Waitlist Control(WL)				Sig
	M	(SD)	n	%	M	(SD)	n	%	
T-Tests									
Age	8.92	(2.02)	13		10.07	(1.83)	15		.13
SES	3.46	(0.88)			3.73	(0.79)			.21
Chi-Square tests									
Gender									.39
M			4	30.8			7	46.7	
F			9	69.2			8	53.3	
Diagnosis									.55
DBD			3	23.1			5	33.3	
nDBD			10	76.9			10	66.7	
Ethnicity									.54
Caucasian			13	100.0			14	93.3	
Other			0	0			1	6.7	

Note: There is missing SES data for four participants in the Waitlist Control group (n is 11, when n should be 15).

Table 3

CHO-PF50 Scales - Mean Score Differences between Family Help Group and Waitlist Control Group at Baseline and Six Months

Scales	Baseline		Two Months		Six Months		Sig.
	FH M (SD)	WL M (SD)	FH M (SD)	WL M (SD)	FH M (SD)	WL M (SD)	
GlbH	76.15(24.08)	90.00(7.32)	88.85(11.39)	81.00(18.34)	88.85(19.17)	83.33(21.44)	.004*
PF	98.13(98.31)	93.67(16.77)	99.54(1.66)	92.60(21.51)	96.15(13.87)	96.67(11.36)	.658
REB	85.54(29.13)	94.07(17.82)	95.77(8.45)	92.60(18.67)	100(0)	93.33(20.53)	.092
RP	93.62(23.02)	83.33(35.06)	97.46(9.15)	86.67(30.37)	94.85(18.58)	95.53(17.30)	.548
BP	83.85(21.03)	76.00(25.01)	85.38(20.26)	79.33(21.20)	73.85(21.03)	88.00(16.99)	.078
BE	71.31(10.16)	73.47(14.85)	74.31(15.31)	74.80(11.74)	77.77(12.21)	74.00(18.10)	.249
GlbB	66.92(20.26)	74.33(20.25)	63.08(18.66)	76.00(20.02)	76.54(14.20)	80.67(16.35)	.309
MH	75.77(13.05)	82.33(9.23)	82.31(7.25)	83.33(11.13)	82.31(8.57)	82.67(8.84)	.154
SE	84.23(13.21)	86.33(18.66)	90.00(9.57)	88.33(13.84)	91.15(6.18)	87.00(14.24)	.443
GH	73.85(23.02)	82.33(17.61)	80.38(20.05)	84.67(18.37)	83.46(19.94)	83.00(19.71)	.462
ChgH	3.00(0.58)	3.33(0.62)	3.08(.64)	3.27(.46)	3.46(0.66)	3.00(0.38)	.055
PE	77.00(27.68)	76.20(25.20)	76.15(14.39)	75.00(23.13)	84.54(12.30)	73.80(22.15)	.355
PT	93.15(16.16)	86.73(16.91)	85.62(15.80)	88.20(20.33)	96.62(6.94)	86.73(20.22)	.237
FAS	75.31(15.02)	74.20(18.34)	80.23(15.48)	80.13(18.30)	89.23(10.55)	84.27(18.11)	.758
FCS	70.77(21.00)	73.67(21.34)	75.00(23.18)	77.67(24.27)	83.46(11.79)	74.33(20.25)	.254
Summary							
Psyc.	49.94(8.04)	52.98(6.49)	52.39(5.58)	53.04(7.48)	55.79(3.55)	51.70(8.73)	.006*
Phys.	54.27(10.56)	51.16(13.08)	55.13(5.28)	51.50(13.64)	53.19(10.25)	55.03(8.29)	.485

Abbreviations: M – Mean; SD – Standard Deviation; FH – Family Help group; WL – Waitlist control group; GlbH – Global Health Scale; PF – Physical Functioning Scale; REB – Role/Social Limitations due to Emotion/Behaviour; RP – Role/Social Limitations due to Physical Health; BP – Bodily Pain and Discomfort Scale; BE – Behaviour Scale; GlbB – Global Behaviour Scale; MH – Mental Health Scale; SE – Self-Esteem Scale; GH – General Health Perceptions; ChgH – Change in Health Perception; PE – Parental Impact – Emotion; PT – Parental Impact – Time; FAS – Family Activities Scale; FCS – Family Cohesion Scale; Psyc. – Psychosocial summary score; Phys – Physical summary score

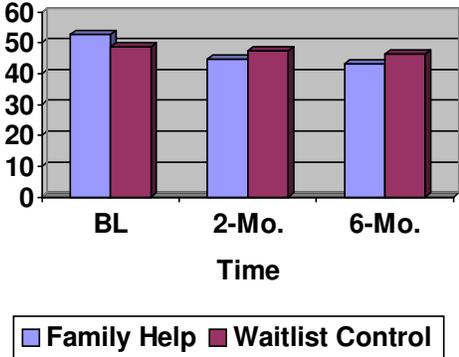
Table 4

Comparison of Group HRQL Domains

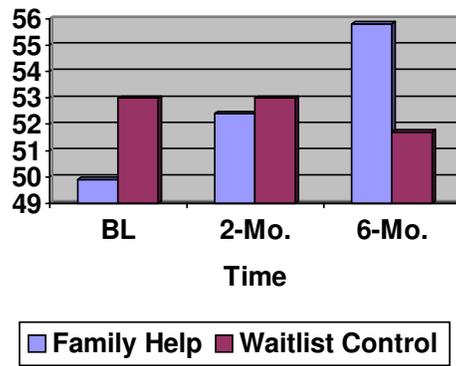
Domains	Baseline		Two Months		Six Months		Sig.
	M (SD)	FH M (SD)	WL M (SD)	FH M (SD)	FH M (SD)	WL M (SD)	
Phys	335.2(58.8)	345.3(44.3)	357.2(36.2)	340.9(53.4)	345.8(61.1)	354.0(51.1)	.131
Social	179.2(34.3)	177.4(47.9)	193.2(11.5)	179.3(44.9)	194.9(18.6)	188.9(25.6)	.586
Emotion	160.0(22.6)	168.7(22.6)	172.3(11.3)	171.7(21.9)	173.5(10.9)	169.7(18.5)	.095
Behave	138.2(25.5)	147.8(32.6)	137.4(31.1)	150.8(30.7)	154.3(22.8)	154.7(32.3)	.360
Family	316.2(59.1)	310.8(70.5)	317.0(32.6)	321.0(67.2)	353.9(25.4)	319.1(61.1)	.086

Graph 1

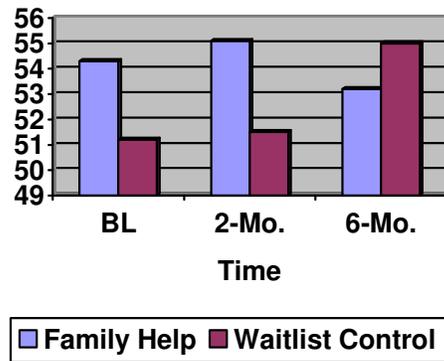
### CSHQ: Total Sleep Disturbance



### Psychosocial Summary Scores

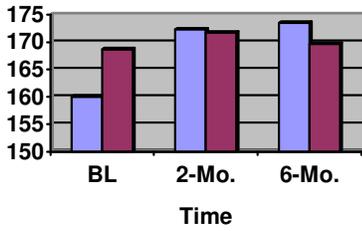


### Physical Summary Scores

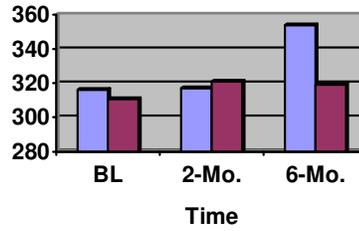


HRQL Domain Graphs

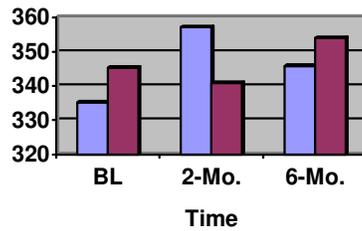
HRQL Domain- Emotion



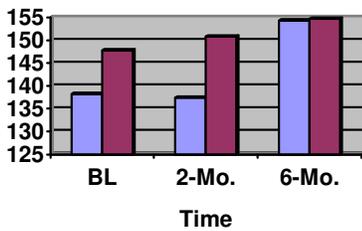
HRQL Domain- Family



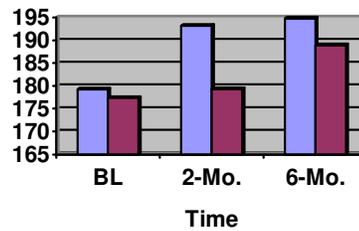
HRQL Domain- Physical



HRQL Domain- Behaviour



HRQL Domain - Social



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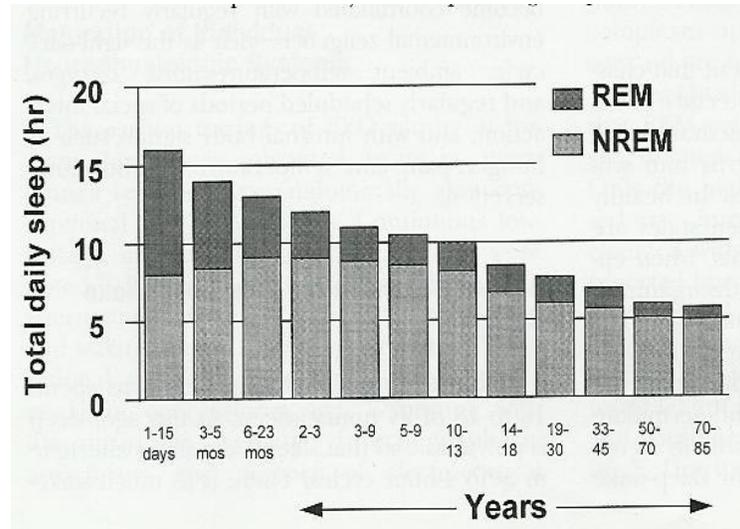
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### Appendix A: Normative Sleep Patterns in Children

The figure is a graph that shows how sleep changes across the life span. As you can see, newborns spend much of a 24-hour period in a sleep state with more time spent in REM sleep whereas older individuals require fewer hours of sleep and spend less time in REM stage sleep.



*Taken From Ferber & Kryger (1995), Principles and Practice of Sleep Medicine in the Child.*

## **Appendix B: Research Design and Procedures of Larger Sleep Treatment Program**

### ***Better Nights, Better Days: Treatment for Sleep Difficulties***

#### *Participants*

Children were recruited through referrals from their family physicians in the Nova Scotia Health Districts 4, 5, 6, and 9, or through flyer advertisements put out into the community (such as in local doctor offices and elementary schools) by Family Help staff. Children have to be between the ages 5 and 12 and attending school in grades primary to 6 only. Children included were deemed by his/her parents, corroborated with child's physician and/or Family Help staff to have sleep problems in the area of dyssomnias, in either/both of the following two areas: 1) bedtime resistance, and/or 2) sleep-onset delay.

#### *Screening:*

Screening of participants was conducted through the Sleep Treatment study (*Better Nights, Better Days: Treatment for Sleep Difficulties*). Participants were asked demographic/contact information as well as inclusion/exclusion criteria for participation. Exclusionary criteria include: 1) moderate to severe cognitive impairment; 2) neurological disorder (e.g., severe visual impairment, epilepsy, cerebral palsy, neuromuscular disease); 3) mental health disorder (e.g., autism, anxiety, depression); 4) participation in a behaviourally-based sleep intervention in the past six months; 5) currently receiving pharmacological intervention for their sleep problems; 6) nocturnal enuresis (bedwetting); and 7) breathing problems/obstructive breathing (e.g., snoring, sleep apnea, asthma). Children with no mental health disorders as well as those with a "disruptive behaviour disorder" (i.e., Attention Deficit/Hyperactivity Disorder,

Oppositional Defiant Disorder, and Conduct Disorder) were accepted into the research program.

### *Randomization*

The children are assigned to one of two treatment groups through a parallel-group randomization: (1) Family Help group that receive the sleep treatment immediately, and (2) Waitlist group (control group) that have to wait six months before starting the sleep treatment. Each child is assigned by an independent, blind random assignment to the Family Help module or to the Waitlist Control. Participants assigned to the Waitlist will have an opportunity to access the treatment once their six months of assessments have been completed and if they are still interested in participating, and as long as there are no changes which would make him/her fall into an exclusion status.

### *Intervention/Behaviourally-Based Sleep Treatment*

All services through the Family Help program at the IWK Health Centre are done through distance (telephone). Family Help provides all manuals and phone calls free of charge to the study participants. The behavioural treatment aims at treating children experiencing difficulties with bedtime resistance and/or delayed sleep onset and night awakenings. The treatment program lasts about 5 weeks with each week corresponding to a chapter in the Sleep Manual. The weekly lessons and activities that include information on: 1) basic sleep physiology and the impact of sleep problems, 2) promoting good sleep habits and sleep hygiene, 3) learning strategies to promote good sleep, 4) the behavioural intervention (e.g., Faded Bedtime and Reward Program), and 5) fine-tuning and fading the program. The coach calls each participant at least once a week to discuss

information and give opportunities for parent to ask questions, review chapter as well as to collect completed chapter exercises, and provide any advice/suggestions to parents regarding aspects of the program that are not working or may hinder the child's success.

### *Measures*

The Sleep Treatment Module, from the *Nights, Better Days: Treatment for Sleep Difficulties* program, uses several measures for initial assessment of the child's sleep problems and outcomes measures. For doctor referrals, the family physician completes the Diagnostic and Referral Checklist (a checklist modeled after other Family Help modules), which consists of questions used to gain demographic and family contact information as well as a screening questions for participation in the study (i.e., inclusion/exclusion criteria).

Two intake measures are obtained over the phone which provides further information about the child and inclusion/exclusion criteria. The first measure is the Kiddie-SADS-Present and Lifetime Version (K-SADS-PL; Kaufman et al, 1996), which is a diagnostic measure that assesses past and present episodes of psychopathology in children and adolescence according to the DSM-IV criteria. Unstructured and Screen Interview components of the parent version are used in this study. To participate in this study, the child may reach diagnostic criteria for a disruptive behaviour disorder, but not diagnostic criteria for any other mental health disorder. The Child Health Questionnaire (CHQ) (Landgraf, 1999) is the second intake measure used to be completed by parents and measures the physical and psychosocial health of the child and other descriptive information about the participant (e.g., socioeconomic status, parental education, marital status).

Outcome measures include those that are used in all of the Family Help treatment modules as well as those used specifically for the Sleep Treatment module. Family Help measures include Satisfaction Rating Scale and the Economic and Service Accessed Assessment Measure. These measures assess parental satisfaction of the intervention and the cost-effectiveness of the intervention, respectively.

Actigraphs, sleep diaries, Children's Sleep Habits Questionnaire (CSHQ), the Child Behaviour Checklist (CBCL), and Parenting Stress Index–Short Form (PSI-SF) measure outcomes of the Sleep Treatment Module. Actigraphs are used to measure objectively one's sleep-wake states. Sleep diaries are completed by parents who collect information over the assessment period. The diaries are primarily used in conjunction with the actigraph in assessing quality of sleep and night awakenings. The sleep diaries, CSHQ, CBCL, and PSI-SF (see below) are completed during the two-week baseline assessment, end-of-treatment assessment (10 to 12 weeks after baseline), and six-month follow-up.

### *Ethics*

The study has been approved by the IWK Research Ethic Board, as well as the authorities in all Health Districts in which recruitment is targeted.

In order to assure confidentiality, calls to Family Help may be recorded as to ensure that quality purposes of the study are carried out. All information that is obtained through recorded calls is kept confidential, and participants cannot be identified by the recordings. All study records will be kept for 10 years past the age of majority of the child in a locked area and then will be destroyed.

Study records may be shown to personnel of the Research Services Offices of the IWK Health Centre and the funding agency, Nova Scotia Health Research Foundation (NSHRF), in order to make sure that the study is being conducted in its proper form. Any results that may be published from the study will not contain any information that would identify any child participant.

Any information that reports any evidence of child abuse or neglect will be reported to the appropriate authorities. Parents are also informed that some of the assessment questions asked by study staff may be of a sensitive nature (e.g., substance abuse, physical abuse, child abuse, stealing) and parents are not required to respond to any questions that they are uncomfortable answering.

**Appendix C: Approval of IWK Health Centre Amendment to Research**

**RESEARCH ETHICS BOARD  
Approval - Amendment**



IWK Health Centre

5850/5980 University Avenue  
PO Box 9700  
Halifax, NS B3K 6R8  
Canada  
tel: [REDACTED]  
www.iwk.nshealth.ca

The Research Ethics Board established by the IWK Health Centre has examined the amendment to the application for research involving human subjects entitled:

**Sleep Module: Family Help - Bringing Health Home - Manual System (PSO-Project-2004-4044)**

**Principal Investigator(s):** Penny Corkum & Patrick J. McGrath

and continues to find the proposed research involving human subjects to be ethically acceptable. The Research Ethics Board operates in compliance with the Tri-Council Policy Statement and ICH/GCP Guidelines.

Date: 27-Oct-06

[REDACTED]  
Peter R. Camfield  
Co-Chair, Research Ethics Board

Members of Committee	
Darlene Baxendale	Nursing (Research Coordinator)
Robert A. Bortolussi	Chief of Research (Ex-Officio)
Kelly Cameron	Lay Representative
Peter Camfield	Pediatrics (Clinical Researcher) (REB Co-Chair)
Kent Dooley	Laboratory Medicine
Cora Fanning	Nursing (Research Coordinator)
Conrad Fernandez	Pediatrics (Clinical Researcher)
Michael Gorman	Lay Representative
Michael Hadskis	Legal Representative
Adam Huber	Pediatrics (Clinical Researcher) (REB Co-Chair)
Lorraine Lafferty	Legal Representative
Noni MacDonald	Pediatrics (Clinical Researcher)
Isabel Smith	Psychology (Clinical Researcher)
Marilyn Tiller	Pharmacy
Joan Wenning	Obstetrics/Gynaecology(Clinical Researcher)

\* REB members do not take part in review of their own proposed research involving human subjects or where there is a conflict of interest with the proposed research.

Appendix D: Approval of UREB of Graduate Studies of Mount Saint  
Vincent University

University Research Ethics Board

**UNIVERSITY RESEARCH ETHICS BOARD**

**Research Ethics Approval for Use of Secondary Data**

Title of project: *Do Better Nights Mean Better Days? An Examination of a Behavioural Sleep Treatment Program on the Health-Related Quality of Life in School-Age Children.*

Researcher(s): Kimberley Woodford

Supervisor: Dr. Penny Corkum

Co-Investigator(s): n/a

File #: 2006-68

The Chair of the University Research Ethics Board (UREB) has reviewed the above named proposal and confirms that it respects the *Tri-Council Policy Statement* and the *MSVU Policies and Procedures: Ethics Review of Research Involving Humans*. This study involves analyzing secondary data from an existing dataset with identifying information removed.

This approval for use of secondary data is valid for one year from the date of issue. A final report is required within 30 days of expiry. Researchers are reminded that any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation.

  
\_\_\_\_\_  
*Dr. Elizabeth Bowering, Chair*  
University Research Ethics Board (UREB)

**February 16, 2007**  
Effective Date

*[Expires: February 15, 2008]*

Renewal is contingent upon submission to the UREB of a written request for renewal accompanied by a satisfactory annual ethics report 30 days prior to expiry.

## Appendix E: Written and Informed Consent for Larger Study

*Parental Information and Authorization Form*  
"Sleep Problems" (Ages 5-12 years)

**Study Title:** Sleep Module, Family Help Program: Bringing Health Home (Phone Version)

**Investigator:** Dr. Penny Corkum, Ph.D., Registered Psychologist and Assistant Professor of Psychology at Dalhousie University, Halifax, N.S.

**Co-investigators:** Dr. Patrick J. McGrath, Ph.D., Psychologist at the IWK Health Centre and Professor of Psychology at Dalhousie University, Halifax, N.S.

Dr. Christine T. Chambers Ph.D., Registered Psychologist and Assistant Professor of Pediatrics and Psychology at Dalhousie University, Halifax NS, and Psychologist at the IWK Health Centre

Jennifer Mullane, M.A., Ph.D. Student in Clinical Psychology at Dalhousie University, Halifax N.S.

**Granting Agency:** Nova Scotia Health Research Foundation

### ***Introduction***

You are being invited to have your child take part in the research study named above. Before you decide whether you want your child to take part, it is important that you understand the purpose of the study, how it may affect your child, the risks and benefits of taking part, and what you will be asked to do. This information and authorization form has information about the study and will help you decide if it is in your child's best interest to take part in the study. Your child does not have to take part in this study. Taking part is entirely voluntary (your choice). If you have any questions that this form does not answer, your coach (the person that you will be talking to at Family Help who is trained to treat children from a distance) or the study investigator will be happy to give you more information.

### **Background to the Study**

Sleep problems in children have a large impact on child and family well-being. Research shows that many children have sleep problems (25-50%), especially children with behavior problems (up to 95%). Sleep problems affect children on a number of levels (e.g., their thoughts, their emotions, and their social and physical health) as well as increasing parental stress and making it harder for families to work well together. Although treatment has been shown to lead to improvements in these problems, there are still three barriers to the treatment of sleep problems. First, broad treatments that deal with many aspects of sleep problems are rarely offered. Second, even when treatments are available there are a number of

things that make it difficult for families to access the treatments (e.g., cost in terms of time off work for visits to specialized clinics, travel costs due to location of the clinic). Third, we need more research to look at the effectiveness of sleep treatments for school-aged children with and without behaviour problems. What is required is an overall approach to treatment that can address all the above problems that families encounter.

The Family Help Program is a new approach to try to help families with these sleep problems. We have found that most families are able to manage these problems if they are given the knowledge and skills to do so. Therefore, Family Help has used the latest research and the help of world recognized specialists in children's health to develop the best possible treatment program. The **Better Nights, Better Days** program is made up of an easy-to-use parent handbook and telephone contact with a professionally trained "Coach" which means that treatment can be conveniently provided to families from a distance. It is a service provided to families in the comfort and privacy of their own home. Our project is designed to help families with children with mild or moderate sleep problems, before they become more severe.

### **Purpose of the Study**

The purpose of this study is to see if treatment from a distance through the Family Help Program is effective in helping parents better manage their child's sleep problems. Family Help treatment is not designed to replace specialist care. A total of 80 children from the Nova Scotia Health Districts 4, 5, and 6, ages 5 to 12 years, with mild to moderate sleep problems will be involved in this study. This study is under the direction of Dr. Penny Corkum, Dr. Patrick McGrath, and Dr. Christine Chambers, all of whom are Registered Psychologists and Professors of Psychology at Dalhousie University and staff members at the IWK Health Centre in Halifax.

### **Study Design**

Children between the ages of 5 and 12 years of age, who are experiencing mild to moderate sleep problems, are being invited to take part in this research study. All contact with the study staff will be by telephone. The telephone calls are recorded so we can find out what works well during discussions, and we can make sure the study is being done properly. All telephone contact will be with the parent/guardian only.

Once you receive this form in the mail, your coach will call you to explain this *Information and Authorization Form*, which he/she will read along with you over the phone. If you agree to have your child take part, your coach will ask you to sign the form attached, during the call. Then the coach will set a convenient time with you to answer many questions about your child. It may take about 2 hours, but this time can be split-up in a couple of calls if you prefer. These questions are a very important part of this program since it is the way we can assess your child, learn about the areas of concern, and make sure that your child meets the requirements of this study. This will also allow us to see if there is any improvement in your child over time.

In order for this study to show that the Family Help Program is of benefit to parents and children, it is important that we compare *Family Help* treatment to a *Wait List* control group (a group that does not receive any treatment during the study time). Therefore, after this form is signed and all of the assessment questions about your child have been answered, it will be decided by chance (like "flipping a coin") which children will be treated in the *Family Help Program* and which will wait six months to start the program. That means that 50% of the children will receive the *Family Help* treatment immediately and 50% will be

assigned to the *Wait List* for six months until they receive the option of beginning the *Family Help*. Neither you, nor the study staff will know in advance which group your child will be placed in. For those children who are chosen by chance to be on the “*Wait List*”, we will want to conduct a sleep assessment after eight weeks and again after six months. After the six -month waiting period, your child may begin the *Family Help* treatment if they are still having sleep problems. You will be compensated for your time commitment for the sleep assessments no matter what group your child is in. See the chart on the next page for more details about what this study will mean for you.

<b><i>Family Help Group (50%)</i></b>	<b><i>Wait List Group (50%)</i></b>
<ul style="list-style-type: none"> <li>- Review and sign <i>Information and Authorization Form</i></li> <li>- Intake Assessment (approximately 2 hours)</li> <li>- Baseline sleep assessment for two weeks (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- Randomized to <i>Family Help</i></li> <li>- Start the six months of the <i>Family Help</i> program (for details about this program see below)</li> <li>- Complete the “End-of Treatment” Sleep Assessment at the eight week point (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- Complete the Six Month Sleep Assessment (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- A Family Help Program Satisfaction Questionnaire will be reviewed with you at the time of the End of Treatment and Six Month Sleep Assessment, to help us learn how to improve our program for future children and families</li> </ul>	<ul style="list-style-type: none"> <li>- Review and sign <i>Information and Authorization Form</i></li> <li>- Intake Assessment (approximately 2 hours)</li> <li>- Baseline sleep assessment for two weeks (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- Randomized to <i>Wait List</i></li> <li>- Start the six months of <i>Wait List</i> (this means that you and your child will not receive any treatment during this time)</li> <li>- Complete the “End-of Treatment” Sleep Assessment at the eight week point (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- Complete the Six Month Sleep Assessment (sleep diary, sleep questionnaires, behaviour questionnaires, actigraph) during which time information about your child’s sleep will be collected for two weeks</li> <li>- At the six month mark, if your child is still having sleep difficulties, you will have the option of receiving <i>Family Help</i> treatment (for details about this program see below)</li> <li>- If you decide to try the <i>Family Help</i> treatment, a Satisfaction Questionnaire will be reviewed with you at the time of the End of Treatment and Six Month Sleep Assessment, to help us learn how to improve our program for future children and families</li> </ul>

## Family Help Sleep Treatment Program (Better Nights, Better Days) (Six Months)

- You will receive a handbook which has five chapters, one for each week of the program
- The chapter titles are as follows: 1) All About Sleep and Children, 2) Promoting Good Sleep Habits, 3) Learning Strategies to Promote Good Sleep, 4) Starting the Faded Bedtime and Reward Program, and 5) Time-Tuning and Fading the Program.
- You will review a chapter each week and complete the chapter exercises
- Your coach will call you each week to review the information and to discuss your responses to the exercises included in each chapter (a few calls will be made for Chapter 4)
- Throughout the entire program, each night you will need to complete a sleep diary which records information about your child's sleep and your child will have to wear the actigraph every day for the entire eight weeks
- At the end of each week of the program, you will need to complete some questionnaires over the phone

### **Potential Harms**

There are no significant risks to participate in this distance telephone treatment program. However, for the “*Family Help*” group, when children begin a sleep treatment it may prove to be challenging for some families and may temporarily increase stress related to their child's bedtime routine. For the “*Wait List*” group, contact will be less frequent during the initial six months (the wait list period). However, at anytime if it is determined through the evaluations that your child is exhibiting severe symptoms and should be seen by mental health services, a referral to Mental Health Services will be made by the family physician in consultation with Dr. Corkum or her designate. For children in both groups, they may find it strange to wear the actigraph (the *special watch* that measures daytime activity and sleep) to bed; however, many children may also find this fun.

### **Potential Benefits**

Most families find that our assessments help them better understand their problems. Early treatment through *Family Help* may decrease symptoms and lessen the problems suffered by your child and family. Parents may learn new, more effective coping and parenting skills in their homes at times that are convenient to them. Knowledge gained from this study may help to further develop an improved distance treatment program. For the 50% of the children who are on the “*Wait List*”, the Family Help Program will be offered to you after the six month sleep assessment is completed and it is determined that your child may benefit from this treatment.

### **Alternatives to the Study**

Before deciding to have your child take part in this study, you should know that your child does not have to take part in the study. You can choose to ask your doctor to refer you to the Mental Health Services to determine if similar help is available.

## **Withdrawal from Participation**

Participation in this study is entirely voluntary (your choice). You may decide not to enroll your child or you may withdraw him/her from the study at anytime. Withdrawing your child will not affect your child's care by his/her family doctor, your Mental Health Services, or at the IWK Health Centre in any way. Your child's participation in the study may be ended, if in the opinion of the study staff it is not reasonable or safe for him/her to continue. If the study is changed in anyway which could affect your decision to continue to have your child participate, you will be told about the change and you may be asked to sign a new updated authorization form.

## **Confidentiality**

Your calls to Family Help may be recorded to ensure that quality purposes. If your call is recorded then all information obtained will be kept strictly confidential, in locked cabinets in the Family Help office and people will not be able to identify you by your tape. All study records will be kept for 10 years beyond the age of majority of your child and then destroyed.

Any information that is learned about your child will be kept private. Study records may be shown to personnel of the Research Services Offices of the IWK Health Centre and the funding agency Nova Scotia Health Research Foundation (NSHRF) who are only interested in making sure that we have conducted this study properly. If the results of this study are published the publication will not contain any information that would identify your child. Study records will be stored in a locked area and will be kept for 10 years past the age of majority as required by the Research Ethics Boards. Your signature on this form indicates that you authorize study staff to have access to your child's medical records/information in the case of an emergency or hospitalization during study participation. Additionally, you should be aware that the law requires us, to report any evidence of child abuse or neglect to the appropriate authorities.

Some of the assessment questions that study staff are required to ask you are of a sensitive nature, for example about substance abuse, physical abuse, child abuse, lying, and stealing. These are standard questions that are routinely asked by the specialists to better understand your child. You are not required to respond to any questions that you are not comfortable answering.

## **Costs and Reimbursement**

Taking part in this study will not result in any expenses to you. All materials are provided free of charge and if you are required to return forms to the Family Help Office, a postage-paid envelope will be provided. All telephone calls are at no expense and you have 24-hour access to our "toll-free" number: 1-866-470-7111.

Participants will be reimbursed for their time commitment for the following assessment stages: 1) Intake, 2) Baseline, 3) End-of-Treatment, and 4) Follow-Up. The participants will receive \$25 for participating in each of the four assessment stages, for a maximum total of \$100. You will receive the reimbursement as gift certificates or by cheque (your choice as discussed with your coach). For income tax purposes, if you chose to receive a cheque you will be asked to complete a form saying you received the cheque. You should be aware that after the study is completed, if the Family Help Program is eventually commercialized as a provided service to others, study participants would not receive further financial reimbursement.

## Research Rights

Your signature on this form will show that you have understood to your satisfaction, the information about this research study. Agreeing to have your child take part does not mean that you waive your legal rights nor does it release the investigator or other involved parties from their legal and professional responsibilities.

If you have any questions at any time during or after the study about these legal rights or about research in general and you would like an independent opinion, you may contact the Research Office of the IWK Health Centre at [REDACTED], Monday to Friday between 9 am to 5 pm.

## Contact Person

We encourage you to call the Family Help Toll-Free number “1-866-470-7111” at anytime if you have any questions or concerns. Please leave your name and number and your coach will return your call within 24-48 hours. If your call is urgent, you can choose an option (Press #1 for urgent calls) to leave your number and a message will trigger the pager of the Family Help staff on-call. They will return your call as soon as possible. If there is an emergency, we ask that you proceed to the nearest emergency department for assistance. If you would like to speak with the Project Manager, Trish Pottie BN, RN, CCRC, the Investigators Dr. Penny Corkum, Dr. Patrick McGrath, or Dr. Christine Chambers please leave a message on the toll-free number “1-866-470-7111” and they will return your call as soon as possible, Monday to Friday between 9am and 5pm. Please be assured that a registered health care professional (e.g., Dr. Penny Corkum, Dr. Patrick McGrath, Dr. Christine Chambers) is available at all times to study staff if they need to consult to assist in resolving urgent calls.

***Please Note:** Keep these five pages of study information with you for future reference. The following page is the signature page that you will complete while talking with your coach, if you decide that you want your child to take part in this study. This signature page is very important and it will need to be returned to the Family Help Office as soon as possible, in the postage-paid envelope attached. We will be sure to make a copy for you and return it promptly.*

*Remember to call us toll free anytime!*  
Family Help Program  
1-866-470-7111

**To be completed by Family Help Staff:**

Participant ID \_\_\_\_\_

Participant Code \_\_\_\_\_

**Study Title: Sleep Module, Family Help Program:**

**Bringing Health Home (Phone Version)** (Ages 5-12 years)

**Randomized Trial**

**Parental or Guardian Authorization** (if participant is living in the care of parent or guardian)

I have read or had read to me this *Information and Authorization Form* and have had the opportunity to ask questions which have been answered to my satisfaction before signing my name. I understand the nature of the study and I understand the potential risks involved (if any). I understand that I have the right to withdraw my child from this study at anytime without affecting my child's care in any way. I have received a copy of the Information Form for future reference. I understand that once I have returned my original signed page, my coach will return a copy along with a copy signed by him/her. I freely agree to have my child participate in this research study.

*To be completed by parent/guardian in consultation with Family Help Staff by Telephone:*

\_\_\_\_\_  
Name of Participant (Print Child's Full Name: *First, Middle, Last*)

\_\_\_\_\_  
Name of Parent/Guardian (Print)

\_\_\_\_\_  
Signature of Parent/Guardian

Date: \_\_\_\_\_

Time: \_\_\_\_\_

**RESEARCH FINDINGS**

*To receive a copy of a summary of the research findings once the study is completed please check the box below.*

I would like to receive a summary of the research findings.

*Please check and initial as applicable:*

I agree to have a copy of this Information and Consent Form sent to:

My family physician  Other health care provider. Specify name: \_\_\_\_\_

Participant initials \_\_\_\_\_

*Please check and initial as applicable:*

I agree to have copies of reports sent to:

My family physician  Other health care provider. Specify name: \_\_\_\_\_

Participant initials \_\_\_\_\_

I give Dr. Corkum/McGrath permission to use information collected for other research purposes as needed as long as IWK ethical approval is granted

*To be completed by Family Help Staff:*

**STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY**

*To be completed by the Family Help Staff at the time of telephone informed consent and a copy will be made for the parent/guardian.*

I have explained the nature and demands of the research study and judge that the Parent/guardian named above understands the nature and demands of the study.

Name (Print) \_\_\_\_\_ Position \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_ Time \_\_\_\_\_

**STATEMENT BY PERSON OBTAINING CONSENT**

*To be completed by the Family Help Staff at the time of telephone informed consent and a copy will be made for the parent/guardian.*

I have explained the nature of the consent process to the person authorized and judge that they understand that participation is voluntary and that they/their child may withdraw at anytime from participating.

Name (Print) \_\_\_\_\_ Position \_\_\_\_\_

Signature \_\_\_\_\_

## Appendix F: Description of *CHQ-PF50* Scales

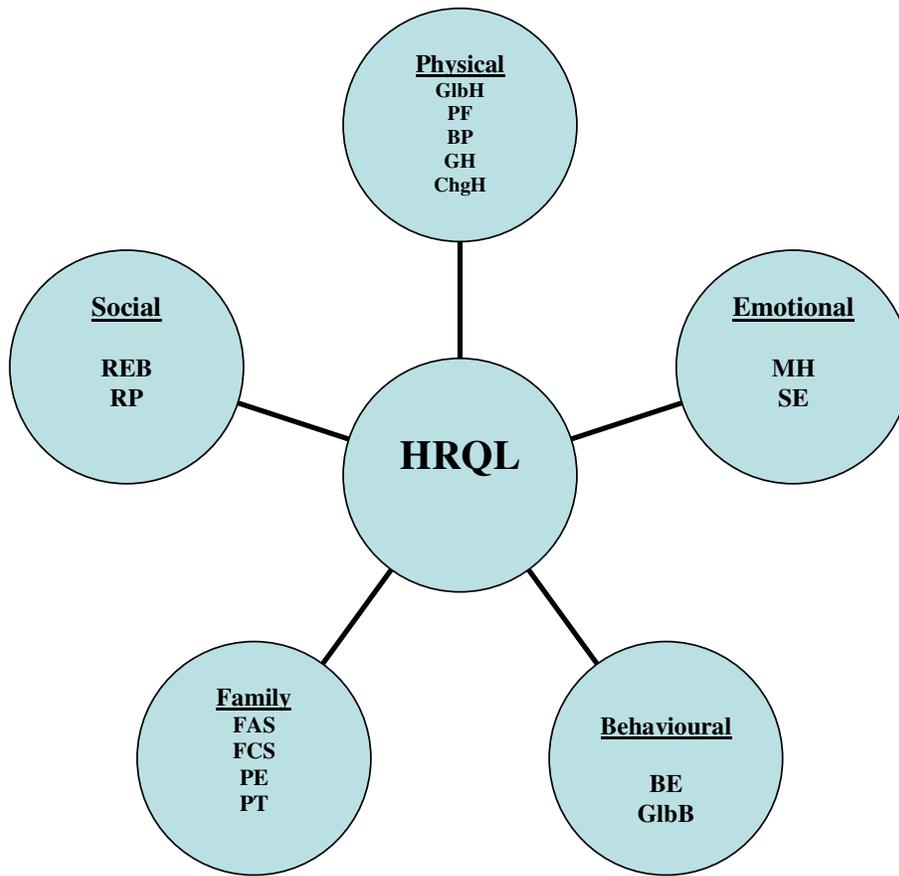
<b>HRQL concepts (<i>CHQ-PF50</i> Scales)</b>	<b>Description</b>
Global Health (GlbH)	An overall rating of the child's general health (from "poor" to "excellent").
Physical Functioning (PF)	Refer to the child's physical daytime activities.
Role/Social – Limitations due to Emotion/Behaviour (REB)	Describes limitations in school work and activities with friends due to child's emotional/behavioural health.
Role/Social – Limitations due to Physical Health (RP)	Describes limitations in school work and activities with friends due to child's physical health.
Bodily Pain and Discomfort (BP)	Measures the frequency and intensity of bodily pain and discomfort of the child in the past four years.
Mental Health Scale (MH)	Measures the frequency of both positive and negative states (e.g., anxiety, depression).
Self-Esteem Scale (SE)	The child's satisfaction with themselves, school, and others (e.g., school ability, athletic ability, feelings about their friendships and family, and life in general).
General Health Perceptions (GH)	Statements in the child's general health (e.g., does my child seem less healthy compared to other children of the same age, has my child been seriously ill, how often are they ill, expectations of the child's health).
Change in Health Perception (ChgH)	Rates the child's present health compared to a year prior.
Parent Impact – Time (PT)	Refers to the child's physical health and emotional well-being and behaviour, and attention or learning abilities and how they limit their time parents can spend on their own personal needs.
Parent Impact – Emotion (PE)	Refers to the how much emotional worry or concern parents and other family members experience regarding the child's physical health, emotional well-being or behaviour, and their attention or learning abilities.
Family Activities Scale (FAS)	How often the child's health or behaviour limits the types or activities that the family participates, interrupts everyday family life, cause tension or conflict in the home, or cause a change family's plans.
Family Cohesion Scale (FCS)	A rating of the family's ability to get along with one another.

**Appendix G: CHO-PF50 - Psychosocial and Physical Summary Scores**  
**(factor weight)**

<b>Scale</b>	<b>k</b>	<b>Psychosocial</b>	<b>Physical</b>
Physical Functioning (PF)	1	-.09243	.37138
Role/Social – Physical Health (RP)	2	-.06973	.34493
General Health (GH)	6	-.05547	.29460
Bodily Pain (BP)	2	-.05514	.27883
Role/Social – Emotion/Behaviour (REB)	3	.21155	-.01178
Parent Impact – Time (PT)	3	.16944	.09113
Parent Impact – Emotion (PE)	3	.19823	.06063
Self-Esteem (SE)	6	.24792	-.09480
Mental Health (MH)	5	.25335	-.09263
Behaviour (BE)	6	.27911	-.12675

k = number of items

Appendix F: HRQL Domains



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